This volume collects the results of the research programme *Home Care Design for Parkinson's Disease*, aimed at defining good design practices to enhance the autonomy and quality of life of people with Parkinson's disease within the home environment.

The programme, promoted and financed by the Fondazione Zoé, was realised by a multidisciplinary work group – which involved the University of Florence for the area of design, the University of Turin for the area of neurology, the Catholic University of Milan for the area of sociology, the Universidade Federal de Minas Gerais (Brazil) for the area of industrial production engineering – in collaboration with the Confederazione Parkinson Italia and the Accademia Limpe-Dismov.

The book proposes an introductory overview of Parkinson's disease from a medical and sociological point of view, analysing the main and most frequent areas of discomfort and/or difficulty experienced by people with Parkinson's disease during activities of daily living and relationships.

The project approach is based on the principles of Design for Inclusion and on the theoretical and methodological approach of Human-Centred Design which, through the direct involvement of users, have made it possible to focus attention on the specific needs and expectations of people with Parkinson's disease and their families and to define the different design solutions.

Specific insights are devoted to the emotional effects of interaction with the environments and products of everyday life, and to the opportunities offered by the use of enabling technologies, which, from robotics to wearable devices to environmental monitoring technologies, can offer concrete solutions for enhancing independence.

The second part of the book is dedicated to the design guidelines that provide solutions and operational indications to ensure maximum usability, safety and pleasantness of use of the home's interior, its furnishings and equipment.

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Francesca Tosi, Mattia Pistolesi

Home Care Design for Parkinson's Disease

Designing the Home Environment for People with Parkinson's Disease

HOME CARE DESIGN
FOR PARKINSON'S DISEASE

Serie di architettura e design
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Ergonomics&**Design**

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The series proposes studies, research and design experiments, conducted in the field of Ergonomics in Design, in the various fields in which the methodological tools of Ergonomics and Human-Centred Design, combined with the creative and propositional dimension of Design, represent important strategic factors for the innovation of products, environments and services and for the competitiveness of the production system.

There are many areas of research and fields of experimentation in which design confronts and integrates both the more consolidated components of Ergonomics (physical, cognitive and organisational) and the more recent contributions of Human-Centred Design and User Experience.

The aim of the series is to provide an overview of the vast scientific panorama in this field, which ranges from the home environment to tools for sporting activity, from personal care to environments and products for health and assistance, from products and services for urban mobility to many other areas, in which the relationship between Ergonomics and Design represents a concrete factor for innovation.

Francesca Tosi, Mattia Pistolesi

Home Care Design for Parkinson's Disease

Designing the Home Environment for People with Parkinson's Disease

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FrancoAngeli

Ergonomics&**Design**

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Contents

Presentation
by *Elena Zambon* 9

Preface
by *Giangi Milesi* 11
- Home, sweet home? 11
- Parkinson, the unknown 12
- To generate usefulness plus beauty 13

Introduction
by *Francesca Tosi, Mattia Pistolesi* 15
- Bibliography 17

1. Parkinson's disease
by *Carlo Alberto Artusi, Leonardo Lopiano* 19
- 1.1 Epidemiological notes 19
- 1.2 The cardinal symptoms of PD 19
  - 1.2.1 Other symptoms 20
- 1.3 Diagnosis and stages of the disease 21
  - 1.3.1 The advanced stage of the disease 22
- 1.4 PD therapy 22
- 1.5 Conclusions 27
- Bibliography 27

2. Beyond the clinical aspects: the social implications of Parkinson's disease
by *Linda Lombi* 29
- 2.1 Introduction 29
- 2.2 The triad "disease-illness and sickness" (DIS) applied to Parkinson's disease 30
- 2.3 The imagery of sickness: the social representation of Parkinson's disease and the problem of stigma 31
- 2.4 Institutional sickness: obstacles to social recognition of the illness 33
- 2.5 Conclusions 34
- Bibliography 35

3. Human-Centred Design - Inclusive Design: design for People with Parkinson's disease
by *Francesca Tosi* 39
3.1 Human-Centred Design: design for people 39
3.2 Recognise needs, design for inclusion 44
3.3 Designing for people with Parkinson's disease 49
Bibliography 52

4. People with Parkinson's disease in the home environment
by *Francesca Tosi*, *Mattia Pistolesi* 53
4.1 The relationship with space and objects 53
4.2 The home for people with Parkinson's disease 64
4.3 Domestic accidents 68
Bibliography and web sites 72

5. Accessibility of domestic environments: the regulatory aspects
by *Mattia Pistolesi*, *Francesca Filippi* 77
5.1 Designing "without barriers": the Inclusive Design approach 79
5.2 The international regulatory scenario 83
Bibliography and web sites 88

6. Design and disability: emotional impact
by *Ester Iacono* 93
6.1 Emotional Design: the role of emotions 93
6.2 The contribution of the Evidence Based Design approach (EBD) 95
6.3 Empathic Design: supporting designers to build empathy, planning for and with people suffering from Parkinson's disease 99
Bibliography 103

7. Design and disability: new enabling technologies
by *Claudia Becchimanzi* 107
7.1 Robotic and wearable technologies: a powerful tool to support caregivers and PwP 107
7.2 Assistive technologies and the Internet of Things: principles, taxonomies and research areas 108
7.3 Assistive robotics: application areas and representative cases 110
7.3.1 Socially assistive robotics: users, activities and types of interaction 112
7.3.2 Assistive robotics for Parkinson's disease: representative cases 114
7.4 A brief outline of ethical issues for new digital technologies 118
7.5 The role of Design 119
Bibliography 120

8. Micro to macro or macro to micro? The project as production of means of life
by *Adson Eduardo Resende* 125
8.1 Use as project reference 125
8.2 Micro and macro: interfaces as a locus of action for designers 127
8.2.1 Notion of interface 128
8.2.2 The theory of activity 128
8.3 Possible answers 130
8.4 Final considerations 134
Bibliography 135

9. The research project *Home Care Design for Parkinson's Disease*
by *Mattia Pistolesi* 137
9.1 Methodological approach 137
9.2 Results 142
9.2.1 Recruitment diary 142
9.2.2 Exploratory semi-structured interview 146
9.2.3 Structured specialised interview and context observation 149
9.2.4 Problem mapping and conceptual matrix 158
Bibliography 163

10. Guidelines for the design of usable home environments for people with Parkinson's disease
by *Francesca Tosi*, *Mattia Pistolesi* 165

Acknowledgements 345

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Presentation

by *Elena Zambon*[1]

Since its inception, the Zoé[2] - Zambon Open Education Foundation has been committed to the dissemination of a health-conscious and caring culture through research and dissemination activities, in the conviction that health is a goal of civilisation. For us, only the continuous development of knowledge and the ability to anticipate, recognise and interpret changes in society and in the concept of health itself are the way to pursue individual and collective well-being.

Our founder Gaetano Zambon wrote as early as 1938:

> *Only the broadening of one's scientific knowledge*
> *and the tireless study of all social and organisational*
> *problems allow us to rise above mediocrity*
> *and make us truly useful and almost indispensable.*

This is why the Foundation is guided by an approach to health as a broader cultural and value issue, also through proper communication. With a philosophy defined as "Human Touch" , the focus is on the person, especially in his or her humanity, in the conviction that this dimension can help to overcome the inevitable fragilities of our nature.

I am thinking first of all of the inexorable ageing process of the population and the consequent issue of chronic diseases, certainly one of the great challenges to be faced also because of the changes in health needs they bring with them, particularly in neurodegenerative diseases.

---

[1] President of Fondazione Zoé - Zambon Open Education, as well as President of Zambon SpA - a multinational pharmaceutical company established in Vicenza in 1906 and present in 23 countries with branches in Europe, America and Asia. She is on the Board of Directors of IIT - Istituto Italiano di Tecnologia; formerly a member of the Board of Directors of UniCredit, Ferrari N.V., Italcementi SpA, Fondo Strategico Italiano, Akros Finanziaria S.p.A. and Salvagnini SpA. She is also Vice-President of Aspen Institute Italia, a member of the Advisory Board of the School of Management of the Politecnico di Milano and of the Campaign Board of Bocconi University, and a Board Member of the Andrea Palladio International Centre for Architectural Studies. She is Honorary President of AIdAF - Italian Family Business, of which she was President until May 2019, and was Vice President of FBN, the international Family Business network. Elena Zambon is a Cavaliere del Lavoro, an Olympic Academician, and has received the "Imprenditore Olivettiano", "Marisa Bellisario", "Premio Masi", "Premio Leonardo" and "Premio Roma" awards.

[2] Fondazione Zoé - Zambon Open Education was established in 2008, at the behest of the Zambon family, to promote a modern culture of health and quality of life, based on the principles of knowledge and prevention, emphasising correct communication. The Foundation organises international conferences, seminars, educational activities and editorial productions. It is also the promoter of the "Human Touch Academy", inspired by a philosophy that looks at the human dimension and relationships as a tool for care, and of the "Future by Quality" programme, which explores, together with major partners such as Aspen Institute Italia, the importance of the life sciences for our country's economic and cultural system.

In recent years, I have been reflecting a lot on a new understanding of spaces as an integral part of the quality of our lives, and the home is certainly our safe haven, especially when we are fragile. We have tried to give extra support to home care with our idea of “human touch” by making our experience and expertise available, particularly to people with Parkinson’s disease and their families. We therefore decided to promote an innovative initiative in the area of health and at the same time part of that all-Italian heritage that is the world of design, through a language capable of uniting functionality and aesthetics, also beyond national boundaries.

Within this vision, the home can become “the ideal home”, a place of care that adopts design solutions and devices that can truly meet the needs of its inhabitants, but without “hospitalising” the living environment. The aim is to encourage maximum autonomy in the performance of activities of daily living and relationships, providing, as far as possible, the best conditions of physical and psychological comfort for patients and caregivers.

At the end of 2019, we initiated the project *Home Care Design for Parkinson’s Disease*, in collaboration with the Laboratory of Ergonomics and Design (LED) at the Department of Architecture DIDA of the University of Florence, under the Scientific Coordination of Prof. Francesca Tosi, one of Italy’s leading experts in Design in the healthcare sector.

It was natural for us to involve the Confederazione Parkinson Italia and the Fondazione Limpe per il Parkinson, which ensured the support and participation of people with Parkinson’s disease and their carers, and the sharing of a research method that is not disconnected from a clinical approach, which is necessary to ensure the correct assessment of the needs of patients as the disease progresses. I want to take this opportunity here to thank all the people - researchers, patients, caregivers, doctors - who have been involved in this project, which is all the more complex because of the pandemic and the social distancing it has imposed.

Our ambition is for this text to be widely adopted to accompany the frail ones in the design and adaptation of living spaces that become necessary as the disease progresses.

The hope is that this proposal can become part of a culture of design and the planning of buildings and living spaces that look at the person in his or her entire life journey, knowing how to adapt to the changing world. I would like to invite companies from all sectors to espouse this philosophy and I would like to thank in advance those who, in the same spirit, will concretely join our project.

Preface

by *Giangi Milesi*[1]

Home, sweet home?

A smoking turkey plummets into the large bathroom, with a clatter of broken glass. Behind the turkey, a cloud of smoke. Out of the smoke, emerges Walter (a very young Tom Hanks), black with soot, his hair ruffled and his shirt scorched and pitted. Anna is scared, but the beautiful wallpaper is safe. At least that.

«I had problems in the kitchen», Walter justified himself.

«However, the turkey is well browned» Anna says in order to play down the situation.

«The kitchen as well», he points out; «we will eat canned food for a while.»

She insists in optimistic tones, but he, showing the two buckets full of hot water he holds in his hands, puts an end to the discussion: he wants to fill the tub and take a relaxing bath. He hands her one of the buckets so she can help him.

---

[1] President of the Confederazione Parkinson Italia. Since being diagnosed with Parkinson's in 2016, he has been involved as a volunteer in the fight against the disease. Since 2019, he has been President of the Confederazione Parkinson Italia. Creator of the collective campaign NonChiamatemiMorbo, he is a member of the Board of the Istituto Virtuale Parkinson and of the Limpe Advisory Board. Since 2019, he has been Vice President of the Fondazione Pubblicità Progresso. In the thirty years he has dedicated to Cesvi - of which he was President from 2005 to 2018 - he has innovated the Italian non-profit sector: in 1992 with "positive advertising"; in 1997 by creating the first integrated fund-raising campaign; in 1998 with the issue of the first social bond; in 2002 with the launch of the SMS Solidale; in 2004 with a company referendum on social issues. The record of three Financial Statements Oscar Awards testifies to its commitment to transparency and accountability.

Parkinson Italia: Confederation of Independent Associations.

Parkinson Italia's mission is to protect the rights of people with Parkinson's, their families and caregivers and to pursue the best quality of life by supporting the work of the Confederated Associations with information, resources and services. Parkinson Italia promotes the growth and development of the national network of associations of people with Parkinson's disease, also by facilitating the establishment of new organisations in order to guarantee a supportive and generative social fabric that integrates people with disabilities. Founded in 1998 as a second-level network thanks to the visionary initiative of some of its members, today it is the best organisational response to the needs of people with Parkinson's, their families and caregivers, because:

- It works on strengthening and expanding the associative network, rooted in the territories, close to the beneficiaries, to improve their quality of life, integrating them socially, informing them, offering them services, and protecting them vis-à-vis the decentralised healthcare system.
- It works nationwide with projects and educational campaigns and advocacy initiatives to protect the rights enshrined in the 1997 World Charter and ensure the best quality of life for people with Parkinson's disease.
- It is in line with the Reform of the Non-profit sector that anticipated, with an innovative stance, the Network concept, based on complete mutual autonomy, in a win-win relationship, between the national and territorial levels.

Through the participation of the individual local associations, Parkinson Italia is open to everyone: patients, relatives, volunteers and sympathisers. Autonomy and cooperation are the Confederation's strengths: the member associations on the one hand retain their freedom of action, on the other they connect to a network of contacts and initiatives.

As soon as they start pouring water, the wooden floor collapses under the weight of the bathtub, which sinks to the floor below.

Anna and Walter look circumspectly into the large hole. They are stunned: she stares at it with bulging eyes, he is unable to stop an interminable hysterical laugh.

This is a scene from the 1986 Spielberg-produced film “Home, Sweet Home?”, a remake of “Our Dream Home”. The film, about an incautious purchase, is a parody of how we organise a house. We long for our dream home, but only when we live in it do we discover that it is unsuitable for our needs, present and future.

We say we think of our children, but statistics show that in furnishing our home we do not care at all, given that in countries like ours, domestic accidents are among the leading causes of death and disability of children under five.

Other surveys warn us that the most dangerous place in the home is the bathroom.

Especially for the elderly. It is no coincidence that part of this research is dedicated to this environment. If we often get out of bed at night, with dizziness and loss of balance, we should mount a handle to support ourselves. We should check that the bathroom floor is not slippery; that the bathtub or shower allows for easy exit; that electrical outlets are away from water taps... Instead of questioning and informing ourselves on how to ward off these hazards, we add more traps, for example deadly mats.

We act as if the ageing process of the population does not affect us; as if the age pyramid is not changing shape to look more and more like a sort of flying saucer making frailties explode.

In this scenario, our approach is to treat “weaker users as a strategic resource for the sustainable development of contemporary society”. In particular, the challenge of this research is to address practical aspects of comfortable living, notwithstanding Parkinson’s disease. We found the answers in the concreteness of Interior Design, but we are aware that more is needed: a paradigm shift in our way of life (especially in the city). A horizon of change in the social aspects of living (“generative” living) and dwelling (“collaborative living” - which is not a hippie thing). Therefore, we hope that the valuable work done so far will not stop and serve as a driver to embrace other experiences and visions. For example, studying co-housing, which originated in Holland in the 1970s and has been germinating in Italy for over ten years. With solutions that rediscover the neighbourhood - no longer made up of strangers, but of people you can count on. With buildings that enhance community relations and lead to collective services (in large spaces that we could not otherwise afford). With expedients that bring savings both in the construction of the houses and in their management.

Parkinson, the unknown

The disease that we think we know and recognise from the tremor of a hand is instead a multifaceted neurological disorder that manifests itself with different, even conflicting symptoms: Dr. James Parkinson, the doctor whose name it bears, called it “agitating paralysis” in 1817. That is, a disease that can make you, even simultaneously, a statue of salt or a puppet gone mad.

Here is a long list of the main symptoms of Parkinson’s that can lead to various forms of incapacity, which can add to the risks, discomforts and living problems, making them even dramatic: muscle rigidity and slowness of movement, up to blocking of the body movements, in particular walking, rigidity and inexpressiveness of the face, difficulty in swallowing, tremor, difficulty in writing. These are the main “motor symptoms”, to which one must add the “non-motor symptoms” that weigh even more heavily on the quality of life of people with Parkinson’s: depression, anxiety, panic attacks, pain, fatigue, cognitive deficiency, orthostatic hypotension, genital-urinary disorders, gastro-intestinal disorders, dementia, reduced sense of smell, sleep disorders, constipation. These other symptoms may arise during the course of the disease, at a more or less early stage, or precede the onset of motor disorders by years.

Non-motor symptoms not only fail to respond to the anti-parkinsonian therapy used to control motor symptoms, but also contribute to isolating a person with Parkinson’s. They push a person to deny the illness, to shut him or herself away. The lowering of the age of Parkinson’s onset - “juvenile Parkinson’s” - also leads to hiding the disease for fear of losing one’s job.

These are among the reasons that make us doubt the official numbers of sick people in Italy. Significant numbers, nonetheless: 260,000 Italians suffer from it, but it could be twice as many. We To which must add the other members of the 260,000, or many more, families whose lives have been disrupted by Parkinson’s. Numbers are set to grow further: while in the long run, progress leads to the containment of infectious diseases, the same progress leads to the growth of neurological diseases.

The study that we publish in the second section of this volume, projecting the evolution of Parkinson’s disease indicators 20 years from now, predicts that it will even surpass that of Alzheimer’s. Therefore, the quality of life of people with Parkinson’s is, and will increasingly be, a major social issue. And it is the main purpose of our Confederation.

Recognising it as a social problem and noting how many people with Parkinson tend to hide in order to conceal the disease and escape the stigma, we proposed to remove the word “disease” from this research, because it evokes contagious epidemics with their load of “plague-ridden ones” and “spreaders”.

To generate usefulness plus beauty

Thus, we deal with the quality of living in order to cope with the multiple disabilities of people with Parkinson’s disease, even for the longer time they spend in the home. But we do not want to shut ourselves in: on the contrary, we demand a holistic approach to illness and the psychosocial components of care. Even against the pandemic we have mobilised (with telecare, telemedicine and web-based training) precisely to combat the three S’s - segregation, solitude and stress - to which Covid forces us.

This is, in short, the background of experience and thought that we share with the Zoé Foundation, which we sincerely thank for having us on board this beautiful project, based on the participatory process.

Listening to needs, identifying expectations and leveraging knowledge is the most effective method of designing the “ideal home” for a person with Parkinson’s disease.

The result is this “usefulness minded” manual, with everything that is needed by professionals - but easy for anyone to consult - with measurements, indications, drawings and plans, reports of Italian and international objects and best practices.

Information tailored to people's needs, to the degree of development of the disease, and the composition of the household.

As early as 22 centuries ago, Vitruvius stipulated that architectural research hinged on solidity, utility and beauty. If the first two are indispensable requirements, beauty is much needed. But beauty cannot be defined once and for all, it must be continually sought, even by questioning paradigms. This is also why we believe that only a process of contamination and cooperation can engage interior design in the creation of canons of beauty alternative to the prevailing ones. Canons according to which, for example, lettering must be microscopic (i.e. unreadable) and control buttons tone on tone, black on black (i.e. invisible).

In designing the Beaubourg, Renzo Piano turned the idea of the museum and its stylistic features upside down; he explained that beauty "is a force for social change: it is around it that a sense of community is created... it is beauty that can change the world, make our cities better, and make us better people".

Introduction

by *Francesca Tosi, Mattia Pistolesi*

Attention to human diversity, and in particular to conditions of disability and reduced physical, sensory or cognitive autonomy, has progressively developed in recent decades in the field of research and design practice, leading, particularly in the field of design, to the consolidation of approaches that are now included in the term *Inclusive Design*.

The World Health Organization (WHO) defines the condition of disability - that is, of reduced or impaired ability compared to the average - as the consequence of a pathology or an accident, and the condition of handicap as the result of the interaction between the person and the physical, perceptual, cognitive, and/or relational barriers that hinder full and effective participation in society based on the equality with other individuals (WHO, 2011). The condition of disability as well as that of handicap - i.e. disadvantage with respect to the enjoyment of the physical and relational environment - can be experienced by anyone at any time, temporarily or permanently, and each of us knows this condition of disadvantage from having experienced it directly or through other people.

From the standpoint of the project disciplines, the objective is the implementation of solutions capable of safeguarding and enhancing the autonomy of the person and his or her possibility of relating to the physical and social environment in which he or she lives, and of guaranteeing the possibility of participation in social life. The topic is obviously vast and involves all levels and scales of design: from the urban context to the building sector, from the service system to the set of furnishings and products - physical and virtual - and of course of aids and support technologies.

The book *Home Care Design for Parkinson's Disease. Designing the Home Environment for People with Parkinson's Disease: Products, Services and Devices for Autonomy* is dedicated to the specific case of people with Parkinson's disease and the criteria for designing the home environment that are most suitable for promoting and enhancing the autonomy and quality of life of a person with a disability as well as his or her family. The focus is therefore on the spaces, products, furniture, objects of use - in which and with which daily living activities are carried out - as well as the aids and enabling technologies that can enhance autonomy and safety levels.

Ideally, the volume is divided into two parts - a theoretical part, from Ch. 1 to Ch. 8, and an application part from Ch. 9 to Ch. 10 - and is aimed at designers, students of design courses and all those involved in design disciplines, as well as people with Parkinson's disease and their families, formal and informal caregivers and, finally, healthcare professionals.

The text collects the results of the research project *Home Care Design for Parkinson's Disease*, financed by the Fondazione Zoé and carried out by a multi-disciplinary working group: the Laboratory of Ergonomics and Design of the University of Florence - for the

Design area; the University of Turin - for the neurology area; the Catholic University of Milan - for the sociology area; and, finally, the Universidade Federal de Minas Gerais (Brazil) - for the area of industrial production engineering.

The research project was carried out in cooperation with the Confederazione Parkinson Italia[1] and the Limpe-Dismov Academy[2].

The research project, carried out between 2020 and 2021, and aimed at investigating the theme of Parkinson's disease in relation to the private domestic environment, had the specific objective of defining design guidelines through which to identify the main and most frequent areas of discomfort and/or difficulty currently experienced by people with Parkinson's disease when carrying out their daily life activities and relationships within the domestic space, and provide the most suitable design solutions to guarantee maximum usability, safety and pleasantness of use of the home environment, its furnishings and equipment.

The objective, in a nutshell, is to propose design solutions that can improve the quality of life of people with Parkinson's disease, as well as their relatives and caregivers - formal and informal - who share the burden of the disease with them.

This undoubtedly ambitious goal was pursued with will and tenacity by the entire working group and the actors actively involved, and despite the considerable difficulties due to the pandemic emergency caused by Covid-19.

In the first part, the book offers a diversified reading on Parkinson's disease, from a medical perspective (chapter 1) and from a sociological perspective (chapter 2).

Chapter 3 deals with the theoretical and methodological contribution of the Human-Centred Design approach to the development of the design process, with particular reference to the design of products and environments specifically for people with Parkinson's and their families. Chapter 4 deals with the relationship between the home environment and Parkinson's disease, while Chapter 5 describes the current regulatory references on home accessibility, both Italian and international.

Chapter 6 deals with the subject of emotions in the field of Design and, in particular, the evaluation of emotional effects associated with interaction with artefacts. This aspect is considered central to the practice of design today, and is particularly relevant in the case of environments and products aimed at frail people, for whom it is not difficult to imagine how interaction with everyday spaces that have become inaccessible to their abilities, and with objects that are incomprehensible and/or difficult to use, can create anxiety, frustration, pain and fear, making them perceive their living environment as hostile and perceive themselves as inadequate or unable to carry out normal everyday activities.

Chapter 7 deals with new enabling technologies. Robotic and wearable technologies are playing, and may play even more a fundamental role in the future, implementing human perceptions and skills and creating the right conditions for improving the quality of life of PwP and services addressed to them, enhancing their mobility and communication possibiliies, increasing their sense of safety and independence and promoting social inclusion.

[1] The Confederazione Parkinson Italia ONLUS, set up in 1998, is a confederation of 25 independent voluntary associations involving over ten thousand people with Parkinson's, their families and caregivers.
https:// www.parkinson-italia.it/chi-siamo/missione/.

[2] The Accademia per lo Studio della Malattia di Parkinson e i Disordini del Movimento (Accademia LIMPE-DISMOV) was founded in 2014 by the merger of the two largest Scientific Associations in Italy that bring together health professionals interested in Parkinson's disease and movement disorders.
https://www.accademialimpedismov.it.

As a conclusion to the theoretical part, Chapter 8 deals with the design and implementation process of everyday objects, understood as essential tools in the life of each individual, with a special focus on the responsibility of the designer, who is called upon to create the artefacts on which the autonomy of the person depends as well as the safety and quality of his or her relations with the surrounding world.

The second part of the book reports the application results of the research project *Home Care Design for Parkinson's Disease*. In particular, Chapter 9 describes the methodological set-up and the results achieved, while Chapter 10 is entirely dedicated to the project guidelines.

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1. Parkinson’s disease

by *Carlo Alberto Artusi*[1]*, Leonardo Lopiano*[2]

Parkinson’s disease (PD) is a degenerative disease of the central nervous system with an estimated prevalence of 1-2% of the population over 65 years of age. The social impact of this disease is significant and, in view of the absence of curative therapies and the demographic trend of the population, will increase in the coming years. The aetiology of PD is unknown, although much scientific evidence correlates it with a coexistence of genetic predisposition and various environmental factors. Contrary to common belief, PD consists of a varied set of a large number of motor and non-motor symptoms. The core symptomatology of PD, on which its diagnosis is mainly based, consists of a triad of cardinal symptoms, referred to as the parkinsonian syndrome or parkinsonism, which identifies a syndrome characterised by rigidity, tremor and bradykinesia, of which PD is the main cause. Generally, in PD the parkinsonian syndrome has an asymmetrical presentation and a good response to dopaminergic therapy, in the absence of additional neurological signs and anamnestic data suggesting different causes responsible for the symptoms.

1.1 Epidemiological notes

With a prevalence of about 0.3% in the general population and 1% in individuals over 60 years of age, PD is the second most common neurodegenerative disease after Alzheimer’s disease. Despite being considered an age-dependent disease, given its characteristic increase prevalently with increasing age, in 10-15% of cases PD has an early onset, before the age of 50, and, more rarely, a “juvenile” onset, i.e. before the age of 40. The prevalence rate is higher in males, with a male to female ratio of 1.2 to 1.5 to 1.

1.2 The cardinal symptoms of PD

The cardinal motor symptoms of PD are tremor at rest, rigidity and bradykinesia. Postural instability is another frequent symptom that usually appears in the the more advanced stages of the disease, while it is generally absent at its onset. Bradykinesia, a fundamental and essential symptom for the diagnostic suspicion of parkinsonian syndro-

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me, initially manifests itself as a reduction in manual dexterity with difficulty in performing fine motor tasks such as fastening shirt buttons or writing (micrographia). Bradykinesia then progresses to the point of interfering with all aspects of daily life, particularly with walking and postural transitions, such as getting up from a chair or turning over in bed.

PD tremor typically occurs at rest, i.e. It appears in the absence of voluntary muscle activity, and is the onset symptom in approximately 70% of cases. It is a tremor with a low oscillation frequency (4-6 Hz) that typically begins on one side and most frequently involves the fingers of the hand. As the disease progresses, it tends to extend to the ipsilateral limb and then contralaterally. In addition to the typical tremor at rest, a postural or intentional tremor of the upper limbs and a head tremor may be present, although more rarely.

Stiffness is an increase in muscle tone involving both flexor and extensor muscles. It is perceived by the examiner as increased resistance to passive mobilisation of the joints in their full range of motion; it is qualitatively characterised as “plastic rigidity”, not speed-dependent, frequently affected by a sensation of brief and regular interruption of movement during passive mobilisation, referred to as “cogwheel” or “trochlea”.

In addition to the three cardinal symptoms, other motor phenomena such as alterations in walking and loss of postural reflexes are typical of PD and deserve to be mentioned. The former are represented by a reduced stride width, often accompanied by foot dragging. Sometimes there is a “festinating” gait, which results from the combination of a posture in flection and the progressive loss of postural reflexes and causes the patient to accelerate in an attempt to “catch up” with their centre of gravity, which shifts anteriorly during walking. Frequent, especially in the more advanced stages of the disease, is the characteristic phenomenon of “freezing”, which is usually observed at the beginning of the walk (“start hesitation”) and/or when changing direction or crossing narrow spaces, and which consists of the temporary inability to take an effective step despite the intention to proceed.

Postural instability, on the other hand, results from a progressive loss of postural reflexes with an increased risk of falls, especially backwards. The presence of significant postural instability with frequent falls in the first year of the disease is strongly suggestive of a diagnosis not of PD but of atypical degenerative parkinsonism.

1.2.1 Other symptoms

Secondary motor symptoms are ocular dysfunction, characterised by mild upward gaze limitation, slowing of saccadic movements and fragmentation of slow pursuit movements; oropharyngeal dysfunction, characterised by hypokinetic dysarthria, sialorrhoea (i.e. excessive salivation) and dysphagia (the latter may appear late in the course of the disease, if present at an early stage it must lead one to suspect an atypical form of Parkinsonism); musculoskeletal changes, represented by deformities of the hands and feet and alterations in the physiological curvature of the spine. The latter can be caused either by an alteration in muscle contraction or by skeletal alterations; they may be present at an early stage of the disease, while in an advanced stage severe antero- or latero deviations of the trunk may also appear, until configuring the pictures of the so-called camptocormia and Pisa syndrome. In PD patients there is also a complex of non-motor symptoms, which may precede the onset of motor ones and become very disabling for the patient as the disease progresses. Non-motor symptoms are often connected with advanced age and disease severity, but some of them, such as olfactory disturbances, constipation, depression and sleep disturbances, may also occur in the early or pre-clinical stages. From a fisiopathological standpoint, it is hypothesised that non-motor symptoms are mainly related to alterations in non-dopaminergic circuits and thus with the involvement of degeneration of different neuronal groups than those causing the main motor symptoms.

Among the most impactful non-motor symptoms are cognitive deficits. Cognitive impairment is frequently associated with PD and can range from a subtle, clinically insignificant deficit to clear dementia. Some studies have identified the presence of sub-clinical cognitive deficits in non-demented parkinsonian patients in up to 90 per cent of cases.

1.3 Diagnosis and stages of the disease

The diagnosis of PD is essentially clinical, although the numerous laboratory and instrumental investigations available may play an important role in differential diagnosis. It is currently formulated based on the verification of clinical criteria such as those proposed by the United Kingdom Parkinson's Disease Society Brain Bank (The Queen Square Brain Bank criteria). A revision of the diagnostic criteria for PD has recently been proposed by the International Parkinson and Movement Disorders Society (MDS). To date, the diagnosis of PD is based on objective findings of the cardinal symptoms of the disease, as well as the exclusion of secondary causes of parkinsonism. It is also supported by a good response to dopaminergic therapy. The correct application of current diagnostic criteria provides an accuracy of about 90%. However, some secondary or degenerative parkinsonian syndromes may mimic the typical clinical picture of PD, making it difficult to correctly diagnose the disease, especially in it early stages.

The progression of symptoms in PD is variable and not predictable in the individual case. It is schematically divided into a number of stages.

Prodromal phase: Stage of the disease that precedes the onset of motor symptoms and thus the diagnosis. According to some studies, it may last for many years. At present, it is not yet possible to identify with certainty those with prodromal disease, although it is increasingly important to pay attention to certain non-motor symptoms (depression, sleep disorders, constipation, hyposmia) that may precede the full development of the disease.

Initial phase: It includes the period between the onset of motor symptoms until the appearance of motor fluctuations.

Intermediate phase: From the appearance of the initial-slightly-predictable motor fluctuations to the advanced phase.

Advanced phase: In this phase, the therapeutic response to antiparkinsonian drugs does not allow for adequate functional compensation of the clinical picture during the day. Patients in this phase may manifest severe motor (on-off phenomena, dyskinesia) and non-motor complications. Cognitive, psychic and dysautonomic disorders may also appear in this phase, as well as loss of balance.

1.3.1 The advanced stage of the disease

After the first 5-10 years of the disease, characterised by a good response to dopaminergic therapy, the clinical manifestations of the advanced phase appear, which can be divided into motor fluctuations and involuntary movements.

Motor fluctuations: Loss or reduction of response to levodopa: expression of reduced plasma and brain availability of levodopa.

- End-of-dose deterioration ("wearing-off", or predictable motor deterioration): the patient experiences the reappearance of symptoms before taking the next dose of levodopa; the patient's motor condition is therefore closely related to levodopa plasma levels. Waking akinesia, often associated with pain dystonia, and nocturnal akinesia fall within this type of predictable fluctuation and both are related to low levodopa plasma levels. The delayed onset of the response (excessive latency of the on phase), often present at this stage, can be attributed to alterations in drug absorption, changes in the passage of levodopa across the blood-brain barrier, loss of the "long-lasting" effect of levodopa, or progressive degeneration of the nigrostriatal pathway; the reappearance of non-motor symptoms is also possible in the end-of-dose period;
- On-off phenomena: fluctuations of the motor response with unpredictable episodes of motor blockage (OFF). In contrast to end-of-dose deterioration, ON-OFF fluctuations are rapid transitions between the ON (good control of parkinsonian symptoms) and OFF phases, often unrelated to the time of medication. During the ON phases, the patient may show discrete mobility, whereas during the OFF phases there may be a real motor blockage, with an inability to stand and walk. It is hypothesised that the abrupt switch from ON to OFF is due to a rapid and transient change in dopamine receptors from a high to a low aphifinity state.

Involuntary movements: Dyskinesia is one of the most frequent and in- validating complications of chronic levodopa treatment. It consist of involuntary movements that generally appear after 5-6 years of therapy and is related to numerous factors, such as levodopa dosage, age of disease onset and disease duration. In addition, the female sex seems more prone to this type of complication.

Dyskinesia consists in involuntary movements, typically choreiform and rapid, that may involve the head, trunk and limbs. They are most evident on the side of the body most affected by the disease in patients who generally respond well to levodopa.

The most common form is peak dyskinesia, which occur coinciding with the plasma peak of each dose of levodopa. For these involuntary movements to occur, the levodopa plasma level must reach a critical level, the threshold of which decreases with the progression of the disease.

1.4 PD therapy

The treatment of PD is nowadays essentially symptomatic, as no therapy has been proven to be effective in slowing down the evolution of the disease. Treatment options are both pharmacological and surgical.

The drugs currently available enable very good control of motor symptomatology at an early stage. As the disease progresses, more problems emerge; in fact, although the response to dopaminergic therapy generally remains excellent over time, the motor complications of therapy, represented by motor fluctuations and dyskinesias, as described in the previous paragraphs, appear in a high percentage of subjects.

As the disease progresses, the therapeutic window of levodopa, the pivotal drug in PD therapy, becomes increasingly narrow, and motor fluctuations become very disabling with major repercussions on patients' quality of life. It is at this stage of the disease that infusion therapies and surgical therapy are indicated: the main options currently available are Deep Brain Stimulation (DBS), continuous duodenal infusion of levodopa (Duodopa®) and continuous subcutaneous infusion of apomorphine.

Moreover, the management of the patient in the advanced stage of the disease is complicated, as so-called drug-resistant symptoms, such as postural instability, hypophonia and dysautonomic disorders, become evident and disabling. These symptoms most often benefit from a physiotherapeutic, speech and care approach that is supplemented by pharmacological treatment.

Levodopa: Levodopa, which has been known since the 1960s, is the most effective and manageable drug for treating PD. The drug is administered in combination with peripheral decarboxylase inhibitors (benserazide and carbidopa) which increase its bioavailability in the central nervous system; it is absorbed in the jejunum-ileum via branched-chain amino acid carriers; in the central nervous system it is converted into dopamine at both residual nigral dopaminergic terminals and at the level of glia and striatal interneurons. The release of exogenous dopamine appears to be pulsatile, not physiological, and this may underlie the occurrence of motor fluctuations and dyskinesias. The plasma half-life of levodopa is approximately 1-2 hours. There are two different types of pharmacological response: the short-lasting response and the long-lasting response. The former defines an improvement in symptoms that lasts from several minutes to hours, occurs after a single administration, and is related to the plasma concentration of the drug. The long-lasting response, on the other hand, occurs after days or weeks of treatment and takes an equally long time to wear off. In the early stages of the disease, the long-lasting response prevails, while the short-lasting response becomes relevant in the complicated phase. There are also extended-release formulations on the market, designed to prolong the half-life of the drug by enabling more continuous dopaminergic stimulation; however, clinical studies have not shown a significant difference in the occurrence of motor complications compared to the use of standard levodopa, so the indications for the use of this formulation are limited (e.g. evening administration for nocturnal akinesia). The tolerability of levodopa is high: side effects, which are common in all dopaminergic drugs (nausea, vomiting, drowsiness, postural hypotension, hallucinations), are rarer and less severe than in other antiparkinsonian drugs, e.g. dopamine agonists. Levodopa dosages vary depending on whether it is used as monotherapy or in combination with other drugs and depending on the stage of the disease, and range on average from 300 to over 1500 mg/day, typically divided into 3-6 doses.

Monoamine oxidase B (MAO-B) inhibitors: selegiline, rasagiline and safinamide: Selegiline is the first irreversible selective MAO-B inhibitor (i-MAO-B), initially developed as an antidepressant, with a symptomatic effect on parkinsonian symptoms. It is used as adjunctive therapy to levodopa, rarely as monotherapy in the early stages of the disease. At low doses it has a potential neuroprotective action. Selegiline metabolites include amphetamine and methamphetamine, which are behind some of the drug's side effects, such as insomnia, confusion and worsening hallucinations. Its use may be useful, however, in patients affected by daytime sleepiness. Rasagiline is the second irreversible MAO-B marketed in Italy. It may also exert a neuroprotective action and has no amphetamine-like metabolites. The most frequent side effects of both MAO-B are insomnia, confusion, hallucinations, orthostatic hypotension and increased dyskinesias. Recent meta-analyses have shown similar efficacy of selegiline and rasagiline in both early and complicated stages of disease. In February 2016, a new drug belonging to the MAO-B category came onto the Italian market: Safinamide. This active ingredient has a dual mechanism of action: on the one hand, it exerts a highly selective and reversible inhibition of MAO-B, and on the other hand, it modulates glutamate overrelease by state-dependent blockade of voltage-gated sodium channels. The current indication is as an add-on to levodopa therapy, alone or in combination, in patients with medium to advanced PD who are affected by motor fluctuations.

Catechol-O-methyltransferase (COMT) inhibitors (entacapone, tolcapone and opicapone): These are drugs that block COMTs, enzymes involved in levodopa catabolism, leading to an increase in its half-life. Three different drugs are currently on the market. The first to be developed were entacapone, a reversible inhibitor of peripheral COMTs, and tolcapone, which also has an action on central COMTs. These drugs enable an increased duration of action of levodopa, with a reduction in the wearing-off phenomenon, an increase in the duration of the on phase and the possibility of reducing the daily levodopa dosage. A possible increase in involuntary movements, diarrhoea, pink discolouration of urine (for entacapone) and, more rarely, a worsening of the central effects of levodopa were observed as side effects. The indication for the use of entacapone, at a dosage of 200 mg per administration of levodopa daily, is the treatment of patients with motor fluctuations; tolcapone, at a dosage of 100 mg x 3/day, has the same therapeutic indications as entacapone; periodic monitoring of liver function of patients on tolcapone therapy is necessary due to its potential hepatotoxicity. A formulation consisting of the combination of the 3 active ingredients levodopa/carbidopa/entacapone (Stalevo®) is also available.

Opicapone is a new COMT inhibitor drug. It is indicated as adjunctive therapy to levodopa/decarboxylase inhibitors combinations in patients with motor fluctuations not adequately controlled by other therapies. Taken at a dosage of 50 mg once daily, opicapone demonstrated a reduction in OFF time without an increase in dyskinesias. The efficacy on COMT inhibition lasts for more than 24 hours and close monitoring of liver function is not necessary as with tolcapone.

Dopamine agonists: Dopamine agonists (DA) are molecules that act directly on striatal dopamine receptors. They differ from each other substantially in their derivation (ergot or non-ergot derivatives), their different affinity towards different dopaminergic receptor subtypes, and their plasma half-life. This class of drugs was initially developed for the treatment of advanced PD, in addition or partial replacement of levodopa, to reduce its dosage and achieve control of dyskinesias without worsening the off phase. At present, they are also used in the early phase of the disease, as monotherapy or in combination with low doses of levodopa. Ergot-derivatives are no longer used in clinical practice due to the possibility of serious side effects. Non-ergot DA derivatives such as Pramipexole, Ropinirole and Rotigotine are used instead.

Peripheral and central dopamine side effects are more frequent with DAs than with levodopa; peripherally, the most important side effects are nausea, vomiting, orthostatic hypotension, declivous oedemas and erythromelalgia; the main central side effects are daytime drowsiness, with possible sudden sleep attacks, confusion, hallucinations, delusions, sleep disturbances and impulse control disorders (e.g. pathological gambling, hyperphagia, hypersexuality, cyber addiction, hobbyism). Central side effects appear in relation to several factors, such as the sex and age of the patient, the severity of the disease, the dosage of dopaminergic therapy and the coexistence of cognitive deficits.

The efficacy of DAs on the cardinal symptoms of PD is lower than with levodopa; however, the frequency and severity of fluctuations/dyskinesias in patients treated with DAs as monotherapy or in combination with low doses of levodopa was lower than with levodopa monotherapy.

Glutamate antagonists: The only drug of this category on the market in Italy is amantadine, initially used as an anti-influenza drug. Its action mechanisms are multiple and it may be useful in the early or advanced stages of the disease for the control of parkinsonian symptoms. However, currently the major indication is the treatment of drug-induced dyskinesias. The most common side effects are oedemas in the lower limbs, insomnia, xerostomia, livedo reticularis, constipation and, mostly in subjects with cognitive impairment, hallucinations and confusional states. The effective dosage ranges from 100 to 400 mg per day.

Anticholinergics: Drugs with anticholinergic activity (trihexyphenidyl, biperiden) act by blocking muscarinic receptors of striatal interneurons, improving Parkinsonian symptoms with a modest effect mainly on tremor and rigidity. Currently, these drugs are very rarely used in the treatment of PD, as they can cause significant side effects due to muscarinic blockade, which also affects other areas of the CNS and the autonomic nervous system. Therefore, anticholinergics are now considered second-choice drugs in PD, their use being reserved for severe tremorigenic forms.

Continuous intestinal infusion of levodopa/carbidopa: Also known by the trade name Duodopa®, it is a combination of levodopa and carbidopa in gel form for continuous intestinal infusion. It enbles constant dopaminergic stimulation by administering levodopa in the duodenum. It is indicated in the treatment of advanced PD responsive to levodopa, with severe motor fluctuations and dyskinesias. The Duodopa® therapy reduces motor fluctuations and increases the on period by maintaining constant plasma concentrations of levodopa. Levodopa administered with this formulation has the same bioavailability as that administered by mouth. To administer the drug, a percutaneous endoscopic gastrostomy (PEG), equipped with a jeujunal extension (PEG-J), is required.

Subcutaneous infusion of apomorphine: Apomorphine is a potent agonist of the D1 and D2 receptors, orally inactive, with a half-life of about 40 minutes. It can be administered in two ways: as needed, in the case of motor blockade, via a subcutaneous injection using a penjet; as a daily continuous infusion via an infusion pump. This second method can be used as an advanced phase therapy in patients with major motor fluctuations in order to achieve continuous dopaminergic stimulation. The most important peripheral side effect is nausea and vomiting; it is therefore necessary to start premedication with domperidone or other antiemetic drugs before starting apomorphine therapy.

As with the intestinal infusion of levodopa/carbidopa gel, apomorfina infusion on pump is considered a late-stage therapy, more invasive and complex to manage than oral therapies, but with benefits in reducing daily off hours.

Surgical therapies: The surgical treatment of PD is indicated in patients in an advanced stage of the disease who present disabling motor fluctuations and dyskinesias that are not responsive to pharmacological therapy modifications. The aim of surgical therapy is to achieve the inactivation of particular brain structures embedded in the basal ganglia system. These structures are represented by the ventral intermediate nucleus of the thalamus (ViM), the subthalamic nucleus (STN) and the internal globus pallidus (GPi). In all neurosurgical techniques applied to PD, the precise localisation of anatomical targets plays a key role. For this reason, the different methods are united by the use of the stereotactic neurosurgery technique.

Nowadays, stereotactic ablation procedures have been largely replaced by high-frequency electrical stimulation of an intracerebral target (Deep Brain Stimulation - DBS), introduced by Benabid and collaborators in Grenoble, France, in the late 1980s.

Compared to ablative procedures, DBS has the advantage that the stimulation parameters can be customised and adapted over time. This method consists of placing an electrocatheter on each side connected to an external pulse generator, usually implanted in the subclavian region and connected to the two electrodes via a cable, which also serves as an interface for setting the stimulation parameters from the outside. The exact mechanism of action of DBS is poorly known and probably not univocal in all locations. Once the transient microlesion effect has worn off within the first few weeks, there are effects related to the interruption of the neuronal circuit, the blocking of depolarisation, the desynchronisation of the tremor pacemaker, the preferential activation of large axons that inhibit the activity of the internal globus pallidus (GPi), the induction of GABA and adenosine release, the disappearance of pathological electrical oscillations with the appearance of regular discharges, and the excitation of the nucleus concerned. The two main anatomic targets of DBS in PD are the internal globus pallidus and the subthalamic nucleus. The subthalamic nucleus, in particular, is the most used and most studied target: indeed, bilateral electrical stimulation of this nucleus provides excellent control of all the cardinal symptoms of PD (tremor, rigidity and bradykinesia), associated with a marked reduction or disappearance of motor fluctuations and dyskinesias. So-called “drug-resistant” symptoms such as orthostatic hypotension and other dysautonomic disorders, balance disorders, dysphagia and freezing (when not responsive to levodopa) do not improve with deep brain stimulation. As far as postural alterations are concerned, data is still scarce and not conclusive. The efficacy of DBS in alleviating the cardinal symptoms of PD is proven and long-lasting, although the progression of the disease and disability is not halted. Exclusion criteria include cerebral atrophy or brain lesions that severely alter the anatomy, dementia, active psychosis, personality disorders that impair intra- and postoperative compliance, poor health, as well as symptomatology that does not respond to drug therapy (with the exception of tremor). Possible complications of the surgical procedure are: infections, intracranial or wound haematomas, dislocation or misplacement of electrodes, cerebral infarctions, skin erosions, confusion, convulsions, dysarthria, worsening of phonemic and semantic fluency, dystonias or dyskinesias, eye deviation, deep vein thrombosis and pulmonary thromboembolism, weight gain and worsening of cognitive status.

1.5 Conclusions

PD is a degenerative disease of the central nervous system that is common in old age but also affects people at a young age. It has a high social impact and an aetiology yet to be elucidated, which is reflected in the lack of decisive therapies. However, there are numerous symptomatic therapies available that are very effective, especially in the early stages. More invasive therapies, such as infusion pumps or neurosurgical therapies, are available for advanced stages of the disease with the possibility of improving day-to-day control of major motor symptoms. Contrary to common belief, PD is, however, made up of a varied symptomatological set of a conspicuous number of both motor and non-motor symptoms, with the appearance over time of disorders that are not responsive to treatment, leading to a progressive loss of autonomy and quality of life. In particular, cognitive and balance disorders tend to dominate the very advanced stages of the disease with the need for continuous care of the patient throughout the day. The great heterogeneity in the presentation and course of PD requires treatment, care and support that is as individualised and tailored to the needs of the individual as possible.

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2. Beyond the clinical aspects: the social implications of Parkinson’s disease

by *Linda Lombi*[1]

2.1 Introduction

In a famous article entitled “Chronic illness as biographical disruption”, Micheal Bury described the experience of people who receive a diagnosis of a chronic degenerative disease in terms of a profound “biographical disruption” (Bury, 1982), explaining how, through the finding of the disease, the doctor traced a watershed in the life of these people, which was divided between a time before and after the diagnosis. These considerations also apply to Parkinson’s disease (PD), a chronic degenerative disease that affects many people globally.

Although it is difficult to know the number of people in the world who are affected by this disease, studies estimate that, in industrialised countries, the prevalence of PD hovers around 0.3 per cent in the general population, reaching, however, 1.0 per cent among people over 60 years of age and 3.0 per cent among those over 80. PD incidence rates are estimated to be between 8 and 18 per 100,000 people per year (Lee, Gilbert, 2016). Parkinson’s is the neurological disease with the highest growth rates, now exceeding those of Alzheimer’s. Indeed, the number of patients doubled between 1990 and 2015, and some forecasts speak of a further doubling by 2040, foreshadowing what some scholars have called “the Parkinson pandemic” (Dorsey, Bloem, 2018; Barker, 2020). Thus, forecasts indicate that the number of people with Parkinson’s disease (PwP) worldwide is set to grow enormously in the coming years.

From a clinical standpoint, Parkinson’s disease (PD) is a severe, disabling neurodegenerative disorder characterised by a progressive and chronic disturbance, mainly (though not exclusively) affecting movement control and balance (Poewe et al., 2017). However, this definition focuses on the clinical aspects of the disease and only captures certain aspects of it. As Gadamer (1994) reminds us, illness is not uniquely what medical science declares it to be (i.e. the outcome of a verifiable clinical assessment), but rather an experience of a suffering individual.

In the case of Parkinson’s disease, there is a large body of literature documenting the effects on the physical (disease) and psychological (illness) level, whereas less attention has been paid to the implications on the social level (sickness). This contribution is primarily aimed at exploring the latter.

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2.2 The triad "disease-illness and sickness" (DIS) applied to Parkinson's disease

The triad disease, illness and sickness is a conceptual model originally proposed by Twaddle (1968) to explain the multidimensionality of illness, and later taken up by many sociologists and health anthropologists (Kleinman et al., 1978; Young, 1982; Maturo, 2007). Briefly, we could say that the term disease refers to illness for medicine, illness is illness for the subject, sickness is illness for society (Maturo, 2007). In further detail:

(1) the concept of disease refers to illness as represented in the bio-medical model, i.e. a problem that essentially concerns the biological sphere and which can be "objectively" measured by giving rise to a diagnosis. In the words of Twaddle: "Disease is a health problem that consists of a physiological malfunction that in turn gives rise to an actual or potential reduction in physical capabilities and/or reduced life expectancy" (1994, p. 8).

(2) Illness is the way in which a person experiences and interprets his or her disease, or the sense of suffering that, in various respects, an individual may experience (Maturo, 2007). In other words, this dimension concerns how the disease is subjectively experienced and experienced by the sick person. It may include pain, weakness, perceptions concerning the adequacy of body functions, feelings of incompetence and fear.

(3) Sickness, on the other hand, concerns the way society represents and interprets the individual's illness. To use an expression by Twaddle (1994), we could say that sickness corresponds to social identity. When a health problem is recognised in terms of sickness, the person affected acquires a social status (he or she is a person living with an illness) that gives him or her rights to access treatment, possible financial support and exemptions from work (Hoffman, 2002). Following Maturo's proposal (2007), we can distinguish two sub-dimensions in sickness. The first corresponds to the "imagery of sickness", which corresponds to social representations of sickness, i.e. how society imagines and represents a specific illness. The second sub-dimension corresponds to the so-called "institutional sickness", i.e. the social recognition of changes to the social role played by the person, which can lead to legitimately obtaining a change in his or her job, to being absent from work for a certain number of days each month, to a reduction of the working day, or to the restriction of daily activities in the family environment.

Now, let us try to apply this model to PD, illustrating in this paragraph mainly the first two concepts (those of disease and illness) and referring the concept of sickness in the sub-dimensions of sickness imaginary (§ 2) and institutional sickness (§ 3) to the following paragraphs.

From the standpoint of disease, as we mentioned at the beginning of this contribution, PD is a neurodegenerative one. In the collective imagination, tremor is the symptom most frequently associated with PD, but this representation does not always correspond to the truth, both because not all PwPs have severe tremors and because the disease involves many other disorders[2].

These are partly motor disorders (in addition to tremor, they include, for example, rigidity, postural instability, bradykinesia, gait disturbances, motor blocks, blinking and eye movement disorders), and partly non-motor disorders (such as, for example, constipation, swallowing problems, hyposmia, urinary problems, hallucinations) (Schapira et

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[2] Please refer to Chapter 1 for more details on these aspects.

al., 2017; Balestrino, Schapira, 2020). These problems have a strong impact on the bio-psycho-social well-being and quality of life of PwP. Moreover, these disorders can limit functional autonomy, i.e. lead to severe difficulties in performing daily activities and taking care of oneself, requiring reorganising living spaces, starting with one's home.

In addition to difficulties strictly related to physical symptoms, we know that PwP are more prone to other problems that adversely affect psychological suffering (illness). Discomfort on the emotional front is frequent, especially in the immediate aftermath of the communication of the diagnosis, or in periods when the disease worsens. There is a strong correlation between PD and affective and behavioural disorders, mood disorders, apathy, alexithymia, anxiety and depression (Schapira et al., 2017). Anxiety and depressive disorders are more frequent among individuals with Parkinson's than in the general population, with the highest incidence rates ranging from 30-40% (Timmer et al., 2017) to 60% (Schapira et al., 2017). Some researchers have pointed out that the manifestation of depressive symptoms may even precede that of motor symptoms. This is a useful indicator for neurological investigations aimed at diagnosing the disease (Aarsland et al., 2012). The chronic-degenerative nature of the disease, then, is a source of strong concerns for the interviewees about the future worsening of the symptomatology: fear can give rise to a vortex of negative emotions that crystallise consciousness and can paralyse people's sense of purpose if they are not adequately supported.

The concept of sickness (and in particular the imagery of sickness and institutional sickness) applied to PD is a topic on which the attention of the literature is more recent and, on the whole, less widespread. Therefore, as anticipated, we will devote the next two paragraphs to these aspects.

2.3 The imagery of sickness: the social representation of Parkinson's disease and the problem of stigma

In terms of the imagery of sickness, PwP often have to deal with experiences associated with a sense of shame due to the fact that illness-related disorders make it difficult to comply with certain shared social norms concerning expected behaviour in public contexts, such as those governing, for example, eating or moving (Nijhof, 1995).

In some areas of the world, falling ill with Parkinson's disease brings social shame on one's family (Mshana et al., 2011). It is also common for PwP to experience embarrassing situations related to motor difficulties, tremor and frequent falls, resulting in withdrawal and social isolation (Soleimani et al., 2014). In addition, the disease can lead to difficulties in communicating due to dysphonia and dysarthria, disorders that create an abnormal pattern in the rhythm of oral speech making it monotonous and unemotional (Schröder et al., 2010). Other studies document difficulties in identifying emotional prosody (i.e. tone, intonation, and rhythm used to convey emotion) also in the speech of others (Mitchell, Bouças, 2009). Facial rigidity, a typical trait of people with this disorder, can lead to communication misunderstandings as well as difficulty in expressing one's emotional status through facial expressiveness (Madeley et al., 1995), which negatively impacts social well-being and quality of life (Gunnery et al., 2016). Communication difficulties are not infrequently at the root of great frustration for PwP, especially in the relationship with their family members and caregivers who tend to want to take their place when decisions need to be made (Chiong-Rivero et al., 2011). Because of these problems, a high risk of social isolation has been documented for PwP. Repeated social isolation can put one at risk of experiencing loneliness, which is a perceived state of persistent and debilitating social disconnection that has negative effects on mental and physical health (Prenger et al., 2020), especially among older people. Several studies have shown that PwP suffered more negative consequences than the general population, with respect to the risk of social isolation, during the lock-downs imposed by the Covid-19 pandemic (Subramanian, Vaughan, 2020).

A diagnosis of Parkinson's frequently has also a strong impact on people's social identity, i.e. their sense of belonging to certain social groups, a key factor in people's well-being (Soundy et al., 2014). The very name of the disease ("Parkinson's disease"), which is still used by some professionals and in numerous mass media communications, although disliked by PwP[3], refers to an infectious, contagious and dangerous disease.

The social isolation and loss of social identity of PwP is particularly worsened by a phenomenon highlighted by many studies on this illness and closely linked to the imagery of sickness: the stigmatisation of PD (Lombi, Marzulli, 2019; Maffoni et al., 2017; Ma et al., 2016). Stigma is meant as a deeply discrediting attribute that negatively impacts on the image of the individual, marks and shames him or her in a tendentially permanent manner. The stigmatisation process is the consequence of the fracture between the virtual identity (i.e. the identity associated with the role we assume in public) and the actual identity (i.e. the identity we display in private and which represents our essential self) (Goffman, 1963). Stigma is particularly associated with facial rigidity (Gunnery et al., 2016) and affects women more than men.

Stigma is nurtured through stereotypes, an expression that, from a sociological standpoint, refers to a complex of simplified images concerning a group of people, in which identical characteristics are attributed to all members of the group, without taking into account the variations between them. They are very simplified images, negative beliefs that one group shares in relation to another group or social category. Stereotypes can feed prejudices and translate, on a behavioural level, into discrimination, i.e. behaviour that treats some people unfairly based on specific characteristics. This is why it is important for illness to receive forms of social recognition (institutional sickness, cf. § 3).

As documented in the study by Maffoni et al. (2017), in addition to the social stigma of PwP, there is also a stigma involving the caregiver thst contributes to the negative perception of PwP.

In the social imagination, PD is often conceived through interpretative models dense with stereotypes. For example, we have already mentioned the widespread belief that the main problem of PwP is tremor, when we know that not all people diagnosed with Parkinson's suffer from this problem. Considering tremor as the only manifestation of the disease leads to a lack of attention - again in the collective imagination - to the many different disorders, both motor and non-motor, which we have referred to when discussing the manifestations of disease and illness in PD (cf. § 1). Stereotypes can give rise to

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[3] There are numerous initiatives set up by the Parkinson's world to counter the stigma of PwP. Among these, we would like to mention here an important campaign against stigmatisation called "Don't call me a disease" (https://nonchiamatemimorbo.info/la-campagna/), which was realised through a talking and travelling photographic exhibition that shows and tells the stories of PwP in order to eradicate stereotypes and prejudices about the disease.

prejudices (such as, for example, thinking that PwP are never able to work), which in turn can fuel discrimination (such as, for example, difficulties in being employed).

In order to avoid being stigmatised and discriminated against, many PwP hide the disease for as long as they can, i.e. until the signs of Parkinson's are visibly unequivocal (Hermanns, 2013; Lombi, Marzulli, 2019).

Another particularly widespread false belief about this disease concerns the affected population. In the collective imagination, PD is conceived as a disease that only affects the elderly. While it is true that this disease mainly affects the over-65 population, it should not be overlooked that there are also many cases of juvenile parkinsonism. The number of people diagnosed with the disease at a young age is around 5-7% in Western countries and reaches 10-14% in Japan out of the diagnosed total (Golbe, 1991). More recent data showed that juvenile Parkinson's affects between 12 and 20 in 100,000 individuals in Europe and up to 45 in Asia (Patil, Anilkumar, 2022).

Finding out that one has Parkinson's disease when still young[4] often entails a greater burden of suffering, not only because of a series of difficulties that may impact on one's social roles (such as parenting young children and working, cf. § 3), but because the effects of the stigmatisation process tend to be more widespread, although - let us repeat, for the avoidance of misunderstanding - this is not only a problem for younger patients.

Unfortunately, stigma becomes a device that multiplies the burden of the illness and has a very negative effect on relationships, because those who are stigmatised tend to feel unfairly embarrassed, inadequate and, as we have seen, to isolate themselves. In other words, stigma can influence not only the way in which PwP are regarded and treated by other people, but also the image they have of themselves and their expectations of their current and future relationships.

An issue that is still little talked about is the sexuality of PwP, although some studies show that the disease has a strongly negative impact on this aspect (especially on men) (Buhmann et al., 2017). This impact is only partly explained by reasons related to the biological implications of PD, but rather by socio-relational reasons, which are primarily linked to a sense of shame.

2.4 Institutional sickness: obstacles to social recognition of the illness

On the level of institutional sickness, the illness can entail a social type of disability, understood as a condition of disadvantage experienced by the person due to the fact that he or she can no longer fulfil roles considered normal based on age, gender and socio-cultural factors (Giarelli, Venneri, 2009). A number of studies document how PwP face a number of obstacles in the recognition of a disability status, in having to justify absences from work, and in obtaining a disability pension with sufficient income to meet their subsistence needs (Banks et al., 2006; Mullin et al., 2018). Falling ill at a young age can lead to several specific problems, for example because the illness comes at a time in life when people have to cope with special social expectations (e.g. related to looking after young children or work assignments) (Calne, Kumar, 2008; Lombi, Marzulli, 2019). Due

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[4] There is some divergence among scholars as to the maximum age threshold at which to speak of Young-Onset Parkinson's Disease (YOPD), which ranges between 40 and 55 years. Cf. Schrag, Schott (2006); Mehanna et al. (2014).

to the fact that people with juvenile Parkinson's disease have to live with the condition for longer, they may suffer more from physical, financial and psychological problems as they grow older. It has been shown that there is a significant relationship between the age of onset of PD and quality of life, which depends on a variety of factors, such as increased marital conflicts, family difficulties, the risk of social isolation and loss of employment (Schrag, Schott, 2006; Schrag et al., 2003).

However, with the lengthening of the working age, there is an increasing number of PwP who have to cope with the change of pace that illness can impose on their working life, so that they are increasingly faced with work-related problems (such as, for example, finding a new job or having to deal with a risk of demotion), the recognition of a disability status and the consequent allocation of a pension-type economic contribution to enable them to have a sufficient income to meet their subsistence needs.

The greatest problems are experienced by those who, at the time they fall ill, do not have adequate economic protection from an occupational standpoint (e.g. self-employed, insecure jobs), or who carry out a profession that requires them to have skills that are impaired by the progress of the disease (e.g. driving, public speaking, manual work requiring a great deal of control of movements). Some research points to much higher unemployment rates for PwP (up to 6 times higher in males, according to the study by Murphy et al., 2013) and an average early retirement risk of 5-7 years (Schrag, Banks, 2006; Martikainen et al., 2006). Workers with Parkinson's disease have special needs, e.g. the need to learn more about the different support options in the world of work, to get help from a professional to cope with work-related challenges, to get more information about the different options for reintegration into work, to benefit from an intervention based on an individualised and flexible approach that can enable them to work (Rafferty et al., 2021). Occupational therapy is also an area that is gaining increasing attention in order to promote the quality of life and employability of PwP (Dixon et al., 2007).

2.5 Conclusions

The distress experienced by people with Parkinson's is multidimensional.

Firstly, it stems from physical disability, the pain experienced in the body, and the difficulties associated with carrying out the actions of daily life (although these problems are very much conditioned by the stage of the disease). Secondly, PD also has a psychological dimension that translates into a personal experience of suffering that cannot be easily translated into the language of medicine. Finally, we have seen how there is also a social dimension to the disease that, due to often inadequate and fallacious social representations that feed stereotypes, prejudices, and forms of stigmatisation, not infrequently give rise to forms of discrimination and social exclusion.

As reported in a study by Haahr et al. (2011), PwP have to learn to live with the unpredictability of events: unexpected reactions of the body, unexpected situations that prevent one from being on time for appointments, the feeling of being a burden to loved ones, the reduction of living and social spaces.

These are are unforeseen situations that affect the well-being of those who encounter this illness on their path.

As Van Der Bruggen and Widdershoven (2005) remind us, the life of a Parkinson's patient is apparently characterised by an existential paradox: life appears at the same time motionless and unpredictably bizarre.

According to the author, this can manifest itself in the physicality of the person, in being in time and space, in relating to things and events, in being in the world and in life, and in being with others as an individual (Ibid.).

If medical research is engaged in finding a cure and improving the currently available treatments for PD from a clinical standpoint, it is society - understood as a network of cooperative and collaborative relationships with the aim of improving living conditions, survival and reproduction of the whole and its members - that must deal with the social aspects of the disease. Care, from a social standpoint, must be based first and foremost on knowledge of the social implications of the disease and the removal of barriers that prevent the full realisation of people who encounter the disease along their path.

A fundamental contribution in this direction is offered by the world of associations and Non-Profit organisations that promote actions to change the perception of sickness (such as the fight against stigma, which we have mentioned in describing some initiatives) or to intervene on institutional sickness (through advocacy actions aimed at promoting the recognition of rights). However, these are actions that require alliances with other social actors - researchers, policy makers, representatives and members of civil society - who are called upon to build a network of relationships that work in synergy to improve the living conditions of PwP and their families.

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3. Human-Centred Design - Inclusive Design: design for People with Parkinson's disease

by *Francesca Tosi*[1]

3.1 Human-Centred Design: design for people

The Human-Centred Design (HCD) approach to design can be defined as "*design for people*"[2], i.e. an approach to design based on attention to the people to whom the project is addressed and, in particular, on understanding and interpreting their characteristics and capabilities, their needs, their desires and expectations in carrying out the activities of daily life and work, in their relations with the environments in which they live, the physical and virtual objects with which they come into contact, the services they can - or cannot - use and, of course, with others[3].

To do this, HCD makes available a now very extensive number of survey and evaluation methods for assessing people's needs, which makes it possible to collect, evaluate and interpret those needs in a structured and systematic way, making it possible to compare the information collected within the same project and, in parallel or over time, in different or subsequent projects (see Fig. 3.1).

Reversing a well-known definition by J. Rubin and D. Chisnell (2011)[4], in fact, the Human-Centred Design approach can be defined as a philosophy of intervention, which

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[2] For a more extensive treatment of these topics see Tosi F., *Ergonomia per il Design, Design per l'Ergonomia*, FrancoAngeli, Milan, 2018 (published in English: *Design for Ergonomics*, Springer 2020) and Tosi F., Rinaldi A., *Il Design per l'Home Care. L'approccio Human-Centred Design nel progetto dei dispositivi medici*, Dida Press, Florence, 2016.

[3] ISO 9241-210:2010, *Ergonomics of human-system interaction. Human-Centred Design for interactive systems defines Human-Centred Design as "an approach to the development of interactive systems that aims at making systems usable and useful by focusing on users, their needs and requirements, applying the knowledge and techniques of Ergonomics/Human Factors and usability. This approach increases efficiency and efficacy, improves people's well-being, user satisfaction, accessibility and sustainability. It also counteracts possible adverse effects of use on health, safety and performance*". Originating in the 1970s in the field of human-computer interaction studies and aimed at evaluating and designing the usability of computer interfaces, the HCD approach has progressively broadened its scope to the design of products, environments, systems and services, extending its investigation methods and tools to the specific contexts of these sectors.

[4] Rubin and Chisnell write: "*UCD represents the techniques, processes, methods, and procedures for Designing usable products and systems, but just as important, it is the philosophy that places the user at the center of the process*". Rubin J., Chisnell D., *Handbook of usability testing: how to plan, Design and conduct effective tests*, Wiley, Indianapolis USA, 2011, p.12.

places people at the centre of the processes of design and creation of products, environments,and systems and, at the same time, as the set of methods and procedures that make it possible to conduct any evaluation and planning intervention starting from information concerning people's needs and expectations.

Fig. 3.1 Human-Centred Design approach: questions and methods for providing answers. Reprocessed image, source: Rubin J., Chisnell D. (2011, p. 15).

Today, a large number of investigation methods have been developed in the field of HCD in various research and design groups, but in a nutshell, they can be divided into *expert evaluations*, i.e. methods involving direct or expert evaluation by researchers, and *empirical evaluations*, i.e. methods directly involving users.

In the field of design, the best known and most used methods among expert evaluations are the *Task analysis* and *heuristic evaluations*; for empirical evaluations, the most frequently used methods include *direct observation*, *Thinking Aloud*, *interviews* and *questionnaires*, *usability tests*, and various *co-design methods*, all of which are conducted with the direct involvement of selected samples of users and aim at evaluating and designing usability and user experience.

The starting point is therefore an attitude towards design that starts with the ability to pay attention to what the literature calls the "context" in which one is called upon to design, and which consists of '"*he users, activities, equipment (hardware, software and materials) and physical and social environments in which a product is used*"[5], or more simply the complex and changing set of all the elements that define the relationship between people and their living environment.

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[5] Cf. ISO 9241/2010 "Ergonomics of human-system interaction. Part 210: Human-Centred Design for interactive systems".

It is in fact the experience of the person - referred to as User Experience (UX), defined by legislation and in literature as the set of “perceptions and responses of the person that result from interaction with a product, system or service, which include all the emotions, beliefs, preferences, user perceptions, physical and psychological responses, types of behaviour and realisations that occur before, during and after such interaction”[6] - that represents the starting point of the design action, and its final objective: to create environments, products and services capable of improving people’s experience by responding to and interpreting in the best possible way the specificity of their needs, desires and expectations, whether explicitly declared or still unexpressed.

The operational objectives of the HCD/UX approach can be stated in three main principles[7]:

- *the ability to immediately focus attention on the user and the task*. It is necessary to identify the persons and/or groups of persons targeted by the project and to identify a representative sample in order to collect information in a structured form on their particularities, needs and expectations.
- *empirical measurement of how the product is used*. This means assessing people’s behaviour and, in particular, the easy learning and user-friendliness of the products, environments or services considered.
- *iterative design through which the product is cyclically designed, modified and tested*. Once the project requirements have been identified, to evaluate the design solutions against these requirements, from the initial concept phase to the development of the final design, “forming the product” through a cyclic process of design, evaluation, re-design and re-testing.

Once the need/willingness to design a new product, system or service has been defined, the project set-up and development phases have as their starting point the knowledge of the context of use - the basic reference of the Human-Centred Design process - which takes the form of the analysis and evaluation of the context variables, i.e. all the factors that contribute to defining the interaction between the individual and the product, i.e., by definition[8]: the users, the activities carried out and their objectives, the physical, organisational and technological environment of reference, and of course the products examined (see Fig. 3.2).

From a strictly operational perspective, this involves describing the context of use by answering some basic questions: *WHAT* needs to be designed? *WHO* will use it (which persons will have a direct or indirect relationship with that product)? *WHY* (for which activities and with which objectives)? *WHEN* (at what time of the year or day and with what

[6] The ISO 9241-210/2010 Standard defines User Experience as “the perceptions and responses of the person that result from the use and/or intended use of a product, system, or service”, stating that: “User experience includes all the emotions, beliefs, preferences, user perceptions, physical and psychological responses, types of behaviour and realisations that occur before, during and after use, and is a consequence of the brand image, presentation, functionality, system performance, interactive behaviour and service capabilities of the interactive system, the inner and physical state of the user deriving from previous experiences, attitudes, skills and personality, as well as the context of use. - Usability, when interpreted from the perspective of the users’ personal goals, may include the kind of perceptual and emotional aspects typically associated with user experience. Usability criteria can be used to evaluate aspects of the user experience”.

[7] Revised from Rubin J., Chisnell D., Handbook of usability testing: how to plan, design and conduct effective tests, Wiley, Indianapolis USA 2011, p. 13.

[8] Cf. ISO 9241/2010 “Ergonomics of human-system interaction. Part 210: Human-Centred Design for interactive systems”.

frequency)? *HOW* and *WHERE* can that product be used? Of course, in order to answer each of these questions, it will be necessary to investigate further: for example, *who are the people who will use or enter into a relationship with the new product? What is their possible age range? Their nationality and cultural affiliation? Their education level? Their level of competence in the use of similar products? What could their characteristics, abilities and limitations be - physical, sensory, cognitive?* etc. A brief outline of the context analysis phase is provided in figure 3.3.

Attention to the specificity of the people to whom the project is addressed, and the aim of responding to their equally specific needs and expectations, is the basis of the close relationship between the Human-Centred Design approach and Design for Inclusion/ Inclusive Design, today considered an integral part of Human Centred Design, defined as "*a specific type of HCD approach to Design. The ID approach focuses specifically on understanding the needs, abilities and aptitudes of people who have some form of disability and applying this knowledge to mainstream design. A central aspect of Inclusive Design is to shift the focus from so-called mainstream needs to a broader framework of needs and expectations*"(E. Elton and C. Nicolle, 2015, p. 3012)[9] [10]. In other words, inclusive design means focusing on people's needs and expectations, taking into account their different specialities, their different levels of autonomy (physical, perceptive and cognitive) and their variability over time, and taking them as project references[11].

Therefore, the two objectives of Inclusive Design are: (i) to create "*mainstream*" products, environments and services that can be used and appreciated by as many people as reasonably possible, including the majority of people, without requiring complicated or costly adaptations; (ii) to create specialised products, environments and services, i.e. capable of meeting specific needs deriving from specific disabilities or inconveniences that can be recognised as their own by very different types of users.

The starting point is to focus on the different levels of ability, and to identify and interpret the needs of the people who will use or have a relationship with the environments, products or services we are designing, and may do so over the years as their personal situations change.

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[9] As E. Elton and C. Nicolle (2015): "*There are many approaches to design. The approach selected is often dependent on the type of value that the product and/or service intends to deliver to final users. (...) the Inclusive Design approach intends to create consumer products or services that are accessible and usable for people with the widest range of abilities within the widest range of situations without the need for special adaptations or design (BS 7000-6-2005). (...) Accessibility and usability are the key criteria of this approach. Accessibility refers to providing users access to functionality through their sensory, physical and cognitive abilities. Design for accessibility also focuses on the principle of extending the design standard to persons with certain types of performance limitations in order to maximise the number of potential customers who can immediately use the product, building or service (BS 7000-6-2005). Usability refers to the extent to which the product or service can be used by specific users, to achieve specific goals with efficacy, efficiency and satisfaction within a specific context of use. In simple terms, accessibility means that a different range of users can perceive, understand and physically interact with the product, and usability refers to whether (and how) users can perform their activities with the product in an efficient, effective and satisfying way.*

[10] Cf. Chap. 5.

[11] Also of interest is the definition given by the Inclusive Toolkit Manual available on Microsoft's website https://www.microsoft.com/Design/inclusive/, according to which Inclusive Design is a design methodology that enables and draws on the full range of human diversity. More importantly, this means including and learning from people with a range of perspectives. Designing inclusively does not mean that you are doing one thing for all people. You are designing a variety of ways by which everyone can participate in an experience with a sense of belonging. Many people are unable to participate in aspects of social life, both physical and digital. Understanding why and how people are excluded gives us actionable steps to take towards Inclusive Design.

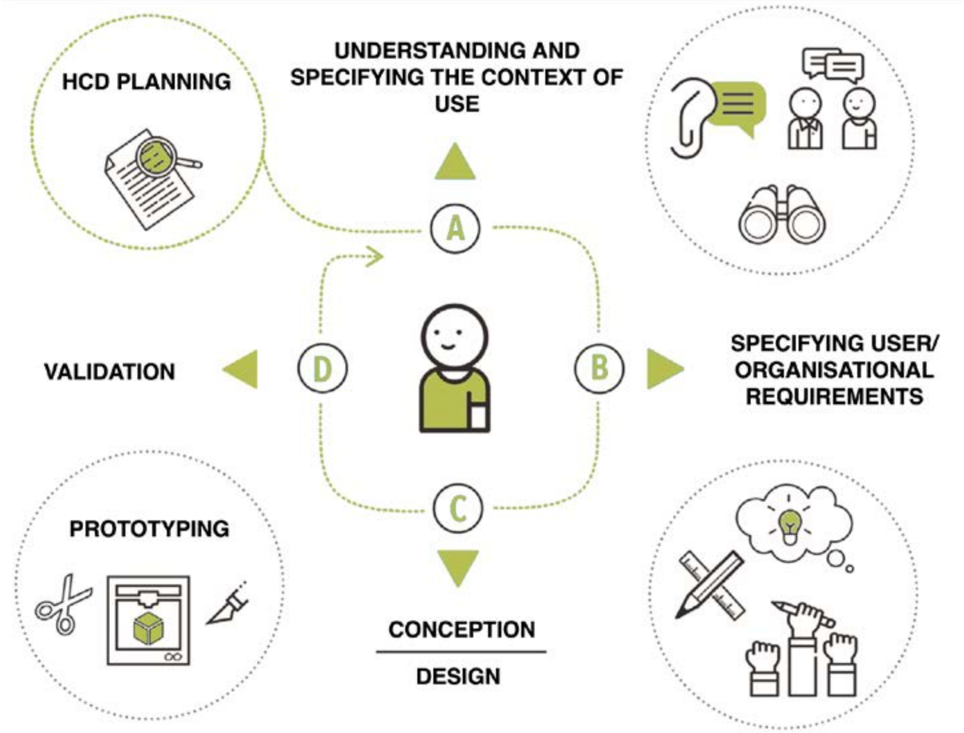

Fig. 3.2 Interdependence of Human-Centred Design activities. Source: ISO 9241-210 p. 12.

WHAT IS the product	Primary and secondary functions Primary and secondary objectives Types of users targeted Types of use (domestic, professional, etc.)
FOR WHAT the product is used	Types of activities performed/planned Level of psycho-physical commitment
WHERE the product is used	The environment of user/product interaction (physical, social, organisational, technological, etc.)
WHO IS the user	Age, gender, nationality, profession, spending capacity, physical, cognitive and sensory abilities, skills, religion, etc.
WHEN the product is used	At what time of year, day, etc. With what duration (for how long) How often (occasionally, continuously, temporarily, etc.)
HOW the product is used	Modes of use by users Conceivable habits of use

Fig. 3.3 Evaluate and interpret context of use variables.

3.2 Recognise needs, design for inclusion

To fully understand the meaning of Inclusive Design, it is useful to start with some terms that define its opposite, whose concrete examples are part of everyone's experience.

Ignorance - understood as non-awareness - of the needs arising from the different situations of discomfort or disability, hence the design of products, environments or services that seem to be designed not for the real and different human capacities but for a small percentage of people acting at full capacity.

The lack or deficiency of attention, often at the root of the lack of knowledge, gives rise to "mainstream" products designed for the so-called average user. The most classic example of this are kitchen furniture and appliances, whose standardised dimensions make the wall cabinets and the simple approach to the worktop inaccessible to wheelchair users, or the high shelves of wall cabinets, bookcases or cupboards inaccessible to seated or short people. Furthermore, handles that are difficult to grip or too small to exert hand and arm strength, unstable shelves, slippery or uneven polished floors or road surfaces, which represent a barrier to movement and sources of tripping or falling, etc.

Exclusion, i.e. the impossibility of relating to the environment, to artefacts, and in many cases to other people, which can arise from environments, objects or services that are badly designed or designed without taking into account the needs of people with discomforts or disabilities[12], characterised by what we can define as a distance, more or less significant, from the abilities and autonomy levels considered "normal".

From the simple inability to read the small print on the packaging of foodstuffs or medicines, or to reach the products to be purchased on the top shelves of a supermarket - everyday experiences for the elderly who have become visually impaired and for people of small stature or with limited mobility, respectively - to the impossibility of using public transport due to the presence of flights of stairs and long corridors in subways and railway stations for people with mobility impairments (or for those who simply have to carry a heavy suitcase).

According to K. Holmes (2018 p. 5), exclusion can be compared to the feeling of "being left out" experienced by a disabled child watching other children play together in

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[12] The term "disability" is defined as "any limitation of the capacity to act, resulting from a state of impairment/disability" followed by a condition of disadvantage or handicap experienced by the person in relation to the actions, activities, types of behaviour or attention-reaction capacity required by the physical and social environment in which he or she lives. Disability is thus a condition of limitation and personal difficulty, which results in a disadvantage, or handicap, that manifests itself in the interaction with the physical and social environment when these prevent or limit the person's autonomy. ICF's "International Classification of Functioning, Disability and Health" describes the limitations or disabilities of the individual according to the pathologies and/or impairments from which they may result and the limitations in individual and social activities they may cause. The ICF classification, published by the World Health Organisation in 2001, constitutes, together with ICD 10 (International Statistical Classification of Diseases and Related Health Problems), the evolution of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), first published in 1980, which contains the definitions of the following terms: (i) impairment: any loss or abnormality in a psychological, physical or anatomical structure or function; (ii) disability: the limitation or loss, resulting from impairment, of the ability to perform an activity in the manner and to the extent of parameters considered normal for a human being; (iii) handicap: the discrepancy between the subject's efficiency and status and the expectations of efficiency and status coming from the environment (social and physical) and from the subject himself. Handicap is thus a limitation of ability that manifests itself in the relationship with the (physical and social) environment in which the person lives and is the consequence of the disability and not the disability itself. Cf. WHO, ICF International Classification of Functioning, Disability and Health, http://www.who.int/classifications/icf/en/.

a playground. Exclusion, in fact, is not only “not being able to do things” but also “not being able to do things together with others”, not “being able to participate” like and with others in active life.

In this sense, disability can be defined both as the *distance of one’s abilities* from those commonly considered normal (as exemplified by the terms “disabled” and “able-bodied”, which are often used in opposition, and in a horrible way, even in everyday language) and as *a distance from others and from the normality of life*, imposed by the physical and social environment in which one lives.

Precisely starting with the concept of *distance*, it is important to emphasise that situations of reduced capacity do not only concern conditions of overt disability, but the wide range of conditions that deviate more or less markedly from what is commonly referred to as normal capacity: physical, perceptive and cognitive.

Different abilities compared to the norm may concern the range and precision of movement, visual or auditory acuity, but also learning abilities as well as the decoding of information from the physical and social environment, which to a different extent limit the person’s autonomy in life and relationships.

The feeling of reduced capacity compared to the “norm” is experienced by children (younger and more fragile than adults), women in the last months of pregnancy, elderly people, and people with sight or hearing problems. And again, many challenging situations can limit our abilities: carrying a suitcase or a bulky parcel, or carrying a child makes it difficult to climb a flight of stairs or to walk long distances, a state of anxiety or fear can limit or affect our ability to correctly understand what is happening around us and/or to react rationally to external stimuli. In other words, situations of reduced capacity, of disability compared to the “norm” are part of everyone’s life, according to the biological phases of growth and ageing, or to temporary or permanent phases resulting from an accident or a disease, or to transitory phases due to contingent situations that are often part of our everyday life.

As J. Clarkson (2015) writes: “Any interaction with a product or service generally requires a cycle in which the user perceives, thinks and acts; where for most (of the cases), *perceiving* requires sensory skills, *thinking* requires cognitive skills and *acting* requires motor skills, taking into account that both perceiving and acting also use some elements of cognitive skills.

Exclusion occurs if some of the sensory, cognitive or motor requirements of the task exceed some of the corresponding capabilities of the user”.

Designing products that are safe and easy to use therefore means meeting the inescapable needs of the most disadvantaged categories of users, but also the needs of very large segments of the population for whom the greater usability of products, environments and services will result in conditions of improved well-being, time and energy savings, and a general improvement in the quality of life.

In parallel, many solutions designed to meet the special needs of equally specialised user groups can be successfully addressed to a much wider range of users. It should be emphasised, in this regard, that an important source of frustration is represented by products immediately identifiable as “products for the disabled” which, although necessary or potentially useful, are experienced as the stigmatisation of one’s own “diversity” in relation to others, and are often rejected by those who might actually use them to their undoubted advantage because of their appearance and their unquestionable difference from “normal products”.

The aim of design is therefore the creation of products and environments that, starting from the specific needs of people with reduced physical, perceptive or cognitive abilities, are easily usable and desirable for all people.

The reasoning obviously applies to everyday products and services, i.e. the so-called "mainstream" products, from household appliances to furniture or living spaces, and cannot be applied, or can only be applied in part, to products designed to meet special needs: e.g. movement aids, bathtubs with doors or cutlery shaped for people with reduced mobility. The objective is therefore not to "design everything for everyone", but to design consumer products that meet the needs of the widest possible range of users, starting from the knowledge and interpretation of the needs of the weaker sections of the population and, in parallel, products designed based on the needs of specific categories of users that can be addressed to all those who express similar needs.

There are many examples: the now more than famous Robson Square staircase in Vancouver (see Fig. 3.4), in Canada, in which the steps are perfectly integrated with the ramps to a very high aesthetic effect, and many similar solutions, including the equally interesting staircase in Pioneer Courthouse Square in Portland, Oregon, USA (see Fig. 3.4); voice reading of texts, as well as dictation, both of which were created to make reading and writing possible for visually impaired people and are now widely used by many people for reading and dictating texts and messages; the possibility of enlarging texts and images on computer screens, which was also created to ensure the accessibility of websites, and is now used as a normal form of reading by everyone on computers, smartphones, etc. with just the swipe of a finger; and the Servetto® lifting system (see Fig. 3.5), trolleys, remote controls, corkscrews (see Fig. 3.6), all products that were born and advertised when they were first marketed as solutions for people with reduced abilities (for those who cannot climb a ladder to reach the top of a wardrobe, for those who cannot get up to change the TV channel, for those who cannot carry heavy suitcases by hand, for those who cannot unscrew sturdy caps, etc.) and often initially refused as signs of one's own physical weakness, and today used by everyone as normal and indispensable objects of everyday life (who among us would want to stand up to change the TV channel or carry a heavy suitcase by hand?).

For whom, then, should we design? The answer is to understand who the project is aimed at and how many people the solution we are proposing could address.

In the case of the project aimed at people with conditions of discomfort or disability, it means starting from the identification and interpretation of specific needs and proposing design solutions capable of meeting those needs by extending their usability to the widest possible number of people.

The designer's attention then shifts from designing for a specific category of *users*, to *designing for a specific category of needs* that may unite people who are also very different from each other, to which the designer must respond with solutions capable of addressing the widest possible number of people.

The project's objective is to offer innovative and appropriate solutions, taking as a reference for the project all those who will enter in relationship with the designed space, artefact or service and ensuring that they will do so, over time, for longer or shorter periods of their lives.

Fig. 3.4 Integrated bleachers with ramps at Robson Square - Vancouver, Canada. Source: https://commons.wikimedia.org/wiki/File:Robson_Square_waterfall_2018.jpg (left). Pioneer Courthouse Square, Portland, Oregon USA. Source: https://commons.wikimedia.org/wiki/Fi- le:Pioneer_Courthouse_Square_-_west_half.jpg (right).

Fig. 3.5 Servetto® wardrobe lifting system, manufactured by Servetto srl. Source:www.servetto.it/en/products/saliscendi.html.

Fig. 3.6 One-Touch Jar Opener, designed by Mark Sanders for Daka International. Easy-to-use can and jar openers for children, the elderly and people with arthritis. Source: https://commons.wikimedia.org/wiki/File:One-Touch_Jar_Opener_Designed_by_Mark_Sanders_for_Daka_International.jpg.

Fig. 3.7 Magnetic Aids System for Tac Tee Objects (Functionable s.r.l). Source: https://www.leonardoausili.com/prodotti/765-tactee.html.

3.3 Designing for people with Parkinson's disease

In the specific case of the project for people with Parkinson's disease, the starting point is, therefore, first of all "to know" (i.e. to pay attention to) the characteristics of the disease and the specificity of the discomforts and limitations that it brings to the person in the course of its evolution and, at the same time, the specificity of the needs of the person with Parkinson's, of his or her family and/or cohabitants and of all those who come into contact with him or her both in the sphere of care activities (formal and informal caregivers) and in the sphere of normal activities and relationships in daily life.

Needs and expectations which, in this specific project area as in the others, can be explicit, i.e. declared by people based on their knowledge and experience, or implicit, i.e. not explicitly declared or translated into specific requests, which require a more elaborate interpretation, closely linked to the evolution of the disease over time.

Indeed, it must be taken into account that the people involved in the survey phase express themselves based on their own experience, often not knowing the possible solutions and design responses to their needs, the intervention alternatives, the products and aids already on the market or otherwise feasible and, in some cases, not being aware of the experience of other people with the same difficulties.

The design proposal will therefore have to meet both explicit needs and expectations and to interpret implicit ones, and it will also have to respond to their possible evolution over time.

This is obviously true in the case of Parkinson's disease, but also in many other cases: for example, the design of a home environment, as well as its furnishings and technological equipment, aimed at young families with children, must propose solutions capable of evolving over time as the needs of a family with adolescent and then adult children change, and of being adaptable, at a later date, to the needs of a new family unit; another example is the adaptability of environments, furnishings, technological equipment, to the safety needs of children, or to the needs of full accessibility (toilets, kitchens, spaces for movement) of elderly persons and/or those with limited autonomy.

In the specific case of people with Parkinson's disease, the projection of design solutions over time is realised in the adaptability of spaces, furnishings and equipment, in the possibility of guaranteeing adequate space for wheelchairs and mobility aids, and in the possibility of inserting walking aids and technological equipment (e.g. for environmental control, fall detection, etc.) with low-cost and easy-to-implement interventions, while maintaining the configuration and general image of the home as unaltered as possible.

In this way, the specificity of needs posed by the different stages of the disease and the consequent different levels of autonomy, as well as the different necessities for support and care, become basic references for the project and translate into the principle of versatility and adaptability over time, which can offer a plurality of options already envisaged and easily adoptable.

Finally, the design solutions identified for the specific case of people with Parkinson's disease can be used in other numerous and diverse contexts, in which full accessibility and safety of the living environment, its full domesticity and its adaptability over time can contribute to improving autonomy and quality of life.

This of course applies to the many other conditions of limited autonomy resulting from illness, disability or the natural ageing process, and can also apply to the even more numerous conditions of limited autonomy that are part of everyone's daily life, as solutions capable of making our life simpler and safer.

The concept "from a project for one to a project for many" means in this sense broadening the view of the opportunities offered by experimentation in the field of so-called specialised design, enriching the design landscape with knowledge and results that can make life safer, simpler and often more pleasant for everyone.

Below are some pictures of the research project *Home Care Design for Parkinson's Disease*, which will be illustrated in more detail in Chapters 9 and 10.

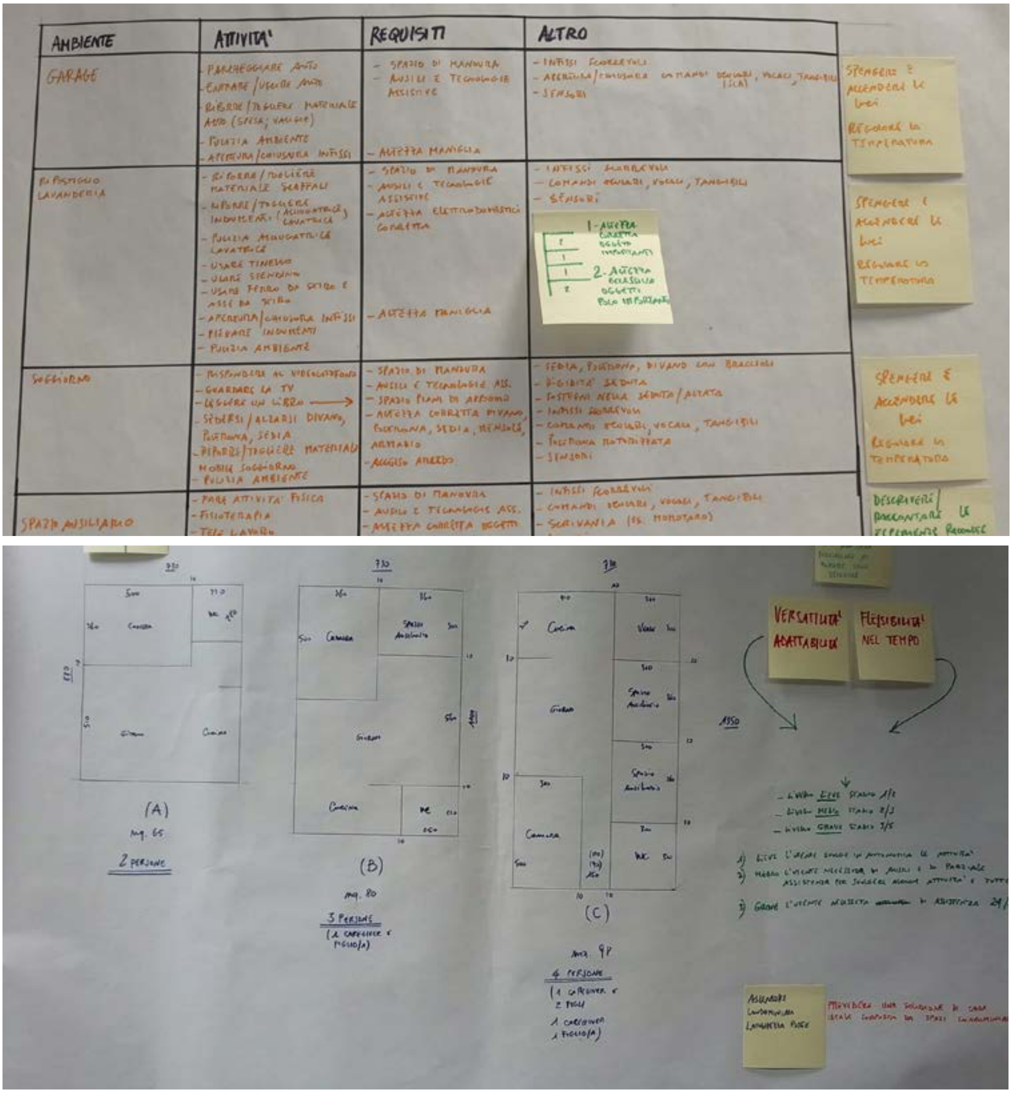

Fig. 3.8 Photo *Home Care Design for Parkinson's Disease*. © Laboratory of Ergonomics and Design LED.

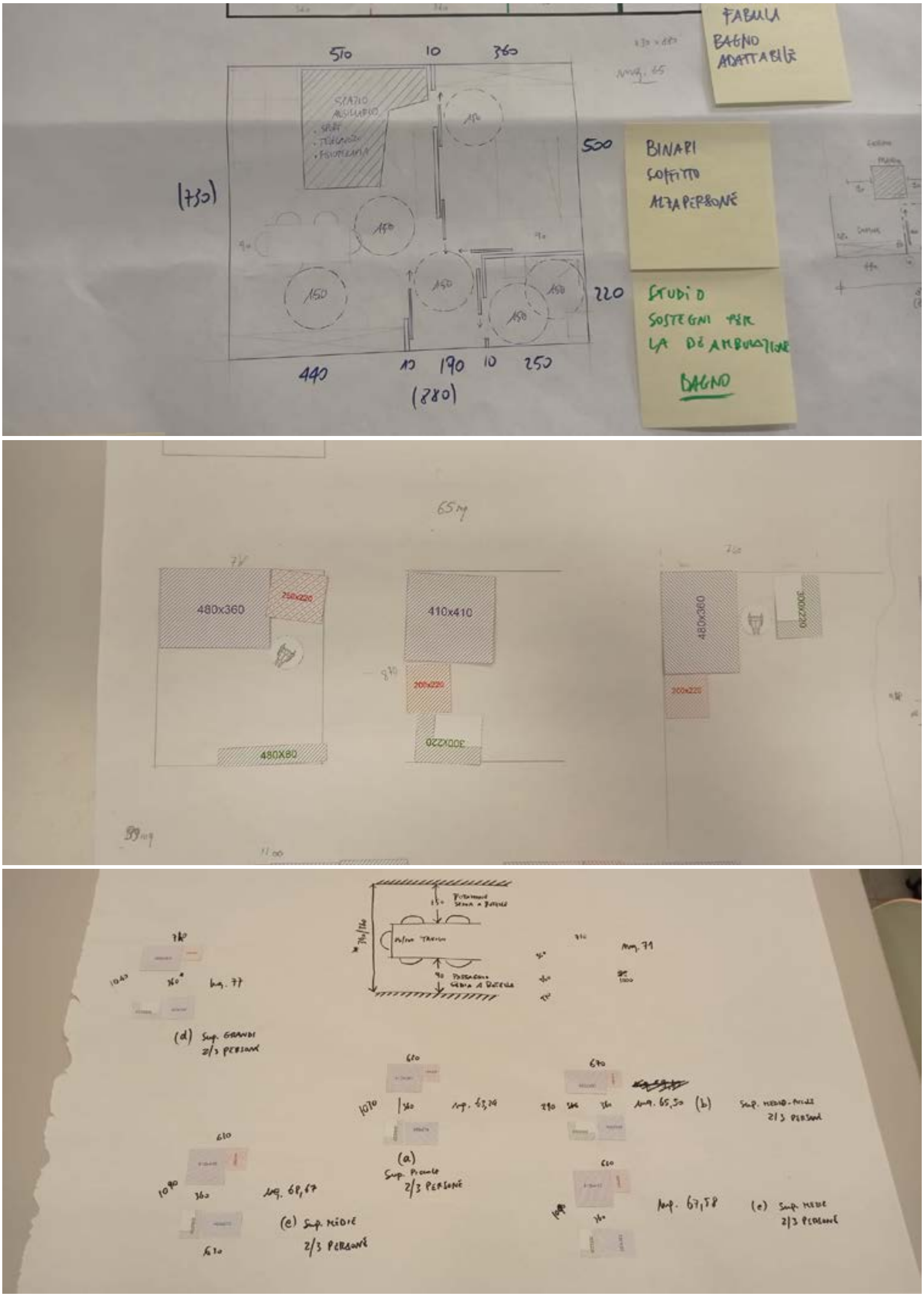

Fig. 3.9 Photo *Home Care Design for Parkinson's Disease*. © Laboratory of Ergonomics and Design LED.

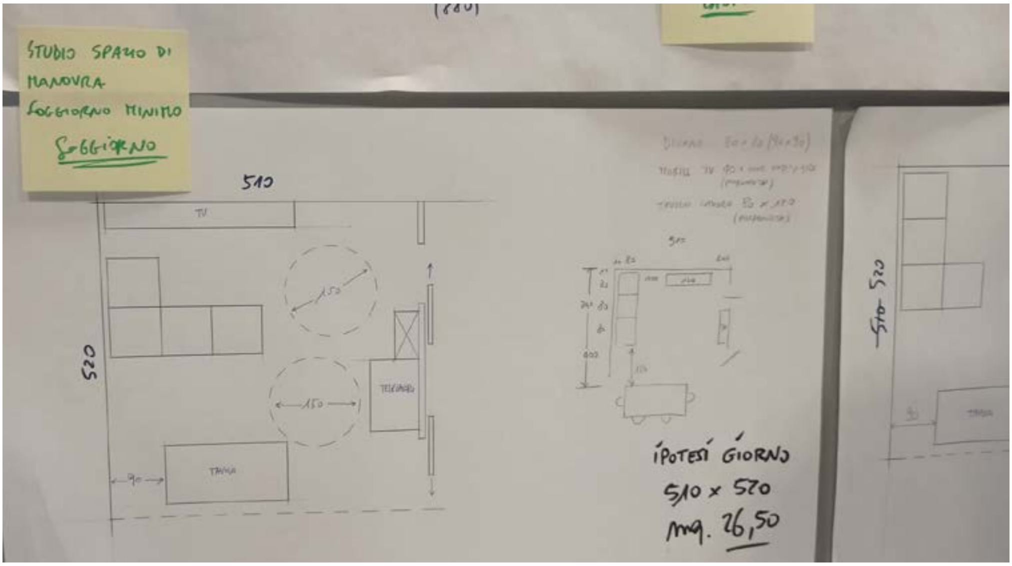

Fig. 3.10 Photo *Home Care Design for Parkinson's Disease*. © Laboratory of Ergonomics and Design LED.

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4. People with Parkinson's disease in the home environment[1]

by *Francesca Tosi*[2], *Mattia Pistolesi*[3]

4.1 The relationship with space and objects

The human being is an individual with many capacities, needs and desires and, in addition to representing the absolute singularity in the social community, he or she lives through personal changes throughout life, by experiencing them for physiological reasons - growth and ageing - and for temporary or permanent ones.

For example, pregnancy, or weight changes, etc. Obviously, important limitations of one's abilities can be caused by a disease or trauma, which has taken place in the course of life or is already present at birth and, as the World Health Organization has pointed out, many people suffer because of a disability or a health condition that leads to a disability condition, which becomes a handicap - i.e. a disadvantage - when the person has to confront the obstacles - or barriers - posed by the physical and/or social environment (WHO, 2011). The handicap can therefore be described not only as a disadvantage in the relationship with the physical and relational environment, but also as the denial of the right to enjoy one's autonomy, participation in social life and, more generally, the right to the quality of one's life. And the right to the quality of life in one's home is obviously essential considering that, for a fragile person or a person with disabilities, the home can represent the place where most or all of the day is spent and, inside, the greater or lesser levels of accessibility and safety of everyday environments and objects translate into the possibility or not to lead a life as autonomous and serene as possible.

With regard to the "home for people with Parkinson's disease", it is important to underline that, in comparison with the great amount of scientific contributions about clinical, diagnostic and therapeutic research related to Parkinson's disease and, as far as the disciplines of the project are concerned, the numerous contributions devoted more generally to the relationship between disability and home space, there is to date a very limited number of studies on environments, products and services specifically aimed at people with this pathology (Imrie, 2006; Preiser, Smith, 2011).

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1 Authors of paragraphs of Chapter 4: Francesca Tosi: Par. 4.1; Mattia Pistolesi: Par. 4.2 and 4.3. 2 Cf. Chap. 3.

2 Cf. Chap. 3.

3 PhD in Design and Designer, he is a contract professor at the degree course in Industrial Design of the University of Florence. Since 2014 he has been carrying out research activities at the Ergonomics & Design Laboratory of the same University, addressing issues related to usability, Interaction Design, Human-centred Design and User-Experience in the field of Health and Care Design. He is the author of books, articles and essays, published in national and international scientific journals and in conference proceedings.

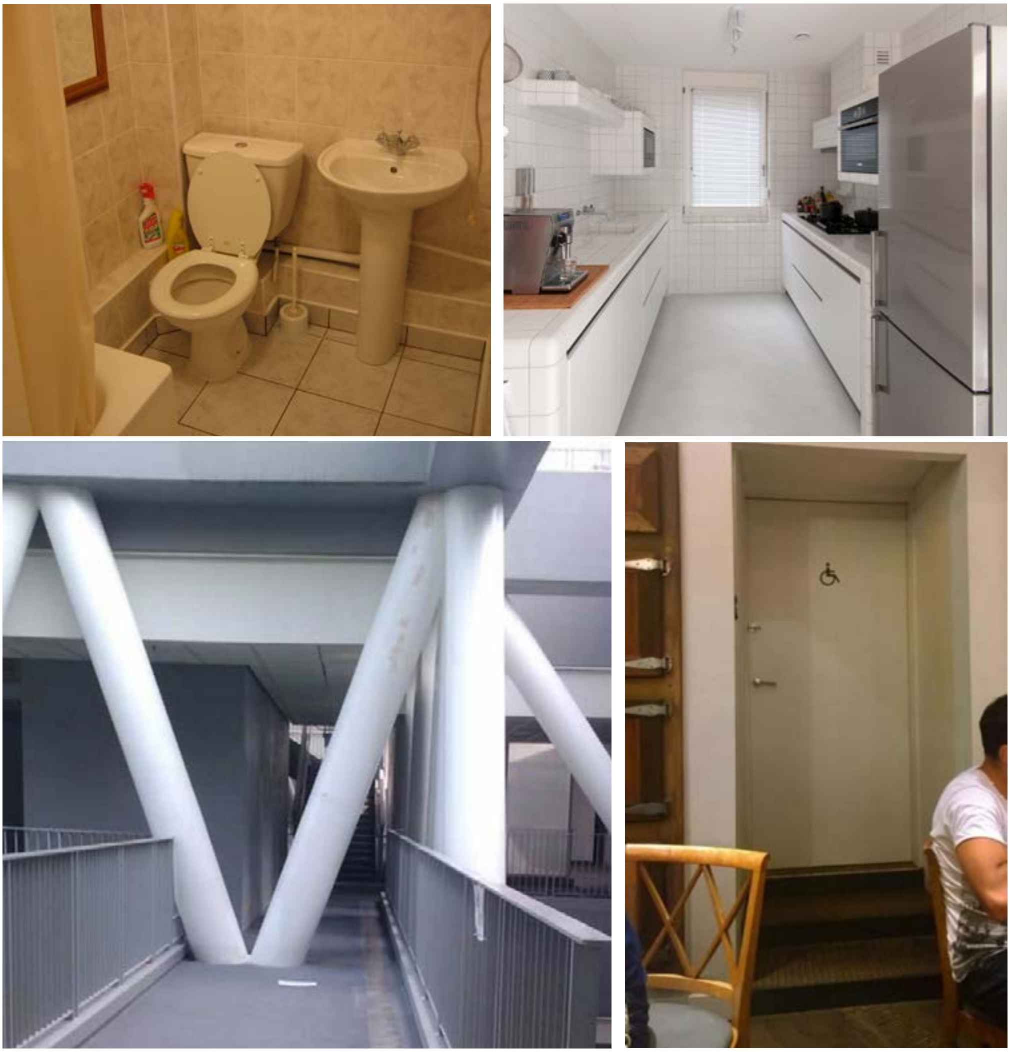

Fig. 4.1 Images of architectural barriers. Source: www.flickr.com/photos/cristiano_betta/361553079 (in alto a sinistra), www.flickr.com/photos/dtile/31092375228 (in alto a destra) e www.repubblica.it/tecnologia/social-network/2015/04/14/foto/in_casa_o_per_strada_il_disastro_e_dietro_l_angolo-111877354/1/ (in basso).

Among these is the document recently published by the *Davis Phinney Foundation's for Parkinson's*[4], which contains guidelines for building a house suitable for the needs of a person with Parkinson's (PwP). The purpose of the document is to inform PwP, carers and designers and to invite them to consider a series of aspects (lights, floors, rooms, etc.) necessary for PwP to be able to use safely and effectively all the spaces in the house where he or she lives.

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[4] Cf. www.davisphinneyfoundation.org

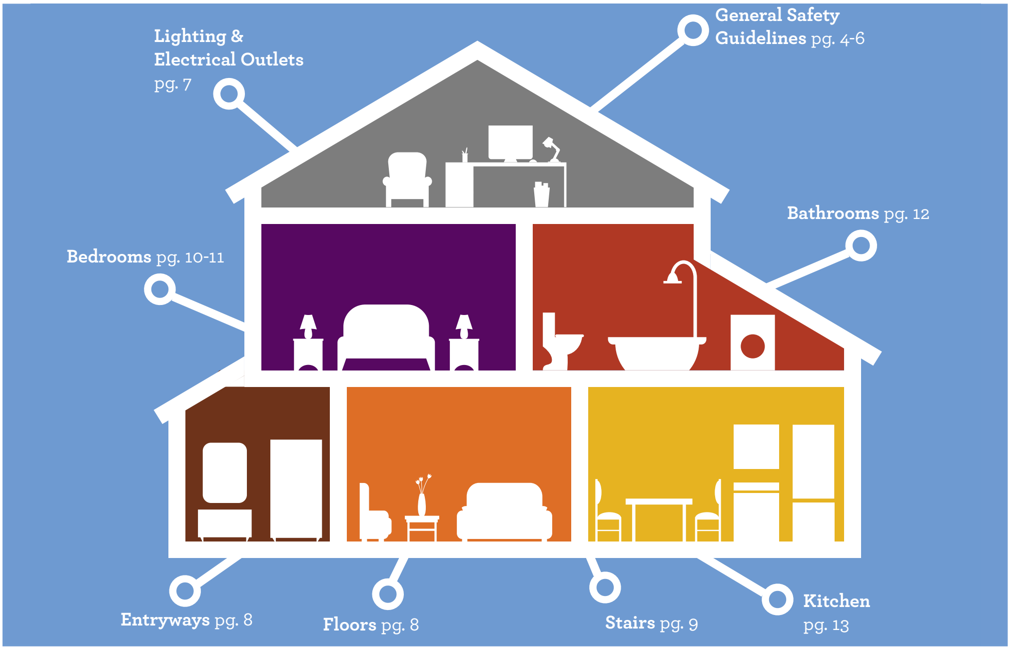

Fig. 4.2 Davis Phinney Foundation's for Parkinson's guidelines. Source: www.davisphinneyfoundation.org.

Another interesting contribution is the second edition of the book Parkinson's disease: 300 Tips for making Life Easier (Schwarz, 2006), which provides about 300 tips to PwP and caregivers to help simplify daily activities, such as knowing the disease, making the home safe and accessible, organising and planning in the home and away from home, in addition to directions to better manage medical care in one's home. As the author argued, the book aims at informing PwP and carers about all aspects of Parkinson's disease and, more specifically, Chapter 2 provides valuable suggestions for designers who, with reference to the various and sometimes tacit facets of Parkinson's disease (PD), can help make home spaces safer and more accessible.

The guidelines produced by the CUED (Centre for Excellence in Universal Design) of the National Disability Authority (NDA)[5] are always of considerable international scientific importance.

The CUED develops and promotes operational standards with the following objectives:

- stimulate and inform scientific research;
- participate with national, European and international bodies in the implementation of operational standards;
- provide advice and inform experts in implementing operational standards;
- encourage compliance with national and international standards in view of the Universal Design approach.

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[5] The purpose of the CUED is to guarantee the principle of universal access, allowing Irish citizens to participate in a society that takes account of human difference and to interact with their environment to the best of their ability. www.universaldesign.ie

In the Italian context, we should mention the publication *Una casa su misura: Domande e risposte per migliorare l'accessibilità domestica* (Trioschi, 2007). The book aims at offering suggestions and information about the usability of the home for elderly or disabled persons.

As mentioned, this bibliographic reference does not deal with a specific disability, but rather relates to disability in general, the built environment and end-users (elderly, disabled, family members and carers). For a few years now the Tuscany Region has been involved in the subject of disability, by financing actions aimed at offering fragile and disabled people an autonomous lifestyle through solutions capable of increasing the levels of accessibility and usability in the territory.

This is the case with the ADA[6] project, a research-action developed by the University of Florence (Dep. DIDA, Interdepartmental Research Unit Florence Accessibility) (Lauria et al., 2019). The scientific contribution examines, in the first place, the personal and environmental factors (both physical and socio-cultural) that characterise the home life of disabled people and their caregivers, and then presents a detailed illustration of the ADA project phases, its objectives, the recipients and the beneficiaries, the procedure and instruments used, the actors and the relations with the agencies involved. In particular, a tool for data collection and needs assessment (the ADA Assessment Model - Adam) is carefully described.

As reported in the first lines of this chapter, disability is part of the human condition, which every human being can experience during his or her life, just because of the ageing process, which with the passing of the years brings with it growing psycho-physical and/or sensory difficulties, or the occurrence of an accident that also causes a temporary reduction in capacity.

Disability conditions, as well as each personal situation, are obviously different and heterogeneous, while the stereotype of invalid or disabled is identified with the person in a wheelchair, or with the blind or deaf.

But disability conditions cover a much higher number of personal situations, from the child born with a congenital disease, to the Parkinson's disease, or to all different forms of cognitive disability.

Attitudes toward disabled people vary greatly in different parts of the world, and are in some cases still highly negative and degrading, and characterised by ignorance of the conditions of disability and/or lack of interaction with disabled people (Imrie, Hall, 2001).

Historically disabled persons have been classified as outsiders, as non-normal, i.e. persons on the margins of social life and, in some cases, to be confined and controlled in places separate from normal social life.

Only to give some historical reference, and to refer to the volume of St. Stilo (2013) for the study of this theme, in ancient Greece, in an age characterised by beauty and care of perfection, disability provoked condemnation and contempt.

The ideal City of Platone is inhabited by perfect individuals who generate healthy children. The disabled was identified as a scapegoat, as a bearer of a guilt, the fruit of the wrath of the gods, come to the world with a divine punishment. Most disabled infants were eliminated at birth, others raised with the sole destiny of becoming scapegoats.

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[6] In 2018 the ADA project was first selected as "good practice" by the Design for all International Foundation and then won the "Design for all Foundation Award 2018", in the category "spaces, products and services already in use".

Throughout the medieval era, this negative conception of disability remained. The mother was considered the only person responsible for the deformity of the child, almost as if it were the mirror of her faults, and with the child condemned or even executed.

In the middle of the 18th century, the birth of the first industries and the introduction of machines into the production chain led to a new focus on people disabled by accidents at work caused by the use of unsafe machinery or heavy or high-risk tasks, and a first shift in the collective mentality. People with physical disabilities or impairments caused by factory work began to be considered as individuals to be helped and to be given the necessary care, also studying the possible aids that would allow their return to working life.

However, when return to work and normal daily life was not possible, the fate of people with disabilities was social marginalisation and, often, solitary life and poverty. Only after the end of the second World War disability began to have a different social connotation, and to be considered a condition to be respected and to which to give answers and support, also through economic aid.

Since the seventies, the consideration of disability has undergone a radical change, attested, as reported in chapter 5, by the approval of internal guidelines and national norms aimed at the protection of people with disabilities, and from the progressive change in the social perception of disability from “deformity or illness” to a “different normality”. Disabled people began to acquire rights rather than be classified as individuals needing assistance.

Recent history has witnessed a momentous change, which has seen the recognition of the rights of disabled people in education, work, and leisure. At present, the definition of disability contains an innovative paradigm, i.e. that of a special normality, made of strengths and critical aspects.

As far as the disciplines of the project are concerned, disability can be understood as a stimulus to creative thinking and contribute to the formal and functional innovation of spaces, products and services. Whatever the scale of intervention, the project must indeed aim at to improving health conditions, safeguarding autonomy levels, preventing disability and improving the interaction between individuals, according to the different situations and their possible evolution over time.

The following are some examples of homes designed to be used by individuals with physical and motor disabilities. This is the case with the *Casa Agevole*[7] project (2004), realised in Rome by architect Fabrizio Vescovo. The organisational/distribution scheme of the experimental housing unit *Casa Agevole* has been imagined taking into account the Universal Design criteria. *Casa agevole* is a container of ideas and a training tool for students and insiders. The housing unit is compact (about 60 square meters), flexible and adaptable, and enables complete use and accessibility of all the domestic spaces by a person on a wheel chair.

The spatial-distribution scheme can be used in the case of single or multi-family buildings, multi-story and with various types of arrangements (terraced, attached, four-leaf, etc.) and enables a considerable diversification both of the internal dimensions and of the related useful surfaces.

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[7] Cf. *La casa agevole*. Source: https://www.superabile.it/cs/superabile/accessibilita/architettura/abitazioni/unita-abitativa-sperimentale-la-casa-agevole.html

Finally, the proposed solutions for the two bathrooms envisage fully accessible and customisable environments while ensuring reduced surfaces.

A second example is *La casa in via Pascoli*[8] in Foligno (PG) (2006), designed by architect Baires Raffaelli. The internal organisation is designed to meet the needs of a person with disabilities on a wheel chair and some of its solutions, from the detail to the general setting, can be taken as ideas for reflection and design.

The apartment is situated on the ground floor of a small building, occupies an area of 115 square meters and extends outside with a courtyard-garden of 90 square meters. The covered part consists of an entrance, a kitchen with dining area, a multi-function living room, two bedrooms, and two bathrooms (see Fig. 4.3).

The *Casattenta* project (Farella et al., 2010) was born with the aim of implementing and experimenting applications of house automation and environmental intelligence aimed at elderly individuals who are not totally self-sufficient, with the aim of making the domestic environment interactive and safer.

The *Casattenta* living concept consists of a prototype of a house automation system built on a wireless network and characterised by two applications:

- one for monitoring electric consumption;
- and the other for controlling the home and the person who lives there.

The user can view video messages sent by family or friends, or read SMS messages using the TV screen and the remote control. Moreover, thanks to a wearable sensor, it is possible to estimate the position of the person inside the house, or to signal, for example to family members or assistance centres, possible emergency situations (see Fig. 4.4).

Again in the field of usability and accessibility of the home, in this case for older users, another example of great interest is represented by the two home automation apartments[9] (Malavasi, 2014) built at the Ausili Area of Corte Roncati in Bologna (former Roncati Psychiatric Hospital).

The two apartments, respectively of 50 and 80 square meters, originally conceived as an experimental laboratory of housing solutions with high accessibility, have changed over time into places where people with disabilities experience directly more autonomous moments of daily life and, at the same time, they provide valuable contributions to the improvement of the solutions already implemented and to the design of new domotic solutions.

In the case of the first apartment, the entrance door opens onto a living area which in turn gives access to a kitchen area. A central space gives access to the bathroom and bedroom areas, directly connected by a door that allows the passage of a mobile lift for moving from the bed to the bathroom (WC and shower). Accommodation for an assistant is also provided.

In the case of the second apartment, there is an open plan living area that includes a kitchen, while a small corridor gives access to the bathroom and to an adjacent bedroom.

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[8] Cf. The house in Via Pascoli. Source: www.superabile.it/cs/superabile/accessibilita-colore-e-creativita-la-ca- SA-in-via-Pascoli-a-f.html.

[9] Cf. The two domotic apartments of Corte Roncati (BO). Source: https://www.ausilioteca.org/WE_Autono- MIA and https://www.ausl.bologna.it/news/archivio-2013/copy_of_auslnews.2013-06-14.5215192317

Fig. 4.3 Plan and internal distribution of *La casa in via Pascoli*. Source: Arch. Baires Raffaelli, 2006.

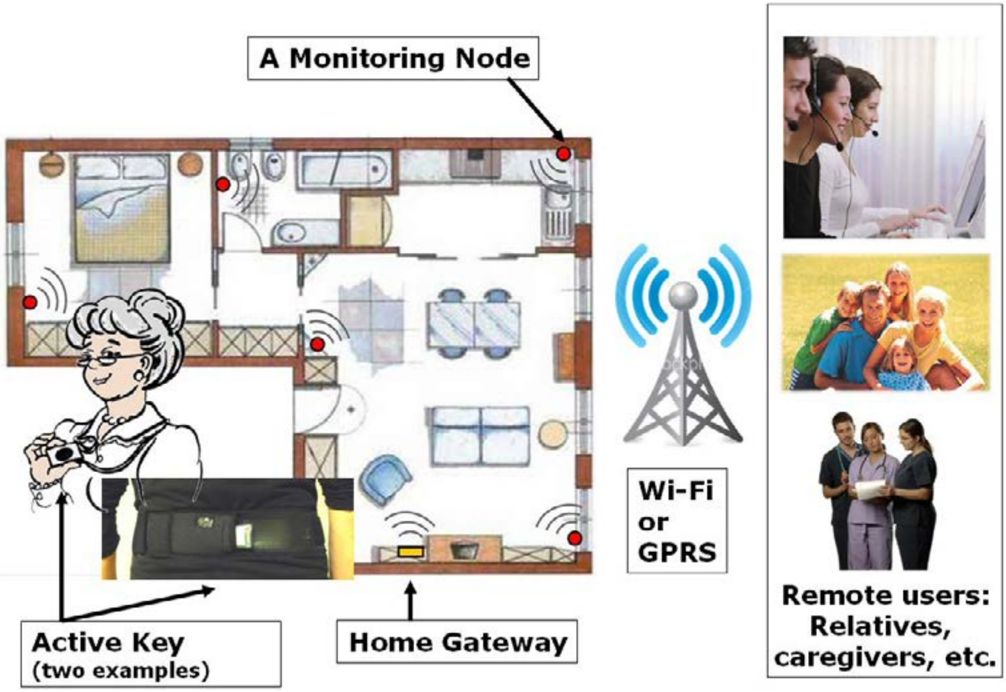

Fig. 4.4 Plan and layout of the *Casattenta* sensors. Source: Farella et al., 2010.

As far as Product Design is concerned, an inclusive design approach, which is not directed solely to the compensation of disabilities but aimed on the contrary to assume the needs of people with disabilities as an integral part of the project references, makes it possible to extend the perspective of the project.

Including people with disabilities or fragility also as an integral part of the users to whom the project is to be addressed and, at the same time, extending the target market of the final product to all possible recipients.

Pullin, in the book *Design meets Disability* (Pullin, 2009), explains how the trickle-down effect, or drop theory, can function as a catalyst for new Design approaches, thus opening fields of action for more diverse Design cultures. In this case, disability is not the target but, on the contrary, it is the starting point of the design process, whose subsequent development can lead to fields of application beyond this context. The basis of this approach is in fact not to consider disability as exceptional or out of the norm but, on the contrary, to consider the characteristics associated with a specific disability as one of the possible conditions of normality. Vanderheiden and Jordan (2012) argue that the approach of the project has three ways to address the problem of those who are unable to use the world around them:

- *the first way is to change the person.* This can be achieved through surgery, education, development and practice, or by teaching strategies to do things as easily as possible. This also includes technologies that become “part of the person” (e.g. goggles, hearing aids, artificial limbs, etc.);

- the second way is to *provide the person with connection tools*. This includes devices and adapters that bridge the individual from traditional technologies (for example, door knob adapters, screen readers, adaptive keyboards, hearing impaired telecommunications devices, TDDs/TTY);
- the third way is to *change the way the world is designed*. By developing inclusive design concepts, and making common products fully accessible and user friendly.

We can add that the third approach can follow two paths: Making products of daily use accessible and easy to use, but also, and vice versa, turning products or systems originally designed to respond to a disability into commonly used commodities.

On this last aspect, let us take as an example eyeglasses that, designed and made to compensate for the visual limitations of individuals, can be fully considered an aid, which does not replace a limiting part of the human body but enhances the impaired sense.

Nowadays in any shop or shopping centre it is possible to find types of glasses of different shape, colour and price, normally sold and purchased by everyone as normal products of use and often as fashion products. A slight visual defect is no longer perceived as a disability but as a normal human condition and, at the same time, glasses are no longer considered as an "aid" but as a normal accessory to be worn.

Good Design, therefore, can enhance and "redesign" the person's abilities and, in the words of Hogan[10] ,"*good Design enables, bad Design disables*".

Of great interest are the formal experiments in the framework of the project *Rethought elderly furniture & accessories that supports and empower life & lifestyle*, carried out by the Italian-Singaporian design studio Lanzavecchia+Wai[11]. The motivation that prompted the two designers was to generate enthusiasm, desirability and sense of ownership, through the design and introduction of new functions for some aids designed for the elderly that still today have an aesthetic that is too hospital-like. Two of their projects are shown in the following figures. In the first we find the *Assunta seat: A chair that helps us to get up*, which assists the movement of the person who uses it, leveraging the body weight and maintaining stability thanks to the armrests that follow the inclination movement. Provided with a new aesthetic language and a new functionality, the seat becomes a real home assistant (see Fig. 4.5).

In the second we find the *Together Canes: walking aids for living, not just mobility*, which not only provides support to the person, but also allows you to literally "carry" the necessary tea, magazines, books etc. and can also be used as a support for a tablet, for example (see Fig. 4.5).

Another concrete example of inclusive design is the Leonardo handle designed by Italian architect Fabrizio Bianchetti and produced by Ghidini Pietro Bosco spa.

Leonardo[12] is considered one of the first Italian products to show attention to the different characteristics and capacities of the users and the different modes of use, so much so that it is now considered a good design icon (see Fig. 4.6).

In the kitchen furniture sector, a very well-known and interesting example is the *Skyline_lab* kitchen from the Skyline line, by the Italian company Snaidero Rino spa, designed by architects Lucci and Orlandini. The *Skyline_lab* model was born with the objective of

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[10] Paul Hogan was a founding member of the Institute for Design and Disability.

[11] Cf. www.lanzavecchia-wai.com.

[12] The Leonardo handle won the good Design Award in 2004.

creating a domestic environment capable of offering to all, and to persons with disability in particular, the possibility to carry out comfortably, in an autonomous way and in full safety, all the fundamental home activities (see Fig. 4.7).

Fig. 4.5 ***Assunta: A chair that helps us to get up*** **(top) and** ***Together Canes: walking aids for living, not just mobility*** **(bottom).** Source: www.lanzavecchia-wai.com.

Fig. 4.6 The *Leonardo* handle, designed by architect Fabrizio Bianchetti for Ghidini Pietro Bosco spa. Source: www.ghidini.com/it/prodotto/ghidini-leonardo-rosetta-ovale-finitura-acp/.

Fig. 4.7 The *Skyline_lab* kitchen, designed by Lucci and Orlandini for Snaidero Rino spa. Source: www.snaidero.it/skyline-versioni.

4.2 The home for people with Parkinson's disease

As regards the dimensional aspects, in attributing a certain amount of surface to each environment, it is necessary first of all to take into account that both a PwP and a caregiver, whether formal or informal, often spend a lot of time inside the house, which, therefore, requires an adequate surface and proper equipment to carry out the vital activities of the person, with respect to and with the objective of a full realisation of his or her existential aspirations.

The dimensional references must obviously take into account the movement spaces connected to the use of the wheel chair or other walking aids.

In the case of older people, account must also be taken of the reduced capacity of movement of the arms, both vertically and horizontally.

Stature tends to decrease with age, as does the ability to reach or manoeuvre objects placed above or below the reach of normal movement of the arms (i.e., bringing the hands to the height of the eye or pelvis without being forced to bend and strain).

A similar decrease relates to the horizontal extension of the arms, due to the lower elasticity of the joints and to the greater sensitivity to fatigue that affect, more generally, the overall capacity of movement of the person.

The differences in height and muscle capacity between the two sexes should also be considered. Women, in particular if elderly and/or affected by PD, generally have a lower stature than males and, above all, stature and ability to move well below those of young and normally able people.

The anthropometric characteristics, and in particular the average stature of the population, also saw a considerable increase in recent decades, and normally the average stature and anthropometric characteristics are the reference for the dimensions (height, depth, diameters of the handles, etc.) of furnishing elements, and all everyday products and components such as handles, buttons, knobs, switches, etc.

It should also be considered that a lack of autonomy can occur suddenly or, as in the case of Parkinson's disease or other neurodegenerative diseases, gradually over time, leading the person to make at first occasional and then increasingly frequent use of movement aids, long before they prove to be indispensable to him or her throughout the day (see Fig. 4.8).

In fact, there are many cases of PwP, as well as of elderly people who retain a relative movement capacity (who can, for example, perform some activities independently and walk and move without needing help, but can only do so for short periods), but for whom it is preferable to use the wheelchair for a considerable part of the day and in particular when they are at home.

As regards the psychological impact of the domestic environment, a subject that will be dealt with in greater depth in Chap. 6, the choice of furnishing elements, colours, aids and assistive technologies within private spaces is of great importance.

Another element of fundamental importance from the psychological standpoint is the concealment of all the sanitary and supports to the movement that can make the appearance of one's own house similar to that of a hospital room.

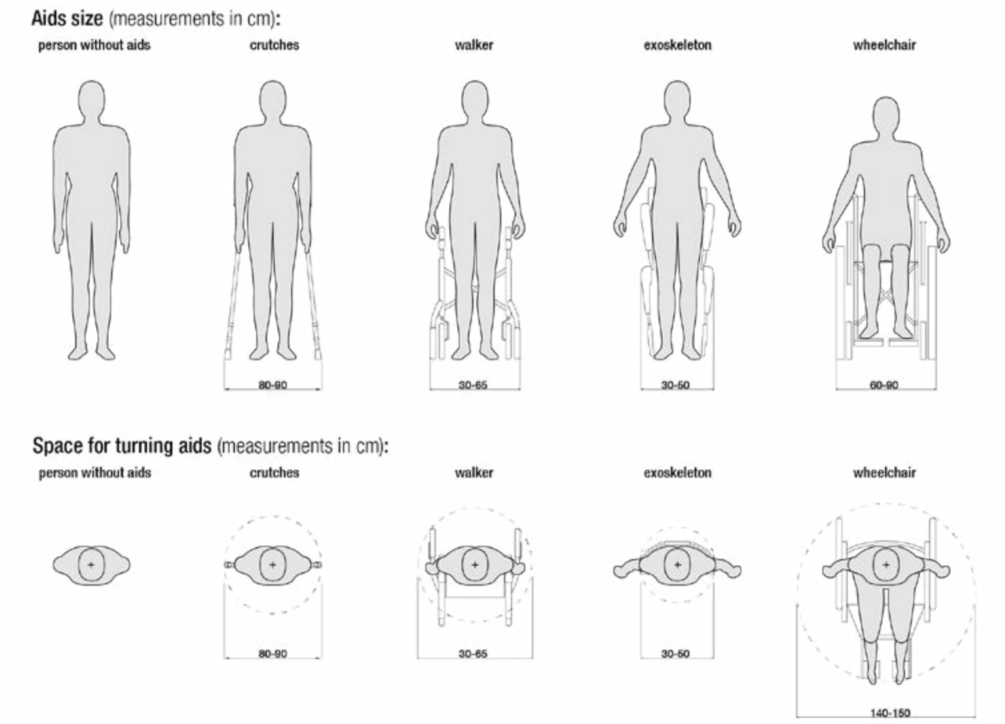

Fig. 4.8 Space occupied in the movement and rotation by people with different levels of autonomy.

One of the main fields of research that works in this direction is the Evidence-Based Design approach (EPD) whose results demonstrate how the spatial, functional, relational and psycho-perceptive characteristics of the hospital and care environment can be decisive during the treatment process, facilitating or slowing down the path of healing or improvement of the patient, and reducing or increasing the likelihood of clinical complications.

Between the 1970s and 1980s, and then until the 2000s, research carried out in this field has shown how the spatial, functional, relational and psycho-perceptive of hospital and care environments - and consequently also of domestic ones - as well as the perceptible properties of artefacts (such as shape symmetry, order, rhythm, colour, contrast, etc.), are potential drivers of emotional reactions and can have a more or less decisive impact during the course of treatment, reducing stress and anxiety, improving patient satisfaction, and promoting health and healing.

For example, research has shown that patients who could enjoy a view of a garden or trees outside the hospital environment were discharged earlier than patients in interior-facing rooms (Wilson, 1972; Verderber, 1986; Ulrich et al., 2004; Ulrich et al., 2008; Cama, 2009).

Further aspects of great importance are the flexibility and versatility of the domestic environment over time, In other words, the possibility of modifying the structure of the internal spaces, which is essential to respond to the progressive change in autonomy levels and needs of people with Parkinson's disease or people with disabilities, and more generally, to respond to the evolution of the lifestyle and the needs of any person or family.

Ensuring the versatility of the domestic environment over time means moving from a static view of the internal space, which can be modified only by renovation, to a vision "in progress" centred on the ability of the living environment to evolve according to the different needs of the people who live in it.

A space that changes its internal configuration, through the use of movable and/or sliding walls, which can be easily dismantled and reassembled, makes it possible, for example, to widen or divide one or more spaces of the house, to modify the space and organisation of bathroom, etc., that is to say to meet the possible changes that each individual person is faced with in daily life and in the course of his or her existence, such as for example a temporary or permanent disability, but also a new job, a period of study to be carried out at home, and obviously the birth of children, the different needs related to their growth, etc.

The following are the main daily activities that must be carried out within the domestic space by the person with Parkinson's and the caregiver.

The whole of these activities can be divided into differentiated spatial contexts, for example in the case of autonomous dwellings with a sufficiently large surface, or be concentrated in multi-functional spatial contexts in the case of small-size housing or studios. The distribution criteria refer to a subdivision made according to the level of privacy of the different parts of the house or according to the period of the day in which the different environments are used the most:

(i) communal areas (living room, dining room, terrace, loggia, outdoor space);
(ii) individual area (bedroom);
(iii) service area (kitchen, storage room, toilet);
(iv) traffic area (entrance);
(v) living area (entrance, living room, kitchen, dining room, terrace, loggia, outside space);
(vi) sleeping area (bedroom, bed, toilet).

In small homes, the sleeping area is identified by the individual sleeping space (the bedroom) and the living area by the collective living space (living room, dining room and kitchen).

In this case, the use of movable walls, sliding partitions and doors, or a different arrangement of the furniture elements, may make it possible to isolate, even partially or temporarily, a specific area, for example in periods of illness or in some hours of the day.

While in larger accommodation it is preferable to maintain the separation between the different individual environments and between these and the living and service areas.

In the case of the coexistence of a PwP with a family, the autonomy of the room, and where possible of the toilet, obviously provides greater independence and rational use of the dwelling.

Also in this case, the provision of sufficient levels of internal flexibility is of fundamental importance in order to enable the possible subdivision or redistribution of the internal environments, as well as to allow possible support elements such as orthopaedic beds or motion aids to be easily integrated.

Environment	Activity	Requirements for the person with Parkinson’s and his or her caregiver
Entrance	• Enter/exit • Answer the intercom • Open/close windows/doors • Turn lights on/off • Clean/sanitise the environment	• Manoeuvring space • Use of equipment, aids and assistive technology • Height of buttons
Living/dining room	• Enter/exit • Watch TV, read a book, etc. • Sit/stand up from the sofa/armchair/chair • Sit at the table • Turn lights on/off • Store/remove items from furniture • Open/close windows/doors • Exercise • Work • Clean/sanitise the environment	• Manoeuvring space • Space for the caregiver • Use of equipment, aids and assistive technology • Height of household appliances • Height of buttons • Height and size of furnishing accessories and furniture • Space for work and physical activity
Bedroom	• Enter/exit • Watch TV, read a book, etc. • Sit/stand out of bed/chair • Turn lights on/off • Open/close windows/doors • Store/remove items from furniture • Dress/undress • Open/close windows • Clean/sanitise the environment	• Manoeuvring space • Space for the caregiver • Use of equipment, aids and assistive technology • Height of buttons • Height and size of furnishing accessories and furniture
Kitchen	• Enter/exit • Use household appliances • Use stove top • Use the sink • Manage garbage • Prepare food • Sit/stand up from the chair • Sit at the table • Turn lights on/off • Open/close windows/doors • Store/remove items from furniture • Clean/sanitise the environment	• Manoeuvring space • Use of equipment, aids and assistive technology • Height of household appliances • Height of buttons • Height and size of furnishing accessories and furniture
Bathroom	• Enter/exit • Sit/stand up from the sanitary ware • Use the bath/shower • Use the sink • Personal hygiene • Turn lights on/off • Open/close windows/doors • Store/remove items from furniture • Clean/sanitise the environment	• Manoeuvring space • Space for the caregiver • Use of equipment, aids and assistive technology • Height of household appliances • Height of buttons • Sanitary ware and shower/tub height and size

Storage area	• Enter/exit • Turn lights on/off • Use household appliances • Open/close windows/doors • Store/remove items from furniture • Clean/sanitise the environment	• Manoeuvring space • Use of equipment, aids and assistive technology • Height of household appliances • Height of buttons
Terrace/ balcony	• Enter/exit • Turn lights on/off • Open/close windows/doors • Manage plants • Clean/sanitise the environment	• Manoeuvring space • Use of equipment, aids and assistive technology • Height of buttons
Garage	• Enter/exit • Turn lights on/off • Use household appliances • Open/close windows/doors • Store/remove items from furniture • Clean/sanitise the environment	• Manoeuvring space • Use of equipment, aids and assistive technology • Height of buttons
Garden	• Enter/exit • Open/close windows/doors • Manage plants • Clean the environment	• Manoeuvring space • Avoid height differences

Tab 4.1 Task Analysis of planned and predictable activities for PwP and caregiver, developed as part of the *Home Care Design for Parkinson's disease* research project.

4.3 Domestic accidents

Accidents are an important public health problem, both for industrialised and developing countries. Many of these accidents happen in the home, a place that should be a safe haven from the pitfalls and barriers outside, but can unfortunately represent yet another hostile environment for human beings.

The Italian Higher Institute of Health (ISS) defines a domestic accident as an accident involving temporary or permanent impairment of the health of a person, not dependent on human will, occurring inside or outside the home.

As I said earlier, the dynamics of domestic accidents are an important public health issue in our country, and not only. In fact, from the latest estimates provided by ISTAT in 2014, nearly 700 thousand people (about 11% of the Italian population) have declared to have been involved in an accident in the domestic environment.

The interior and exterior of the house have different levels of danger, depending on factors including furniture elements, objects, floors, malfunctioning or incorrect use of household appliances, electricity, gas, etc. and, in addition, the amount of time a person spends in one of these spaces. As we can imagine, the most dangerous environment of the house is the kitchen, which is the space dedicated to the preparation and consumption of food and domestic chores, involving most of the appliances and objects that due to their form, material and use increase the risk of an accident (see tab. 4.2).

The duration and intensity of household activities lead to an increase in exposure to the risk of injury. The proportion of accident victims increases as the weekly hours for this type of activity increase. Among those who work and stay in the house more than 30 hours a week, 21 people per thousand, especially women between 45 and 64 years of age, were injured (ISTAT, 2014).

Household tasks are therefore among the most endangered activities, followed by DIY and DIY repairs, play or leisure time pastimes, physiological activities and finally other activities (see tab. 4.3).

Environment	**Males and females**			
	Age classes			
	0-24	**25-64**	**65 and more**	**Total**
Kitchen	21,1	48,3	29,1	38,0
Bathroom	12,1	10,3	13,7	11,7
Bedroom	10,6	7,6	13,4	10,0
Living room	24,2	9,1	4,4	9,4
Balcony, terrace, garden	7,7	6,0	14,2	9,1
Stairs inside the house	7,7	6,8	5,0	6,3
Hallway, entrance	8,7	2,6	8,4	5,4
Cellar, garage, other room	4,1	5,0	6,6	5,4
Stairs outside the house	3,8	3,8	4,9	4,2
Not indicated	-	0,5	0,3	0,4
Total	100	100	100	100

Tab. 4.2 incidence of injury within every household. Reprocessed table, source: ISTAT, 2014, p. 7.

Type of domestic accident	**Males and females**
	Total
Fall	
Fall from the same level	41,8
Floor	36,2
Shower	3,2
Bathtub	2,4
Fall from height difference	36,0
Fall from stairs	29,7
Fall from fixed stairs	20,4
Fall from movable stairs	9,3
Fall from chairs, high chairs	6,3

Wound	
Kitchen utensils	53,7
Knife	40,4
Kitchen appliances	3,8
Ovens and stoves	3,5
Scissors	2,8
Other kitchen utensils	2,4
Pots	0,8
DIY tools, DIY activities	17,8
Impact or crushing	
Furniture and chairs	32,0
Other parts of the house	18,2
Doors and windows	18,1
DIY tools, DIY activities	6,0
Burn	
Kitchen utensils	73,1
Hot foods	27,1
Ovens and stoves	22,7

Tab. 4.3 The main causes by type of accident. Reprocessed table, source: ISTAT, 2014, p. 5.

The report shows, as do also other authoritative sector documents (ARS, 2019; WHO, 2021), that falls[13], whose origins can be attributed for example to slips, stumbles, loss of balance, presence of obstacles, water or other liquids that create slippery surfaces, as in the case of the bathroom and kitchen, are the most frequent domestic accident, followed in order of frequency by wounds, impacts or crushing, burns, foreign bodies inside the eyes, and finally by suffocation.

Falls are very frequent among children and the elderly, with a incidence of 684 deaths per year, followed by 37,3 million falls serious enough to require medical attention (WHO, 2021).

The incidence of this phenomenon, although very common in the older population, becomes significantly more important for people with Parkinson's disease (PwP) due to the risk factors[14] related to this disease that can increase exponentially the risk of falling, and have devastating consequences on the quality of life and autonomy of the PwP, thereby increasing the burden of care on the carer, which is already very heavy in itself.

As reported by some scientific contributions (Rubenstein, 2006; Bhidayasiri et al., 2015; Lamont et al., 2017), fall risk factors are recognised as multi-factorial, i.e. determi-

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[13] The World Health Organization defines a fall as an event that leads a person to stop inadvertently on the ground or on the floor or on another lower level.

[14] Cf. Chap. 1

ned by the interaction between intrinsic factors (balance problems) and extrinsic factors (environmental hazards), and 80% of falls occur inside the house (Ashburn et al., 2008).

For example, falls outdoors are mainly caused by stumbling, slips, loss of balance or loss of concentration, while falls within the domestic environment are mainly due to muscle failure, dizziness and loss of balance (Mak, Pang, 2010; Lamont et al., 2017).

Rubenstein (2006) provides a clear picture of the inherent risk factors, including: weakness, balance deficit, gait deficit, visual deficit, limitation of mobility, cognitive impairment, impaired functional status and postural hypotension.

Whereas extrinsic or environmental risk factors, some of which are directly attributable to the domestic environment, can be summarised as:

- type and morphology of the external ground, road, sidewalk and pavement.
- postural transitions, such as from sitting to standing, direction changes inside and outside the domestic environment.
- physical efforts, such as opening a door and window, taking and manipulating objects placed either too high or too low.
- presence of protruding carpets and doormats, poor lighting of the residential environments and outside the house.
- non-rounded protrusions and corners.
- beds, seats or sofas that are too high.
- bare electrical wires.
- inadequate kitchens.

The problem of falls, in addition to being a physical issue for the individual with direct effects on the need for medical care and rehabilitation programs, on the costs of the health system and on the increased assistance burden required of the caregiver, can also have emotional effects on the affected person, such as anxiety, psychological discomfort and embarrassment, which can result in a limitation in one's physical activities to avoid damage and an excessive fear of falling again.

In order to safeguard and facilitate autonomy within and outside the home, the PwP needs to maintain appropriate physical activity and be able to adapt the domestic environment over time in accordance with the inconvenience and new and ongoing needs created by the PD.

When health declines, environmental conditions often do not correspond to the individual's abilities, causing numerous problems of person-environmental fit with negative health outcomes.

The definition person-environmental fit (P-E fit) refers to the relationship between the environment and the person (Murrel, Norris, 1983; Bhidayasiri et al., 2015), and literally means person-environment adaptation, understood as correspondence or congruence between individuals and their environments, key determinant of the well-being and safety of the person (Kristof-Brown et al., 2005) (see Fig. 4.9).

The objective, therefore, as indicated by the legislation and addressed and promoted by the numerous national and international initiatives in the field of home accessibility that will be described in Chapter 5, is to improve accessibility and usability in the home in relation to daily life activities, removing all barriers that can facilitate domestic accidents.

Since PD is a chronic neurodegenerative disorder, and many PwP spend a lot of their time at home and in some cases the whole day, it is necessary to create accessible, usable, welcoming and ultimately versatile spaces. Able to respond in a timely manner to the evolution of the needs and desires of both PwP and their caregivers, until the PD obliges them to move to more specific care facilities.

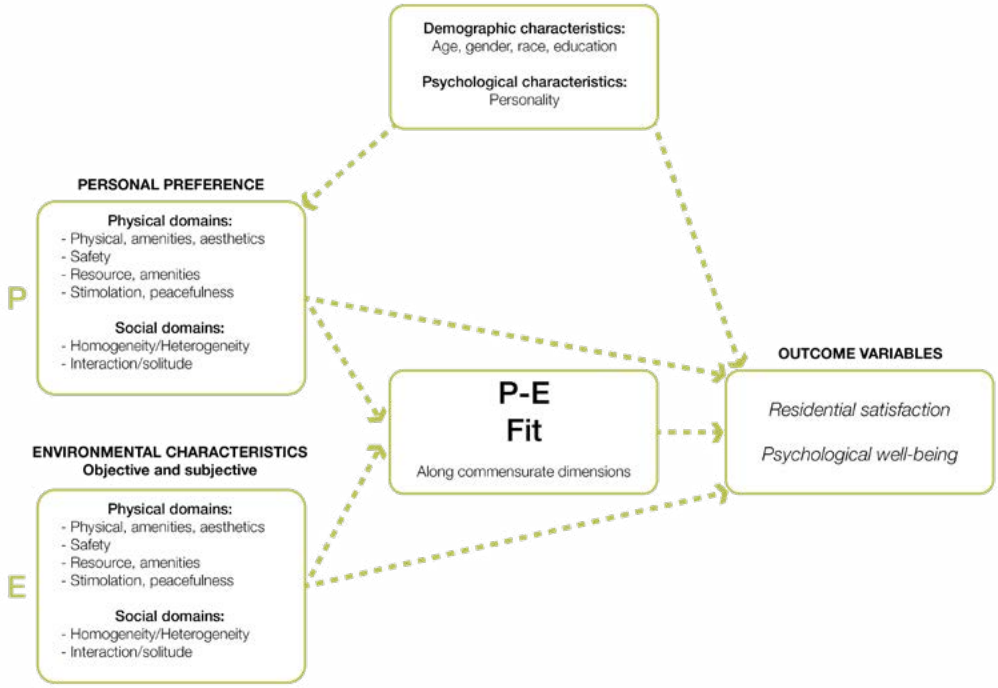

Fig. 4.9 the person Environment Fit report. Reprocessed image, source: Kahana et al., 2003.

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5. Accessibility of domestic environments: the regulatory aspects[1]

by *Mattia Pistolesi[2], Francesca Filippi[3]*

The World Health Organization, through the International Classification of Functioning, Disability and Health (ICF), defines disability as a dynamic interaction between health conditions and personal and environmental factors (the International Classification of Functioning, 2001; WHO, 2011), which hinders the full and effective participation of the disabled person in society.

Personal and environmental factors, also called contextual factors, represent the entire background of the life and the conduct of the individual's existence (see Fig. 5.1).

More specifically, personal factors are sex, race, age, but also health, fitness, lifestyle, habits, education, ability to adapt, social background, education, profession, and general patterns of behaviour and character styles, which can have a positive or negative impact on an individual's disability.

While environmental factors are the physical environment and the social environment in which individuals live and lead their lives.

Environmental factors can in turn be divided into two levels: Social and individual (the International Classification of Functioning, 2001). These include (WHO, 2011):

- products;
- technologies;
- natural and built environments;
- support and relationships;
- attitudes;
- and services, systems and policies.

The social environmental factor is represented by social structures, services and the main interactions of society that have an impact on individuals, such as organisations and services connected to work, communication services, transport services, regulations, rules, laws, social networks, attitudes and ideologies.

Finally, the individual environmental factor is the personal environment of the individual, such as the domestic environment, the working environment and the school environment.

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[2] Cf. Chap. 4.

[3] Architect and Doctor of Research in Design. Since 2008 she has been carrying out didactic and research activities at the Architecture Department of the University of Florence. Her research activity has been directed toward the thematic area of Product Design and Innovation, in particular investigating new perspectives and the development of innovative materials. She has specialised in the writing of research projects according to the techniques and methods of Eurodesign. She is the author of books, essays and articles on the culture of the project and on territorial enhancement through Design.

This factor comes into contact with the individual through the physical and material characteristics of each environment, as well as the presence of other persons, such as family members, acquaintances, companions and strangers.

An environment with barriers will limit an individual's performance, while more facilitating environments will help it. Even society can hinder the performance of an individual, either by creating barriers (e.g. inaccessible buildings) or by not providing facilitating elements (e.g. lack of availability of aids) (the International Classification of Functioning, 2001).

The now universally recognised awareness of the relationship between disability and socio-environmental factors has led to the implementation of strategies aimed at guaranteeing both the rights of people with disabilities and the elimination of architectural barriers.

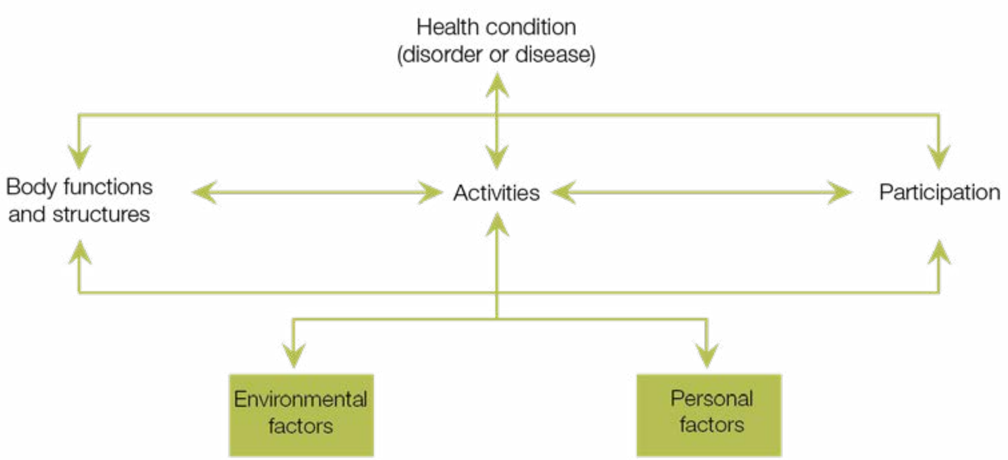

Fig. 5.1 The interaction between disability and contextual factors. Reprocessed image, source: WHO, 2011, p. 5.

In this sense, the results achieved by initiatives and laws promoted at the international level (United Nations, 1948; United Nations, 1993; United Nations, 2006; the International Classification of Functioning, 2001; WHO, 2011) and at the national level have led to a new and growing awareness of the human rights of people with disabilities.

For example, the Convention on the Rights of persons with Disabilities (CRPD), the most recent document on the human rights of people with disabilities, outlines the civil, cultural, political, social and economic rights of that group of people.

More specifically, the Convention emphasises the following 8 general principles (United Nations, 2006):

1. respect for intrinsic dignity, individual autonomy, including freedom to make their own choices, and the independence of persons;
2. non-discrimination;
3. full and effective participation and inclusion in society;
4. respect for difference and acceptance of people with disabilities as part of human diversity and humanity in general;
5. equal opportunities;
6. accessibility;

7. equality between men and women;
8. respect for the evolutionary abilities of children with disabilities and respect for the right of children with disabilities to preserve their identity.

The main purpose of the CRPD is to consider disabled persons as subjects deserving the same respect as other individuals and not as *objects* to be managed.

5.1 Designing “without barriers”: the Inclusive Design approach

The Inclusive Design (ID) approach can be considered an umbrella definition that includes different approaches to Design, all based on the principle of inclusion, and among them, in particular, *Design for All (*DfA) and *Universal Design* (UD) (LaGatta et al., 2015). The three definitions are very often used as synonyms because their literal meaning - “Design for All”, “Universal Design” and “Inclusive Design” - can be deceiving, but even though their goal is to design for the greatest number of people possible, the three approaches have different facets.

ID was used for the first time in Europe in 1994, and later developed in other countries, thanks to the collaboration between industry, designers, research workers and educators (Coleman, 1994; Clarkson et al., 2003).

It is not a new approach to design, but rather a general approach to projects, based on two main approaches, i.e. DfA - developed in Europe - and UD - developed in the United States - where designers ensure that their products and services meet the needs of the widest possible audience, regardless of age or skill, without the need for special adaptations or specialised Design.

Inclusive design	Non-inclusive design
Concern about meaning and context	Concern about style and ornamentation
Participatory	Non-participatory
Oriented to humans	Corporate or institutional orientation
Customer redefined to include users	Owner as an exclusive customer
Low cost	High cost
Design approach from the bottom	Design approach from top to bottom
Democratic	Authoritarian
Try to change design attitudes	Acceptance of prevailing design attitudes
Use of appropriate technology	Use of high technology
Use alternative models of the development process	Business interest controlled development process
Heterogeneity	Homogeneity

Tab 5.1 Comparison between Inclusive Design and Non-Inclusive Design. Reprocessed table, source: Imrie, Hall, 2001, p. 19.

ID is essentially the reverse of the DfA and UD approaches, aimed at the design for disabled and elderly people as a subset of the population, but is an integral part of a more recent international trend toward the integration of older and disabled people into society (Clarkson, Coleman, 2013).

This trend has been manifested in different ways depending on local circumstances, culture and social conditions. For example, in the United States, disabled people's right to access the built environment and public places was made possible by the *Americans with Disabilities Act 1990* (ADA, 1990), while in the United Kingdom, this was made possible by the *Disability discrimination Act 1995* (DDA, 1995) first, and later with the *Equality Act 2010* (UK, 2010).

The results achieved by these developments have progressively shifted attention from them (elderly and disabled) to us (Clarkson, Coleman, 2013), demonstrating that:

- people differ in their mental and physical abilities, and these abilities can change during the long course of life;
- disability is directly linked to the interactions between the individual and the surrounding environment;
- the goal is to include people with a wide range of perspectives and experiences and learn from them.

This approach aims at having a holistic view of users: (i) recognizes that people differ from each other in many different ways and sees each particular disability simply as one of the dimensions along which people may differ; (ii) recognises that projects that adapt to people with particular disabilities may bring advantages, or at least not create disadvantages, to able-bodied people.

This means that Design for the disabled should not always be seen as an alternative to Design for the able-bodied. Actually, in commercial terms, the manufacturing of products that are suitable for both the able-bodied and the disabled is simply a way of extending the potential customer base for a product (Jordan, 1999).

The ID approach aims at realising products or services of wide consumption that are accessible and usable for people with the widest spectrum of abilities within the most diverse situations without the need for special adaptations or designs (BS 7000-6:2005). Accessibility and usability are the key criteria of this approach. Accessibility refers to allowing users to access functionality through their sensory, physical and cognitive capabilities.

Design for Accessibility focuses on the principle of extending the standard of Design to people with certain types of performance limitations in order to maximise the number of potential customers who can immediately use the product, building or service.

Usability refers to the extent to which the product or service can be used by specific users, to achieve specific goals with effectiveness, efficiency and satisfaction within a specific context of use.

In simpler terms, accessibility means that a different range of users can perceive, understand, and physically interact with the product, and usability refers to whether – and how – users can carry out their task with the product effectively, efficiently, and with satisfaction. An essential aspect of the Inclusive Design approach is that it benefits many more people without disabilities than those with disabilities.

The curb cut is a shining example, as are ramps in general.

Although originally designed for wheelchair users, they are also used by parents who push baby carts, people who tow luggage, cyclists, skateboard users, children in tricycle and a huge number of others.

The study of the use of the products by persons with functional limitations may also provide ideas for a Design that otherwise may not be realised. For example, it is much easier to determine which elements of a kitchen require more force, by testing a weak person or a person who has little control of his or her movements, compared to a person with a normal or extraordinary force.

UD, on the other hand, developed in the United States around the 1980s, is defined as the design of products and environments usable by all people, to the greatest extent possible, without the need for adaptations or specialised design (Mace, 1985; Presier, Smith, 2011).

Finally, DfA, born around the 1990s in Northern Europe (Accolla, 2008), is a design model that embraces differences and enhances human diversity. DfA is essentially aimed at satisfying and including the greatest number of people, with different cognitive, perceptive and motor skills, and is aimed at the creation of environments and products compatible with the greatest number of abilities and autonomy levels.

The particular difference between these approaches is that although UD and DfA are about creating a common design that works for everyone, ID has the freedom to co-create a design system that can adapt, transform itself or extend to meet each individual's design needs (see tab. 5.2).

As claimed by a number of authors (RNIB, 1995; Goldsmith, 1997; Imrie, Hall, 2001, Ostroff, 2001), some limitations of universal design (UD and DfA) derive from the fact that its objective is the search for the lowest common denominator able to reconcile the often conflicting needs of the different minority groups of society.

Therefore, Universal Design leads to a single solution, conceived to accommodate the needs of as many users as possible, which means that some will be excluded.

The concept of *inclusion* in the design and development of environments and products is not a matter limited to the disability project itself but is, on the contrary, a matter of equity and quality (of life) for all (Imrie, Hall, 2001).

This mentality "brings" users to the centre of design processes rather than to their margins, and therefore means working with people rather than working for them. It is essential that project professionals listen to and engage future users during the design process, from the beginning to the end.

The reason for active user participation is also the fact that people have the right to greater control of their environment, and not to be placed on the margins of the design and realisation processes of private and public environments and, therefore, to demand that designers directly involve in their work those for which they design.

In this way, Inclusive Design can ensure that all users, including those that may generally be excluded, are considered during the design process.

Approach	Principles	Description
Inclusive Design	1. Put people at the centre of the design	Inclusive design is seen as an essential component of sustainable communities.
	2. Recognise diversity and difference	It recognises the wide diversity of needs, including wheelchair users, but also sensory disabilities, learning difficulties, mental illness, hidden disabilities and the needs of children and parents.
	3. Offer a choice to users by recognising that a unique solution that fits all users is not possible	Welcome all people regardless of age, gender, mobility, ethnicity or circumstances.
	4. Flexibility of use	Link to sustainability principles through the need for adaptability in the project to meet different needs in different phases.
	5. Convenient and pleasant places for everyone	Buildings and roads well connected so that everyone knows where they are and can locate their destination.
Universal Design	1. Fair use	Design is useful and marketable for people with different abilities.
	2. Flexibility of use	The project adapts to a wide range of individual preferences and skills.
	3. Simple and intuitive operation	The use of the Design is easy to understand, regardless of the user's experience, knowledge, linguistic skills or current level of concentration.
	4. Perceivable information	The Design effectively communicates to the user the necessary information, regardless of the environmental conditions or the sensory capabilities of the recipient.
	5. Fault tolerance	The design minimises the hazards and adverse consequences of accidental or unintended actions.
	6. Low physical effort	The design can be used efficiently and with a minimum effort.
	7. Dimension and space for approach and use	The appropriate size and space are provided for approaching, reaching, handling and using, regardless of the size of the user's body, posture or mobility.
Design for All	1. Support human diversity	The use of the product is easy and pleasant for all potential users.
	2. Promote social inclusion and equality	The use of the product does not discriminate physically or psychologically.
		The product is pleasant.
	3. Improve people's quality of life	It is socially, environmentally, economically sustainable.

Tab. 5.2 Inclusive Design, Universal Design and Design for all: Principles in comparison. Reprocessed table, Source: Imrie, Hall, 2001; Clarkson et al., 2003; LaGatta et al., 2015; Manley, 2016

5.2 The international regulatory scenario

This paragraph presents a summary outline of the development of international legislation on accessibility and social inclusion of persons with disabilities and, more generally, persons in a fragile state.

At the end of the paragraph there will be a summary outline of some of the principles of international standards currently in force.

The basic text that defines human rights and respect for fundamental freedoms for every individual is the *Universal Declaration of Human Rights*, adopted by the United Nations General Assembly on 10 December 1948.

The Declaration is addressed to all human beings without distinction of sex, race, religion or culture, or individual differences, and establishes the fundamental rights of individuals: The right to life, freedom and security of one's person; education; freedom of thought, conscience and religion; freedom of opinion and expression; right to work; right to seek and obtain asylum from persecution in other countries.

The text, which was translated, in addition to the five official languages of the United Nations, into other languages to allow maximum diffusion, declares "human rights as a common ideal to be reached by all peoples and nations, in order that every individual and every body of society, having constantly this Declaration as a reference, endeavours to promote, through teaching and education, respect for these rights and freedoms and ensure, through progressive measures of a national and international nature, universal and effective recognition and respect both among the peoples of the Member States themselves, as well as those of the territories under their jurisdiction" (United Nations Human Rights, 1948).

In 1971, the UN approved the Declaration of the Rights of the mentally Disabled[4], which equates the rights of persons with mental disabilities to those of all human beings, with particular reference to the protection from exploitation.

Another fundamental step was reached on 9 December 1975 when the UN General Assembly adopted the Declaration of the Rights of the Disabled[5], with the objective of ensuring equal civil and political rights for people with disabilities. Subsequently, on 13 December 2006, the United Nations General Assembly approved the UN Convention on the Rights of persons with Disabilities (CRPD) Making it binding on all Member States and thus achieving a very important result, which is part of the wider context of the protection and promotion of human rights.

The Convention does not introduce new rights for people with disabilities, but it has the aim of ensuring that they are granted the same rights as other people under the systems of their own States and is therefore a concrete instrument for the effective implementation of the principle of equality and social inclusion of all disadvantaged people.

The Convention states that "Disability is an evolving concept and is the result of interaction between people with behavioural and environmental impairments and barriers, which prevent their full and effective participation in society based on equality with others" and stresses that: "Persons with disabilities are those who have lasting physical, mental,

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[4] United Nation Human Rights, office of high commissioner, Declaration on the Rights of Mentally Retarded Persons, https://www.ohchr.org/EN/ProfessionalInterest/Pages/RightsOfMentallyRetardedPersons.aspx.

[5] United Nation Human Rights, office of high commissioner, Declaration on the Rights of Disabled Persons, https://www.ohchr.org/EN/ProfessionalInterest/Pages/RightsOfDisabledPersons.aspx.

intellectual or sensory impairments that, interacting with different barriers, can hinder their full and effective participation in society based on equality with others" (UN Convention, 2006).

The text of the Convention defines disability as the result of the interaction between the individual and the set of barriers which hinder the full use of goods and services and participation in social life. It requires each State to submit a report on the measures taken to fulfil its obligations and on the progress achieved in overcoming these barriers.

For example, the Italian State has ratified and implemented both the United Nations Convention on the Rights of persons with Disabilities and its optional protocol through Law no. 18 of 3 March 2009[6].

At the European level, in December 2000, the Charter of Fundamental Rights of the European Union[7] was adopted, which is a legally binding instrument with the entry into force of the Treaty of Lisbon in 2007.

The Charter, consisting of an introductory preamble and fifty-four articles (divided into seven chapters: dignity, freedom, equality, solidarity, citizenship, justice, general provisions), is applied to the European institutions in accordance with the principle of subsidiarity (in no case can it extend the competences and tasks assigned to them by the Treaties) and is monitored annually through a report drawn up by the European Commission.

In 2010, the European Union officially acceded to the International Convention on the Rights of persons with Disabilities, becoming the first intergovernmental organisation to sign a human rights treaty and accept its obligations in full. The Convention obliges the institutions of the European Union (such as the Commission, Parliament, the Council and the Court of Justice) to support the rights of disability, but does not imply that the same will happen in all Member States, since each State must provide for specific formal accession.

The European Commission has renewed its commitment to disability by defining *the European Disability Strategy*[8] aimed at improving social inclusion, well-being and the full exercise of the rights of disabled people according to a complementary action at the European and national level.

The Commission supports the Member States in defining national strategies and action plans for the implementation of the United Nations Convention on the Rights of persons with Disabilities by promoting priority actions and initiatives in various areas.

In particular, the aim of the new strategy is to ensure that all persons with disabilities enjoy full human rights and freedom as well as equal access to society and the economy in accordance with the sustainable development of United Nations Agenda 2030.

In this perspective, most of the objectives set out in the Agenda mention disabled people explicitly or as part of particularly vulnerable people, stressing the importance of ensuring social inclusion.

The table below lists the main international regulatory references for accessibility and social inclusion of people with disabilities.

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[6] Italian government, Ministry of Labor and Social Policies, https://www.lavoro.gov.it/temi-e-priorita/ disabilita-e-non-autosufficienza/focus-on/Convenzione-ONU/Pagine/Convenzione%20Onu.aspx.

[7] EUR-Lex, Access to European Union law https://eur-lex.europa.eu/legal-content/IT/TXT/?uri=LEGISSUM:l33501.

[8] EUR-Lex, Access to European Union law https://eur-lex.europa.eu/legal-content/IT/TXT/?uri=LEGISSUM:em0047.

Country	Regulation/Law
Albania	Law 7995/1995 “On the Encouragement of Employment” Articles 15, 16 National Strategy on People with Disabilities www.osce.org/files/f/documents/1/f/40201.pdf
Australia	2010, Disability (Access to Buildings) Standards
Austria	- Baurecht und Bauordnungen (Diritto edile e regolamenti edilizi) www.oesterreich.gv.at/themen/bauen_wohnen_und_umwelt/bauen/Seite.2260200.html - Barrierefreies Bauen (Edificio senza barriere) www.oesterreich.gv.at/themen/bauen_wohnen_und_umwelt/bauen/1.html
Belgium	Fiandre: - Access regulation of the Flemish Government of 5/6/2009 (modified 18/02/2011, applied since 31/03/2011) - New application file for a building permit, 28/5/2004 Vallonia: - Walloon Code for Spatial Planning, Planning and Heritage. Chapter XVII ter: General Regulation on buildings accessibility and parts of buildings open to the public or collective use by disabled persons (AGW 25/02/1999, Article 1) - Art. 415 / 5. Floors not accessible by ramps under Article 415 / 1 are accessible, without the help of a third party, by at least one elevator or platform lift Bruxelles: Regional Planning Regulation of the Brussels Capital Region of 21/11/2006, Title IV: building accessibility for disabled
Bulgaria	- Natural Persons & Family Act (NPFA) + Civil Procedural Code (CPC) - State Gazette 120 of 29/12/2002
Canada	CSA B651 Accessibility of the Built Environment Standard
Cyprus	Disabled People’s Act N.127 (I) 2000 www.legislationline.org/download/id/7078/file/Cyprus_Persons%20with%20Disabilities%20Law_2000_am2007_en.pdf www.mcw.gov.cy/mcw/dbpd/disabledaccess.nsf/dbpd05/dbp%20d05?OpenDocument
China	Wuzhang’ai Sheji Guifan Guojia Biaozhun Banbu Shishi (National Standards of Barrier-Free Design Specifications Promulgated and Effective) www.gov.cn/zwgk/2012-07/10/content_2179864.htm
Croatia	- Official Gazette 151/2005 and 61/2007 - Official gazette 6/84, 42/05 – consolidated text
Denmark	- Compulsory national legislation BR10 (Danish building code) - Legislation 1250 dated 13/12/2004 about accessibility requirements when “remodeling” existing buildings
Estonia	Legislation for buildings in Estonia, e.g. Building Act (adopted in 2002, latest review in 2011) www.riigiteataja.ee/akt/125052012022

Finland	- The National Building Code of Finland section F1 “Barrier-free building”, several regulations addressing administrative, service, business and work facilities. www.ymparisto.fi/download.asp?contentid=26493&lan=fi - Specific requirements: The National Building Code of Finland Section G1 “Housing Design” on residential buildings www.ymparisto.fi/download.asp?contentid=26494&lan=fi
France	- Law 2005-102 11/02/05 - Decree 2006/55 17/05/06 - Arrest 1/8/06, Accessibility of persons with impaired mobility in buildings accessible to the public (ERP & IOP) in case of transformation.
Germany	- Musterbauordnung MBO (Recommendation from the German government to the federal states on how to build correctly). - LandesBauordnungen LBOs (Regulation in each federal state on how to build correctly), different for heights and/or for floors.
Greece	- Law 4067/2012 New Urban Planning Regulations (article 26) - Decision 3046/304/3- 2-1989 / article 29 - Law 2831 /2000
Ireland	Technical Guidance Document www.gov.ie/en/publication/78e67-technical-guidance-document-m-access-and-use/#
Italy	- Law 13/1989 - Ministerial Decree 236/1986 (Decree implementing Law 13/1989) - Presidential Decree 503/1996 - Ministerial Decree 5/7/1975 - Presidential Decree 380/2001, as amended
Latvia	LB 208-08 (The Latvian legislation does not provide any international or local interest standards).
Luxembourg	- Regulations of the Grand Duchy on security in public bodies 1979 - The modification of the accessibility act in 2008 - 29/03/2001+23/11/2001+17 /03/2008 http://www.legilux.public.lu/leg/a/archives/1995/0090/a090.pdf http://www.legilux.public.lu/leg/a/archives/2001/0043 http://www.mfi.public.lu/publications/Handicap/GuidedesNormes_b rochure_FR.pdf http://www.legilux.public.lu/leg/a/archives/2008/0040/a040.pdf http://www.sante.public.lu/publications/sante-filvie/handicap/guide-normes-accessibilite-environnement/guide-normes-accessibilite-environnement.pdf
Norway	- National standards on accessibility: NS 11001- 1:2009 and NS 11001-1:2009 - LOV 2008-06-27 nr 71: Law related to requirement s for building. - Codes related to the law (TEK) and guidelines related to the codes. (VTEK)
New Zealand	2001, New Zealand Standard Specification No 4121
The Netherlands	Compulsory national legislation (Legislation applies to new buildings, built after Jan. 1, 2003, granting date of the permit validates)

Poland	- Act of 7 July 1994 – Building law - Compulsory national legislation (Building law), more demanding for public buildings
Portugal	Law 46/2006 of 28 August (specific requirements are established in the Decree-Law 163/2006 of 8 August)
United Kingdom	- British Standard BS 8300:2009 - BS 5810:1979 Code of Practice for Access for the Disabled to Buildings www.hse.gov.uk/pubns/books/l24.htm
Czech Republic	National obligatory legislation. Notice No. 398/2009 Coll. www.zakonyprolidi.cz/cs/2009-398
Slovak Republic	- 532/2002- DECREE Ministry of Environment of the Slovak Republic setting General technical requirements for buildings and for buildings used by persons with limited mobility and orientation - 237/2000 Building Act - STN EN 81- 70/A1:2004 - STN EN 81- 40:2011
Romania	- Law 448/2006 concerning protection and promoting the rights of people with disabilities-compulsory - Article 62 related to Accessibility for people with disabilities www.legislationline.org/download/id/7082/file/Romania_Law_protection_promotion_rights_disabled_persons_2006_am2008_en.pdf
Singapore	- Building and Construction Authority, BCA (2007), “Code on Accessibility in the Built Environment”. - Building and Construction Authority, BCA (2007), “Universal Design Guide”.
Slovenia	- Construction Act buildings (OJ RS, No. 110/02) - Regulation concerning the requirement s for barrier free access, entry and use of facilities in the public domain and multi residential buildings (OJ RS, No. 97/03)
Spain	- Law 26/2011, of 1 August 2011 - Royal Decree 173/2010 www.boe.es/buscar/doc.php?id=BOE-A-2010-4056
United States	- Fair Housing Act Accessibility Guidelines www.hud.gov/program_offices/fair_housing_equal_opp/disabilities/fhefhag - Rehabilitation Act (Section 504: Disability Rights in HUD Programs) www.hud.gov/program_offices/fair_housing_equal_opp/disability_main - Americans with Disabilities Act of 1990 (ADA) www.ada.gov/
Sweden	Compulsory national legislation
Switzerland	National standard SIA 500:2009 (barrier-free buildings)
South Africa	SANS 10400-S: South African, National Building Regulations - Part S. “Facilities for Persons with Disabilities”
Hungary	- 253/1997, Government al Decree about Building Rules - 1998, XXVI, Law about Equality of Chances

Tab. 5.3 Summary table on the main laws and regulations on accessibility of the home space for EU and non-EU countries. Reprocessed table, source: CEN/BTWG 207, 2011; ECA, 2013; FRA, 2014.

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6. Design and disability: emotional impact

by *Ester Iacono*[1]

6.1 Emotional Design: the role of emotions

It is well known that emotions play an important role in influencing perceptions, attitudes, motivations and types of behaviour.

The emotional state can influence human cognition on the processing of information and the interaction of humans with products, systems or other persons. Human beings, in fact, at the behavioural level, tend toward stimuli associated with positive emotions, avoiding those linked to negative affections.

Numerous scientific studies, conducted by affective sciences, social neurosciences and co-cognitive sciences, show the strong link between body and mind and how the stimulation of positive emotions can influence the state of well-being and physical, psychogical and social health (Immordino-Yang, 2011; Porges, 2011).

Today, the introduction of emotions, within the scientific debate, has led designers and researchers to pay greater attention to the role that emotions play in user-product interaction.

Indeed, the increase in scientific contributions on design and emotions, participation in conferences related to the sector (for example the "*Design & emotion conference*") applied in different fields (health, well-being, culture, experience, etc.), the activities of *Design & emotion Society*[2] and European projects such as Engage[3] confirm a growing interest of Design in the world of emotions - the latter today considered a significant element of human factors in the research of Design, both in theory and in practice (Hanington, 2017).

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[2] the Design & Emotion Society is a non-profit organisation that aims at facilitating dialogue between professionals, researchers and industries on issues related to emotions in Design. The network is used to share initiatives, intuitions, studies and methods that make it possible to support the emotional experience of products. For further information: www.Designandemotion.org

[3] Engage, Designing for emotion is a Knowledge community developed on the basis of European funding within the 6th Framework Program, involving 21 project partners from 9 European countries. The project partners have a background in the fields of affective Design and Design for emotion.

Considerable progress can be attributed to a number of studies that in recent decades, in various fields (social sciences, cognitive psychology, etc.), have contributed to extending knowledge about emotions, such as Ekman's coding scheme, the model for cognitive analysis of emotions (Lewis & Haviland-Jones, 2000) and, within the discipline of Design, the research of Jordan (2000), Norman (2004, 2013) and Desmet (2008, 2018).

Most of the first works that recognise emotions within the design concept originate in the Netherlands, where the *Design & Emotion Society* was founded in 1999, as a promoter of international conferences gathering professionals and academics from the world of Industrial Design, Interaction Design, User experience (UX), Human computer interaction (HCI), Graphic Design, Communication Design, etc. (Hanington, 2017).

In particular, the relationship between *experience Design and emotion* was clearly cited in Norman's work (2004), which coined the term *Emotional Design* from the experiment conducted by two Japanese researchers, Masaaki Kurosu and Kaori Kashimura. This experiment showed that with more attractive ATMs, people performed operations faster, better and were even happier. This shows that aesthetic pleasantness plays a significant role not only in satisfaction, but also in performance.

Experiments conducted by the psychologist Alice Isen, in the early '90 years, have also shown that pleasing products make people happier and facilitate a proactive approach that can simplify interaction and thus obtain more satisfactory results (Isen, 2001).

Conversely, if the user is not emotionally satisfied, even if the product is well designed, the user-product interaction is affected. That is why creating products that evoke emotions and translate into positive experiences for the user becomes the main objective of Emotional Design.

Based on years of research in cognitive psychology, Norman exposes the urgency of focusing the attention of the HCI world from practical to emotional and subjective aspects, starting precisely from the assumption that the experiences of people are permeated by continuous emotional responses. Therefore, the inclusion of emotions in the practice of Design makes it possible to consider the various emotional nuances associated with the interaction with artefacts and therefore represents a challenge in trying to overcome design processes that limit their attention to usability alone.

An investigation of user behaviour, also from an emotional standpoint, leads to the need to consider not only the functional requirements of the product, but primarily the emotional ones. Also ISO 9241-210: 2019, by defining the User Experience, makes reference to the emotions, preferences, perceptions, and physical and psychological responses of the user before, during and after the use of a product or service.

Today, Emotional Design has a sufficiently wide scope to be attractive and relevant for all the design disciplines and for all the possible fields related to it. One of these sectors is the domestic one, where the intervention of Design on aesthetics, products, communication, and services, can lead to a reduction in stress and anxiety, improving user satisfaction (Tosi, Rinaldi, 2015).

In particular, if we talk about vulnerable users, elderly users or people with disabilities, it is not hard to imagine how much the home space can create anxiety, frustration, pain, fear and many other feelings that can arise when you are in contact with it.

Often, even specific products and equipment can induce the perception of a threat, rather than a positive mood, in addition to stigmatising the physical and psychic condition of the user.

This is linked to the interest in the functional aspects, and to the lack of attention to the possible metaphorical communication given by the shape of the products (Maiocchi, 2010) and to the emotions that the domestic environment can generate.

These emotions are amplified if the user is a person suffering from Parkinson's disease (PwP), since, because of his or her own neurodegenerative condition, which involves limits to the activities and impairments of physical, mental and psychosocial functions (Narme et al., 2013; Schiavolin et al., 2017), this person needs a domestic system that takes into account not only psycho-emotional needs, opinions and necessities, but also those of carers (Van Rumund et al., 2014; Bourazeri, Stumpf, 2018; Martínez-Martín et al., 2007). The latter, in fact, are subject to a progressively more significant burden as the disease progresses, which has repercussions on the load and mental aspects linked to the quality of their lives.

The domestic experience, for this type of fragile users (PwP) and for their caregivers, is therefore the meeting point between the physical environment - from the architecture of the building to the arrangement of rooms and furniture to the configuration of equipment/ aids - and the possible provision of health services.

For this reason, in this chapter it was considered appropriate to examine the contribution of Evidence based Design (EBD), an approach capable of influencing the design process, studying the physical and psychological influence of the environment tailored to its users and based on the evidence of the results obtained from experiments with users (Alfonsi et al., 2014; Alvaro et al., 2016; MacAllister et al., 2017).

6.2 The contribution of the Evidence Based Design approach (EBD)

It is demonstrated, through experimental data, that mind, brain and nervous system can be directly and indirectly, positively or negatively influenced by elements of the environment.

A characteristic of Parkinson's disease is causing sensory (visual-spatial) dysfunctions relative to the perception of space, which is altered.

In those affected by the disease, behavioural difficulties, linked to the impossibility of obtaining good information about the surrounding environment, cause serious discomfort, which may be reduced through a specific design of the space and its elements.

Therefore, it is essential to pay particular attention not only to the shapes used, to the volumes of the spaces, to the height and configuration of the rooms, to the presence of accessories or not, to the furniture and equipment, but above all to the perceptive/ sensory component that must become prevalent with respect to the functional one in the design criteria of the domestic environment (De Luca, 2021).

Indeed, every environment can provoke on each person different emotions and states of mind and, if we speak of users suffering from a neurodegenerative disease, this influence is even stronger (see Fig. 6.1).

As demonstrated by Psyconeuroimmunology (PNI), the science that creates environments that prevent diseases, accelerate the process of healing and promote health and well-being, there is a strong connection between biological responses and sensory stimuli. According to Gappell (1992), the biological mechanisms require continuous variations and sensory stimuli in order function correctly.

For example, sensory deprivation or monotony of the environment inevitably lead to pathological disorders. In this regard, an effective practice that helps, above all, categories of vulnerable or elderly people to train their minds and their motor abilities and improve their health is multisensory stimulation through elements that offer continuous stimuli.

In particular, reference is made to the design of the so-called “Snoezelen” (Merrick, 2004), multisensory environments consisting of pleasant sensory experiences and designed for people with cognitive impairment, from moderate to severe, and pathologies such as Parkinson’s, dementia and Alzheimer’s (see Fig. 6.2).

As reported in the study conducted by Duchi et al. (2019), the project of a multisensory black room for elderly patients with neurodegenerative diseases and brain deficit has helped, through various elements of sensory stimulation, the cognitive and functional sphere (fine-coarse motor skills) of the subjects involved (PwP).

The room is composed of a series of multisensory devices that provide visual (fiber optic shower, colour scale, star tent, virtual reality glasses), tactile (texture path) and auditory (sound therapy) stimulations as well as an interactive lighting system for the environment. It recreates emotions that promote an atmosphere of well-being, relaxation and above all provides a series of advantages that are reflected not only on the will to increase the quality of life of patients, but also on the reduction of the perception of the workload and the stress of carers.

Ultimately, it was possible to observe how much the built environment could have a positive impact on the perception of space for people with Parkinson’s disease (PwP).

In particular, the creation of a multisensory environment can guarantee an improvement in the cognitive functions of people, which results in the reduction of negative feelings (aggressiveness, fear, confusion, etc.), the promotion of positive behaviour, the improvement of motor skills, and the relationship with their social and personal environment.

Therefore, the EBD approach, which identifies the physical and behavioural effects, through the classical scientific method, provides a fundamental contribution, according to the sequential procedure that starts from the survey of the current status in order to identify previously achieved results and hypothesise innovative solutions.

It then continues with the processing and collection of actual user data, analysis and measurement and, at the end of the process, it concludes by sharing the results (Alfonsi et al., 2014).

EBD’s research extends to any project environment and allows for the resolution of environmental, perceptual-sensory and stress factors, in order to slow the course of the disease and ensure greater well-being.

The experimental studies of many researchers in this area provide concrete evidence supporting this theoretical and operational perspective and show, for example, as vulnerable users or those suffering from particular diseases who can enjoy a view of nature or look at works of art for emotional support, they are less subject to depressive States (Wilson, 1972), suffer from less sleep disorders, visual problems and hallucinations (Keep et al., 1980), are subject to positive emotional states and feel less isolated, depressed and anxious (Verderber, Reuman, 1987).

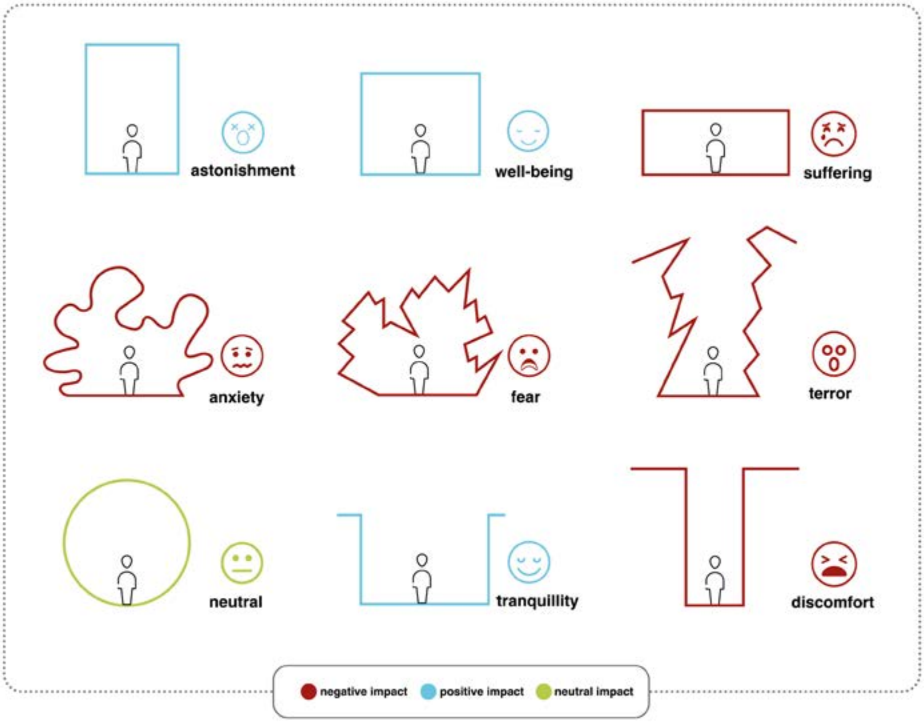

Fig. 6.1 Emotional states relating to the built environment. Graphic elaboration of the author, source: Ferrari (2018, p.3).

Fig. 6.2 "Snoezelen" multisensory rooms of the LudoVico Company. Source: www.ludovico.it/stanze-multisensoriali-snoezelen-room/.

Therefore, the physical space, with its functional, morphological-dimensional and environmental characteristics can also have a therapeutic value in the treatment of the physical and mental disability of Parkinson's patients (PwP), reducing not only the patient's mobility difficulties, but also fears and frustrations through the sense of security they can perceive around themselves. As De Luca (2021) argues in relation to his "House of Parkinson" project, the main objective of a designer must be to create environments that are free, not only of architectural barriers, but primarily of the psychological-physical ones, which most often make the interaction of PwP with the environment more complex. As demonstrated in the literature, the potential of some environmental factors can have positive effects both on patients, in terms of improving the clinical outcomes of the disease (Ulrich, 1991), and on caregivers, in terms of improving working efficiency and reducing psycho-physical fatigue (Del Nord et al., 2015).

These studies and many others show that the aesthetics of the care environments, the products, the communication and the services, if well designed, can have positive effects on both staff and patients, reducing their anxiety and stress and ensuring their health and well-being.

Virtual environments have also been shown to have a therapeutic effect and great potential in neurological rehabilitation, as in the specific case of the study conducted by Pérez-Sanpablo et al. (2014), which provided for the implementation of the EBD approach and the development of a virtual reality treadmill (VR) system for a more immediate and pleasant rehabilitation of Parkinson's patients.

It uses a digital camera to measure the spatial-time parameters of the gait and provides interfaces where patients can interact within virtual worlds that simulate real ones. All this is accompanied by visual stimuli (transversal lines placed on the floor of the virtual environment) and auditory ones (high frequency beats) that guarantee the complete immersion of the subject in the virtual environment when walking on the treadmill.

Furthermore, communication can also become a powerful tool in support of PwP (Myers et al., 2020) such as in the case of a research, conducted by Janssen et al. (2016), which highlights the effectiveness of a simple communicative ploy that makes movement of Parkinson's patients easier and more fluid.

It has been shown that freezing of gait is a symptom common in PwP and that this is a sudden and often unexpected experience, as if their feet were firmly glued to the floor. This significantly influences their daily activities, due to reduced mobility, feelings of insecurity, and fear of falling.

Despite examples of non-pharmacological interventions, such as the use of 2D visual signals (fixed lines glued at a distance on the floor, chessboard tiles or laser lines projected on the floor), which allow patients to walk, these are not always effective solutions for all PwP.

Some people with Parkinson's, in fact, walk up and down the stairs easily, but experience gait freezing on level ground.

This is what has been analysed in the research carried out by the Product Designer Mileha Soneji, who, observing her uncle with Parkinson's disease, thought of creating the illusion of a staircase that crossed all the rooms of the house.

So she found a solution to the freezing problem by creating the "*Staircase Illusion*"[4], a 3D optical illusion of a staircase that, placed inside the house, on the floor, made users feel like climbing stairs and not walking on level ground. The results have shown that PwP can more easily walk over areas where the illusory mat is placed, as a continuous movement deceives the brain so that tremors disappear. This is a remarkable example of how gait freezing can be alleviated by visual signals presented as a 3D illusion, which are more effective than 2D visual signals (Janssen et al., 2016), as they require patients to raise their feet higher and shift their weight more laterally. This non-technological floor covering can be placed in all rooms of the house, to create a space in which PwP can move with safety and fluidity, but also within hospitals. Soneji's solution is really low-tech, although in the future such 3D visual signals could be provided through augmented reality that, in combination with eye glasses or other wearable sensors, could provide an effective 3D signal on-demand.

Also interesting is the development of PwP products such as "*No Spill Cup*"[5], a product again created by Soneji in response to the uncontrollable tremors of her uncle that made actions as simple as handling a cup extremely difficult. Designed with an inward curve, at the top, to divert the liquid inside the cup in case of tremor, It allows patients with Parkinson's disease to drink without spilling the content and can be considered a non-specialist or non-discriminatory product for any user who is simply a bit clumsy. In his 2016 TED Talk[6] Soneji, after sharing these inclusive, human-centred projects that make life easier for Parkinson's patients, argued that technology is not always the solution. But that what makes Design great is the ability to observe and have empathy. That is, to be able to put oneself in the shoes of the other person, as well as to imagine simple solutions that can have a positive emotional impact on suffering patients. In short, it can be said that the Design of emotions and the EBD approach play a significant role in improving the user experience, especially if belonging to a category of more vulnerable subjects. Indeed, designers should consider including emotions throughout the design process as an important element. Many products, intended for specific users such as the elderly and the disabled, still need the emotional contribution of Design, since they evoke emotions often considered immaterial and impossible to modify; it is up to the Designers to influence the emotional impact of their projects, through an empathic approach.

6.3 Empathic Design: supporting designers to build empathy, planning for and with people suffering from Parkinson's disease

Although Rayport & Leonard-Barton (1997)[7] were among the first to talk about *Empathic Design*, there is still no definition of empathy widely accepted and consistently used in Design.

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[4] Cf. www.improvisedlife.com/2018/03/20/use-empathy-and-observation-to-find-simple-solutions-mi- le ha-soneji/

[5] Cf. www.nospill.weebly.com

[6] The final part of Mileha Soneji's speech at the TED Talk in 2016: "We find these complex problems. We must not be afraid of them. Let us analyse them, let us reduce them to much smaller problems and then find simple solutions. Let us test these solutions, fail if necessary, but with new insights to improve them. Imagine what we could do if we found simple solutions. How would the world be if we combined all our simple solutions? Let's make a smarter world, but with simplicity." The full speech can be found at the following link: https://www.ted.com/talks/mileha_soneji_simple_hacks_for_ life_with_parkinson_s?language=it

[7] Rayport & Leonard-Barton (1997) introduced the term Empathic Design for the first time, creating guidelines to obtain, analyse and apply information collected by the application in the field.

Studies conducted in literature (Kouprie, Visser, 2009; Strobel et al., 2013; Walther et al., 2017) used definitions adopted by psychology (Surma-Aho et al., 2018; Wong et al., 2016) and, since empathy is commonly associated with the user's capacity for total understanding, the empathic approach, in Design, is often associated with participatory and co-design methods (Rinaldi, 2018; McDonagh, 2008; Wright, McCarthy, 2008; Stanton et al., 2014) which allow users to be understood through the combination of data collection, surveys and sensor measurements (Ghosh et al., 2017). Designing, therefore, by paying particular attention to the feelings and emotions that the user feels about a product is possible thanks to *Empathic Design* (Heylighen, Dong, 2019; Thomas, McDonagh, 2013; Hess et al., 2016; Hess, Fila, 2016; Walther et al., 2017).

In recent years, this has evolved rapidly in response to the concept of Design for the user experience, which is reflected in 4 principles at the basis of empathic Design (Postma et al., 2012):

1. *Balancing rationality and emotions* in building an understanding of the user experiences to help researchers and Designers "*understand those human traits that are responsible for people's enjoyment, use and desire to live with the products they design*" (Dandavate et al., 1996, p. 415). In empathic planning, this balance is achieved by combining the observations of what people do with interpretations of what people think, feel and dream of (Dandavate et al., 1996; Fulton Suri, 2003).
2. *Need to make empathic inferences about users and their possible future*. In Empathic Design, people's feelings and experiences are believed to be better understood through empathy (Dandavate et al., 1996; Segal & Fulton Suri, 1997). Therefore, the empathic capabilities of Designers and researchers make it possible not only to interpret what people think, feel and dream of, but also to imagine possible future situations of use of the product (Black, 1998; Fulton Suri, 2003).
3. *Involving users* as partners in the development of a new product and build an understanding of these experiences of which they are experts (McDonagh, 2008; Wright , McCarthy, 2008).
4. *Engaging design team members* as multidisciplinary experts in user research. Empathic Design suggests that researchers and Designers join forces in designing and conducting user research to ensure that the user's perspective is included in the development of a new product (Black, 1998).

The four principles are not exclusively related to Empathic Design, but there are different approaches to design research, such as participatory design and critical design, which share one or more of these principles.

Another important contribution in this sector is that offered by Fulton Suri (2003), which distinguishes three fundamental steps for Empathic Design (see Fig. 6.3):

1. observe what people do in their own context through observation techniques (Stanton et al., 2014).
2. ask people to participate by reflecting on their personal experiences and expressing their thoughts, feelings and desires through methods and techniques such as context mapping (Sleeswijk Visser et al., 2005), Design probe[8] (Mattelmäki, 2005). In particular,

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[8] The *probes* are small kits (postcard, camera, post-it, diary, open questions), These are designed by the Design team and assigned as exercises to those involved in the design process. They allow the user to record specific events, feelings or interactions, without being affected by the presence of an observer who could indi-

there are “emotional toolkits” – visual, playful, and narrative techniques that focus on dreams, fears, and aspirations (Koskinen et al., 2003) – and “cognitive toolkits” such as maps, mappings, 3D models, relationship diagrams and process flow charts that capture visual thought and imagination.

3. try things out yourself and learn the experiences of others by approximating their practical knowledge. This class of methods and techniques includes experience prototyping (Buchenau & Fulton Suri, 2000), role playing (Boess et al., 2007) and empathic testing (Thomas et al., 2012).

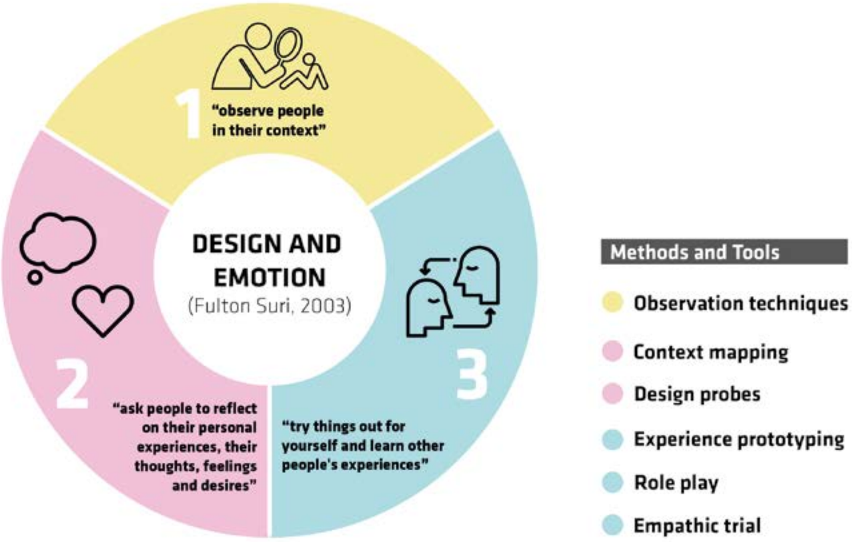

Fig. 6.3 the 3 categories of Design & Emotion. Graphic elaboration of the author, source: Fulton Suri (2003).

Interesting, in this regard, are the research experiences that propose valid tools to support designers in the construction of empathy with fragile users, in order to design for and with them (Black, 1998; Sanders, 2001). In particular, participatory and co-design methods allow the empathic approach of Design to be strengthened through different types of research techniques (Kouprie, Visser, 2009, p. 439):

- *Techniques to establish direct contact between Designer and users*. Among these are video ethnography and contextual interviews to acquire empathy, understand user experiences and identify their unmet needs.

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rectly influence events and behaviour. The aim is to collect data and information from people, in order to better understand their culture, their thoughts and values, and thus stimulate the designer’s imagination (Gaver et al., 1999). Although they are valid instruments, they have an experimental and uncertain nature, but the challenge is represented by the ability of the Designer to structure them in order to allow the user to identify the criticalities and indicate possible solutions. “*Probes become a tool for users to communicate their emotions and experiences and for designers to activate a process of empathy, putting themselves in the shoes of the user*” (Rinaldi, 2018, p. 163).

- *Techniques for communicating the results of user studies to design teams*. Examples include the use of personas (Cooper, 1999) to communicate detailed narrative views of end-users, storytelling that provides information about users' thoughts, feelings, and experiences, as well as creating "empathic Design Solutions" (Carmel-Gilfilen, Portillo, 2016).

- *Ideation techniques to evoke the experiences of the Designer about the life of the user*. In order to understand the emotional perspective of the other, the designer must assume not only the mental perspective, but also the bodily perspective of the user, for example through the use of wearable simulators such as gloves, goggles or integral overalls. They limit the movement of the wearer and evoke the experiences of those who have difficulty in carrying out certain physical activities.

In this regard, the research of Rosati et al. (2013) and Boffi et al. (2014), which aims at constructing the empathic approach towards PwP and their caregivers through the introduction, in the design process, of a wearable device capable of simulating the tremor in the hands of PwP or of inducing the sensation of visual/motor disability associated with ageing.

In the specific case of the study conducted by Boffi et al. (2014), the Designers, wearing the simulator, were able not only to use the gas hob and to avoid physical effects and body limitations caused by Parkinson's disease, But above all, they could start a process of understanding with regard to their personal experience of physical simulation of the tremor of the hand and the possible opportunities for improving existing gas hobs and make them accessible to PwP.

Obviously, a physical limitation simulator can express its empathic potential when enriched by immersion in the real context and by the observation of real users interacting with the product and experiencing physical limitation for reasons of illness or ageing.

Therefore, it is essential for designers to understand, through ethnographic design tools, what these limitations really mean for real-life users.

Moreover, numerous scientific articles show how close collaboration with users can enable designers to develop innovative concepts, products, services, strategies and systems that meet the real needs and the concrete wishes of users (Raviselvam et al., 2018).

It is therefore crucial to ask how PwP and their carers can be involved as equal research and design partners in the co-creation process. In order to answer this question, we can mention the case study by Bourazeri & Stumpf (2018), concerning the use of co-participation and co-design methods in the design of a set of technological tools for the smart home that allows PwP and caregivers to plan, monitor, and self-manage their home life and well-being more effectively.

The PERCEPT (PERsona-Centred Participatory Technology) approach that employs co-created personas in the exploration, design and evaluation of technology during co-design has enabled researchers and Designers to interact better with target groups in all phases of co-design.

Also the study conducted by McNaney et al. (2015) with regard to the design and development of rehabilitative exergame with PwP and their caregivers, has highlighted how these groups of individuals can be involved in a user-centric design process, in order to understand how these rehabilitative products can be designed to reflect the values, objectives and lifestyles of PwP, as well as to enhance their use within the home environment.

The ways in which users are involved range from approaches that envisage “designing for PwP”, in which their needs are analysed and translated into solutions, to approaches involving “designing with PwP”, in which a deep and direct involvement of a small group of users is obtained in all phases of the project process, trying to break down the barriers deriving from the difficulties generated by the disease and improving their participation.

In conclusion, it can be said that planning for and with people with Parkinson’s is a challenge that goes far beyond the disability and physical and cognitive limitations of individuals, since it also involves the empathic and emotional skills of the designer. Thus, the inclusion of empathy in the design process becomes one of the most powerful guidance tools offered to the designer for a truly inclusive design.

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7. Design and disability: new enabling technologies

by *Claudia Becchimanzi*[1]

7.1 Robotic and wearable technologies: a powerful tool to support caregivers and PwP

Robotic and wearable digital technologies are making significant progress in a wide range of fields (Yang et al., 2018), including medicine and social-health care. They are currently playing, and will be able to play, a key role in the future, implementing human perception and skills and creating the right conditions for improving the quality of life of PwP (people with Parkinson's) and services addressed to them, improving their mobility, communication possibilities, increasing their sense of security and independence and promoting social inclusion (Ancona et al., 2021; Sapci & Sapci, 2019).

Assistive robotics has seen a strong development in recent decades: Japan has been the pioneer country, investing a lot of resources in developing but also experimenting with increasingly sophisticated and intelligent platforms. Europe is also pursuing the same objectives, through the most recent strategic research programmes such as the European Strategic Research Agenda for Robotics in Europe 2014-2020 (SPARC)[2]. Similarly, the RAS 2020 (Robotics and Autonomous Systems)[3] programme in the United Kingdom also pursues the objective of developing robotics aimed at social and health care. Advanced robotics is among the five revolutionary technologies that will transform private life, work and the global economy (Manyika et al., 2013) by actively cooperating with humans (Čaić et al., 2018; Alwardat & Etoom, 2019). Furthermore, with regard to the domestic robotics market alone, the number of adopted robotic systems increased by 31 million between 2016 and 2019 (IFR, 2020). The market value of robots for performing strenuous and/or risky household tasks has grown by 13 billion in this timeframe. In addition, the assistive robotics market is expected to increase from $4.1 billion in 2019 to $11.2 billion in 2024 with a Compound Annual Growth Rate (CAGR) of 22.3% (Markets and Markets, 2019). Wearable devices, compact and miniaturised, are worn directly by people, creating a constant interaction between computer and user. The wearable technology which

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[2] Cf. www.eu-robotics.net/sparc/.

[3] Cf. www.ukras.org.

includes a wide range of devices, services and systems developed with a view to incorporating technology into homes and everyday products, is opening new avenues for their application and major opportunities for research and design (Piwek et al., 2016; Møller & Kettley, 2017; Rinaldi et al. 2018). The network-connected devices (and among them the Internet of things - IoT), which in 2015 were more than 5 billion, will be about 28 billion by 2025 for a value of about 11.000 billion, or 11% of the entire world economy (Manyika et al., 2015). The integration of new technologies into interconnected systems can facilitate the activities of health workers (for example, health monitoring, drug control, environmental safety) and can prevent loneliness and isolation by supporting PwP in Activities of Daily Living (ADLs) and by facilkitating socialisation and an active emotional and cognitive stimulation. Wearable and robotic technologies can contribute to home autonomy, monitoring health and safety (Iecovich, 2014) to ensure a viable and less expensive alternative to institutionalised care (who, 2007), but also to support the diagnosis and treatment of Parkinson's disease (Rovini et al., 2017; Paff et al., 2020; Hubble et al. 2015; Pardoel et al., 2019).

This chapter investigates the research areas and the main areas of application of assistive technologies in relation to PwP, with a focus on the state of the art at the international level through the analysis of representative case studies and on ethical issues related to the dissemination of *Assistive Technologies* (ATs). In addition, this paper briefly questions the role and challenges of Design in relation to the Human-Robot interaction (HRI) and the subject of technology acceptability. They concern both design and research through Design: The Designer plays a key role not only as a professional able to identify people's needs and translate them into tangible solutions but also as responsible, from an ethical and social standpoint, for the use and dissemination of technologies designed to support and not replace human activities and relationships.

7.2 Assistive technologies and the Internet of Things: principles, taxonomies and research areas

Digital technologies are becoming increasingly widespread and developed, due both to the progress of software and hardware research and to the increase of functions and, therefore, of application fields. Assistive Technologies (ATs) are defined by the World Health Organization (WHO)[4] as "*any product, instrument, equipment or technology adapted or specially designed to enhance an individual's ability and independence to facilitate participation and improve overall well-being*". According to the Association for the advancement of Assistive Technology in Europe (AAATE)[5] "*assistive technology is a term for any technology-based product or service that can facilitate people with functional limitations of all ages in daily life, work, and leisure*".

Hersh & Johnson (2008) propose an explanation of the term in a broader sense, inclusive of products, environmental changes, services and processes that allow access to and use of ATs, in particular by people with disabilities and the elderly. So ATs help users overcome infrastructure barriers to enable their full participation in social activities, safely and easily.

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[4] Cf. www.who.int/disabilities/technology/en/.

[5] Cf. www.aaate.net/about-aaate/.

Cook & Polgar (2014) proposed five principles for the effectiveness of ATs: Services must be person-centred; the objective is to allow the person to participate in the desired activities; the provision of assistance services must occur through a process based on evidence and information; assistive technologies must comply with ethical standards; ATs must be sustainable.

According to the latest report from SAPEA (Science advice for Policy by European Academics), the main areas of implementation of new assistive technologies are (Michel et al., 2019):

(i) physical health and applications for social and cognitive health, whereby m-health, based on smartphone use, plays an increasingly important role in health monitoring and in supporting the adoption of correct lifestyles, in a preventive prespective;

(ii) design according to the principles of Inclusive Design: this means that smart home technologies provide greater safety and support for daily activities and social connection (a fundamental contribution is also made by the rapid spread of social and assistive robots, wearable products and/or interconnected systems);

(iii) care technologies and wearables: they facilitate permanent follow-up of health, chronic clinical conditions and functional capabilities through remote monitoring, physical rehabilitation at home, brain training and drug intake/administration control;

(iv) applications of machine learning algorithms (AI) for diagnostic and surgical procedures, which offer enormous possibilities.

Part of the research concerns the integration of robotic or micro-robotic systems into the use of everyday products or furniture, such as smart cabinets capable of monitoring and/or remembering drug use (Ennis et al., 2017). Other projects concern the development of wearable devices to monitor and communicate any diagnosis directly to health professionals (German et al., 2017). McNaney et al. (2014) investigated the acceptability of Google Glass as PwP and caregiver assistive devices, both in the home and outdoors. Research has revealed generally positive trends toward the device, which instils confidence and security, even if it gives rise to concerns about the possible stigmatisation of users and the need to ensure as much as possible the independence of the others.

Moreover, the potential of digital assistants such as Alexa (developed by Amazon[6]) or Siri (developed by Apple[7]) in the health and care sector is very broad, though still limited in comparison to the state of the art in the robotic field (Wicklund, 2018; Reis et al., 2017). IoT (Yan et al., 2008) describes the connection of devices and products to the Internet, including household and sanitary appliances, motor vehicles, etc. Once connected, each product can store and process information on the network independently but also communicate with other devices in the network.

It is clear, therefore, that IoT technologies can be a valuable tool in support of the Ageing in Place and the diverse needs of PwP, in the smart home, in telemedicine and in remote monitoring. According to Asakawa et al., (2019) digital technologies, including virtual reality and interconnected wearable and robotic systems, can improve both the diagnosis and treatment of Parkinson's disease. The use of these technologies can support a safe, objective and real-time assessment. That is why their development can revolutionise the treatment of neurological diseases.

[6] Cf. www.amazon.it.

[7] Cf. www.apple.com/it/siri/.

However, there are several studies that highlight the problems of assistive technologies. Sometimes there is a lack of adaptation between people's daily lives, their needs and the available technologies (Greenhalgh et al., 2015; Sanders et al., 2012). In other cases, the low rate of ATs adoption may depend on inefficient interface design, privacy or security concerns (Yusif et al., 2016) or economic or socio-cultural barriers (Wang et al., 2016).

As many solutions are identified in the greater inclusion of users and of formal and/or informal caregivers in the design processes, for example through co-design sessions (Beringer et al., 2011), but also through an evaluation of such systems based on the real needs of the end users (PIETRZAK et al., 2014).

However, despite the obvious revolutionary scale of these new technologies, whose benefits have been demonstrated globally through a variety of research and experimentation programs, it is important to bear in mind that they must be integrated into domestic environments and people's daily routine, still without being invasive or incurring the risk of distorting environments and habits.

In order to avoid the risk of creating an incompatibility between technology and human activities, it is essential to ensure the effective adoption and management of these digital products, so that the interaction between people, social and domestic space and technological dimension can be pleasant and comfortable (Rodden & Benford, 2003), but also reliable and acceptable.

7.3 Assistive robotics: application areas and representative cases

The scientific community provides different taxonomies and classifications of *assistive robotics*, dividing platforms according to the type of assistance provided (physical or non-physical), the ability to socialise or establish an effective interaction from the psycho-emotional standpoint (Feil-Seifer & Matarić, 2011) and formal and morphological characteristics (automata, zoomorphic or humanoid robots) (Dautenhahn, 2013).

Social and assistive robotics can counter solitude and social isolation, especially in facilitating a human-human interaction that is independent of direct contact. From this perspective, robotics can optimise the workload and services offered by healthcare workers and caregivers, while safeguarding collective health (Yang et al., 2020).

Social/assistive robots and *educational robots* have made considerable progress in recent years, both from regarding social recognition and linguistic expression. For this reason, robot-human interaction becomes more intuitive and fluid and robots are more effective from the standpoint of cognitive assistance, social interaction and user involvement in various activities (Lee & Davis, 2020). *Therapeutic robots*, very often zoomorphic, have shown benefits in the interaction with PwP, Alzheimer's or cognitive problems. Service robots, oriented to efficiency and functionality, guarantee the support to the performance of ADLs. *Companion robots*, combining artificial intelligence and learning skills, have considerable potential in mitigating the sense of solitude and maintaining psycho-emotional well-being (Odekerken-Schröder et al., 2020).

Medical robots can support doctors and surgeons during medical exams or surgery and support patients during rehabilitation, while prosthetic robots can replace limbs, muscles and perform analogous functions.

In relation to Parkinson's disease, research is investigating how robotic systems, connected in the cloud with wearable devices and sensors integrated into the home environment, can help PwP to be as independent as possible, but also support carers in their tasks (Asakawa et al., 2019; Valenti et al., 2020; Wilson et al., 2020).

In addition, many of the studies in literature focus on identifying frameworks for future developments in service and assistance robotics (McGinn et al., 2018) while others emphasise the importance of recognising and including in the design brief the specific and particular requirements and needs of PwP (Wilson et al., 2020), which are not generally comparable to those of other types of users.

Prescott & Caleb-Polly (2017), as part of the white paper of the UK Robotics and Autonomous Systems (UK-RAS) network, outline a real roadmap for the development of social and welfare robotics, identifying the necessary advances in physical capabilities, artificial intelligence and integration between technologies in order to generate a sustainable and ethical connected care ecosystem (connected care Ecosystem for independent living) to support the maintenance of an autonomous life in the home for as long as possible.

The Multi-Annual Roadmap (Robotics 2020, Multi-Annual Roadmap for Robotics in Europe)[8] identifies the main issues to be addressed for the application of robotics, especially in relation to healthcare:

(i) reliability (dependability): the ability of the system to perform assigned tasks without errors, so that end users depend on and rely on the proper functioning of the robotic service. In fact, assistance structures can delegate some activities to the robots only if they are reliable and, in order to guarantee the safety of the users, they should have qualified personnel as well as highly tested robotic systems;

(ii) ability of social interaction: the robot's ability to interact with humans, correctly interpreting social and subjective signals and reacting accordingly. In the field of assistance, robots are involved in the interaction with primary users but also with other actors (family members, caregivers, doctors, etc.), so that the interaction must be simple and intuitive for all;

(iii) human-robot interaction skills: today's robotic systems are not always able to perform predefined actions independently while interacting with humans. In order to be effective, a service robot should guarantee its own autonomy or in any case safety in case of remote control;

(iv) decision-making autonomy: The constant changes in real environments require a solid technology (robustness) able to handle uncertain data. It is therefore necessary to validate robotic systems in realistic environments and scenarios to verify their decision-making processes in critical situations.

The area of "socially Assisted Robotics (SAR)", consisting of the intersection between the two categories of *Socially Interactive Robotics* (SIR) and *Assistive Robotics* (AR), includes all robots that create an effective interaction with human beings but not with regard to the interaction itself (as is the case with SIR) or based solely on physical interaction (as in the case of AR) but in order to provide assistance or support to users.

The aim of SAR is to use social interaction to achieve insurable progress in the fields of rehabilitation, convalescence, education and treatment, etc. (Feil-Seifer & Matarić, 2005).

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[8] Cf. www.eu-robotics.net/cms/upload/downloads/ppp-documents/Multi-Annual_Roadmap2020_ICT-24_Rev_B_full.pdf.

Lee & Riek (2018) propose a further subdivision of SARs, highlighting that social and welfare robots have been conceived primarily as “compensation” technologies, that is, to compensate for a physical, cognitive and/or psychosocial decline:

- Physical compensation: some robots aim at alleviating physical decline by supporting people in carrying out daily activities (cooking, eating, washing, etc.) or to prevent falls. Examples in this field are Care-O-Bot or Hobbit, able to perform various activities and provided with semi-humanoid bodies (with robotic arms) which allow them to manipulate objects and perform various services.
- Cognitive compensation: some robots aim at compensating for some cognitive deficits, from mild memory loss to severe dementia. In these cases, service robots support drug management, act as reminders for appointments, or enhance cognitive well-being through daily interactions. An excellent example is represented by Paro, zoomorphic robot with validated therapeutic abilities.
- Psycho-social compensation: solitude and social isolation are frequent problems in the elderly population that can lead to serious physical and psycho-cognitive problems. In this field there are two types of robots: company and conversation robots (such as Paro or iCat) and telepresence robots.

In short, social and service robots can offer assistance at different levels (Rich & Sidner, 2009):

(a) to support the cognitive or functional capabilities of the user (e.g., reminder and monitoring of activities, navigation aid);

(b) to offer the user the opportunity to improve social participation and psychological well-being (e.g. communication and social applications, telepresence, company);

(c) provide remote and continuous monitoring of the user’s health status (for example, blood pressure or fall detection sensors);

(d) instruct the user to facilitate the promotion of healthy behaviour and the achievement of health-related objectives (for example, improvement of nutrition, physical activity).

In addition, attention to the therapeutic use of social and assistive robots is increasing in recent years, especially for people with dementia or specific diseases such as Alzheimer’s (Libin & Cohen-Mansfield, 2004).

Regarding the benefits of SARs in the specific area of mental health and cognitive abilities, Rabbitt et al. (2015) have identified the main roles of robots: companion (e.g. SAR working in a similar way to trained therapy animals); therapeutic gaming partners (e.g. SAR used to help children develop clinically relevant skills); coach or trainer (e.g. SAR providing instructions, encouragement and supervision to users in activities such as weight loss or exercise).

7.3.1 Socially assisted robotics: users, activities, and types of interaction

The area of the Socially Assistive Robotics (SAR), based on a human-robot interaction without physical contact, is safer, proven to be more effective in testing and experimentation and promotes the learning of skills and models of behaviour more useful and valid in the long term (Feil-Seifer & Mataric, 2005).

Therefore, starting from the taxonomy proposed by Fong (2003), Feil-Seifer & Mataric (2005) identify the properties that characterise a SAR, in terms of users, activities and sophistication of interaction (vadi Tables 7.1, 7.2, and 7.3).

Based on the above properties, it is clear that SAR, by establishing social rather than physical interactions with people, has the potential to improve the quality of life of many types of users, including PwP, the elderly, persons with specific physical and/or cognitive needs and/or in rehabilitation.

For these reasons, the investigation and research of Human-Robot-interaction (HRI) in SAR are rapidly spreading and require transdisciplinary efforts in countless areas (medicine, robotics, social sciences, neuroscience, design, etc.).

Users (SARs may assist one or more types of users.)	Elderly and non-autonomous people: Robots can provide care to elderly or fragile people, provide company to relieve stress and depression, or support information management such as nursing home schedules.
	Individuals with different levels of physical ability: Robots can act as mobile prosthetic devices, with features traditionally associated with wheelchairs or other mobility support systems.
	Convalescent individuals: Robots can provide care in hospitals or nursing homes.
	Individuals with different cognitive needs: Robots can effectively assist people with autism, with particular cognitive or behavioural needs.

Tab. 7.1 The main types of users that SARs can assist and support.

Activity (SARs can perform a variety of tasks, according to the nees of users they interact with).	Tutors: Robots can be good assistants to support teaching, especially practical. Although they cannot replace human teaching, they allow the teacher to focus on individual interactions, supporting them in the course of personal exercises or tutoring for small groups of students.
	Therapy and rehabilitation: SARs are widely used for therapies related to specific diseases (Parkinson's, Alzheimer's), for cognitive and/or physical stimulation. They find great application in the field of rehabilitation activities or similar exercises, supporting the operators in the achievement of rehabilitation objectives.
	Daily care: Robots can assist individuals both from a cognitive and physical perspective, in carrying out common and frequent daily tasks.
	Emotional expression: SARs can be an important incentive to express emotions, as is the case, for example, in children with autism or with serious diseases. Moreover, by stimulating the communication of emotions, they can facilitate socialisation and interaction between humans.

Tab. 7.2 The main activities SARs can perform in relation to the different types of users with which they interact. Some activities are included as examples only.

Interaction sophistication (interactions established by SARs may vary by type but also by refinement and are different from the personality shown by robots).	Verbal communication: Conversation is a natural mode of interaction between people and, therefore, it would be appropriate with robots as well. A robot, in this case, can use a pre-recorded human voice or generate a synthetic voice.
	Gestures: Body language is a fundamental component of human communication, especially when it completes those meanings expressed only partially with a speech. For this reason, this type of interaction is very useful to increase the effectiveness of communication between humans and robots. For example, in a real environment, it can be very important for a robot to point an object or even just use gestures to focus attention in an interaction.
	Direct input: The ability to provide direct guidance or information to a robot can help in situations where voice or gesture commands are redundant or too tedious. It may be useful, for example, to provide direct input to the robot via a touch screen or a mouse, so as to make the human-robot interaction effective, albeit less natural. Moreover, for some users this type of interaction may be the only suitable form, due to physical and/or cognitive problems or disabilities.

Tab. 7.3 The most common types of interactions established by SARs. The interaction can vary both in type and in refinement.

7.3.2 Assisted robotics for Parkinson's disease: representative cases

In the literature, several scholars have categorised and divided SARs according to different criteria, based on the level of sociality and the type of interaction and/or assistance provided and the activities carried out. From the morphological standpoint they can be subdivided into (Dautenhahn, 2013): Automata or mechanoid (with a mechanical aspect), zoomorphic (animal-like) and humanoid (human-like). This latter category includes android robots, i.e. those designed starting from basic human characteristics but not realised in such a way as to be aesthetically identical and almost indistinguishable from a true human being (as in the case of humanoids).

The category of automata robots includes both mobile and non-mobile platforms, without appendices (for example, arms or manipulators of any kind). This category includes: VGO[9], a telepresence robot primarily dedicated to doctors and healthcare professionals for remote patient monitoring; Hobbit[10], a robot for prevention and detection of falls; Kompai[11], an assistant for the communication and management of physiological parameters by carers; Giraff (and the subsequent GiraffPlus)[12], a robot for company and telepresence.

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9 Cf. www.vgocom.com.
10 Cf. www.hobbit.acin.tuwien.ac.at.
11 Cf. www.kompairobotics.com/robot-kompai/.
12 Cf. www.giraff.org/?lang=en.

One of the most exemplary zoomorphic robots is PARO[13], with the appearance of a seal, produced in 1993 by Takanori Shibata, developed in Japan by the National Institute of Advanced Industrial Science and Technology (AIST) and marketed in 2004 by Shibata Intelligent System Co. PARO has been designed to provide all the benefits of pet therapy in hospitals or care facilities, environments where the use of real animals can be difficult or complicated from a logistical standpoint. It is equipped with five types of sensors through which it perceives the environment and interacts with people: tactile, temperature, light and sound sensors, posture sensors. PARO is able to distinguish light and darkness, to respond to voice commands and also to "learn" how to behave based on previous experiences. The robot seal reduces the stress of patients and caregivers, stimulates interaction, improves motivation of people, and supports socialisation between patients and health workers. One of the main limitations, however, is that it can only be used in specialised nursing facilities.

Older and functional systems of zoomorphic robots are JustoCat[14] and Joyforall[15], similar to dogs or cats with soft fur that react to contact. The robot with a dog-like appearance, Miro[16], is dedicated to the safety of the house and the owners. It is entirely programmable and has been developed for researchers, educators, developers and professionals in the health sector.

Another example of a zoomorphic robot is AIBO[17]. This robotic dog was developed by Sony from 1999 until the release of the latest model in 2017. AIBO can hear sounds and noises, see what surrounds it, so it can move on its own. Interaction with people mainly occurs through voice commands but the robot is able to react to external stimuli, coming not only from people but also from the surrounding environment. It has artificial intelligence (AI) connected to a proprietary cloud, which allows it to evolve from a puppy to adulthood, but also to configure its own personality, behaviour and knowledge based on experiences and interactions with humans.

Androids also include platforms very similar to real desktop digital assistants, such as ElliQ[18], Mabu[19] and Matilda[20], specifically designed for company and assistance in the domestic environment and nursing homes. To promote social interaction and connection and emotional care of PwP and the elderly in general. Their contribution is also addressed to carers, as these robots can facilitate control and assistance operations.

Matilda is a service robot for communication, assistance and company, developed in collaboration between NEC Corporation - Japan and RECCSI[21] at the University La Trobe in Melbourne. The small robot has human similarities terms of appearance and behaviour (interacts with voice, gestures, expressions and emotions), is able to trace and recognize faces and react to touch thanks to sensors. The wireless connection allows it to be connected to the cloud so as to build a network integrated with other ICT technologies. It has been tested mainly with PwP and the elderly, revealing a high level of acceptance by

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[13] Cf. www.parorobots.com.
[14] Cf. www.justocat.com/.
[15] Cf. www.joyforall.hasbro.com/en-us.
[16] Cf. www.consequentialrobotics.com/miro/.
[17] Cf. www.us.aibo.com.
[18] Cf. www.intuitionrobotics.com/elliq/.
[19] Cf. www.cataliahealth.com/introducing-the-mabu-personal-healthcare-companion/.
[20] Cf. www.latrobe.edu.au/reccsi.
[21] Cf. www.latrobe.edu.au/reccsi.

users and, above all, effectiveness in involving them in individual and/or group activities, to improve the personalisation of care and overall well-being (Khosla et al., 2012). The people involved in the study used Matilda to play games, send mail to relatives, know the calendar of the day's activities both through voice and touch commands, according to their needs.

The different interaction modes allow the robot to customise its assistance for the various participants. Games with Matilda had a positive impact on the cognitive activity and on the sense of usefulness among the participants.

Experiments carried out with Matilda show that the synergy of artificial intelligence with techniques measuring emotion (and generating emotional emotions in users) can support and increase the psychological well-being of people, involve them positively, and making them productive and resilient (Khosla et al., 2013).

The ElliQ[22] robot was developed by Intuition robotics and presented at CES in Las Vegas in 2019. Designed specifically for the elderly, ElliQ aims at supporting them in autonomous, active and connected conditions while staying at home.

Fig. 7.1 the ElliQ robot, with artificial intelligence, designed by Intuition Robotics. Image: Intuition Robotics, source: www.intuitionrobotics.com.

Thanks to the artificial intelligence and the possibility to connect with other smart objects in the house, ElliQ is both a companion and social robot and a full assistant.

It can initiate video calls, play music and videos, or simply show photos. Reminds of appointments and when it's time to take any drugs It suggests initiatives to keep active,

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[22] Cf. www.elliq.com.

such as courses, lectures and other digital content, learning more and more about the owner's behaviour and personality over time. It can calm the person and call emergency relief and offer cognitive support and stimulation. ElliQ responds to the individual's voice, touch, and gaze and reacts with movement and voice; interaction is facilitated by the presence of a tablet. Its appearance is not humanoid or zoomorphic but recalls a kind of table lamp with minimal design. It is likely that the designers have chosen a clear reference to objects common and familiar to the reference users, so as to increase the acceptability of the robot. ElliQ is an innovative project not only for its functionality but also from the standpoint of the Design and the formal elements that characterise it (see Fig. 7.1). There are also mobile and non-mobile robots that are more commercial and, in addition to being excellent companions for the elderly, are real assistants for the whole family.

The main examples are Jibo[23], Kuri[24], Zenbo[25], Aido[26] and Buddy[27]: they can perform many functions, from support to communication and home security.

Finally, there are manipulative robots, of which Pepper[28] is the most representative. In addition to providing emotional support, it has two arms that allow it to grip and move light objects.

In the same category are Care-O-Bot IV[29] and Personal Robot 2[30], mobile robotic assistants able to support people in the home with the activities of Daily Life (ADL).

Riba II[31] (Robobear) is dedicated to healthcare, it can lift weights and help patients in walking.

The humanoid robot NAO[32] (see Fig. 7.2), by Softbank Robotics and totally programmable, is widely used in educational, health and research fields in various sectors. From the experiment of Torta et al. (2014), it can be seen that NAO has improved human-robot interaction and user confidence acceptance. NAO has been used by Briggs et al. (2015) in a study on facial masking of Parkinson's disease. Such a symptom, in fact, can be interpreted as apathy or dishonesty by carers and adversely affect social relations.

The study aims at the development of future "robotic mediators", which could alleviate any tension in the caregiver-patient relationship, intervening in the event of ambiguity or misunderstanding. The research also investigates the level of acceptance of a robot within health processes by PwP. Participants reacted positively to the robot, despite preference for interaction with a human being. A similar study was conducted by Valenti et al. (2020) as part of a project for the development of a prototype of social welfare robots for people with Parkinson's disease. The aim of the research is to implement the robot's ability to detect and express emotions through different modes (for example, it can detect emotions from a speech and return them in the form of gestures or images). The results of the study are particularly relevant in the perspective of the use of technologies and support to the expression of emotions through digital communication systems, which do

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[23] Cf. www.jibo.com.

[24] Cf. www.heykuri.com.

[25] Cf. www.zenbo.asus.com/.

[26] Cf. www.tuvie.com/aidoadvancedsocialrobotforsmarthomeinspiredbydolphins/.

[27] Cf. www.bluefrogrobotics.com.

[28] Cf. www.softbankrobotics.com/emea/en/pepper.

[29] Cf. www.care-o-bot.de/en/care-o-bot-4.html.

[30] Cf. www.willowgarage.com/pages/pr2/overview.

[31] Cf. www.riken.jp/en/news_pubs/researCH_news/PR/2015/20150223_2/.

[32] Cf. www.softbankrobotics.com/emea/en/nao.

not always provide for the possibility of expressing emotions through all possible channels (facial expressions, gestures, posture, tone of voice, etc.).

Wilson et al. (2020) on the other hand, apply NAO in the context of research into the development of robotic and/or artificial intelligence systems that are actually useful, acceptable and capable of supporting PwP. Scholars, therefore, develop and evaluate the architecture for a fully autonomous robot designed to assist older people with Parkinson's disease in sorting out their drugs. The robot's main objective is to help PwP maintain independence for as long as possible, by providing cognitive and social support at different levels, depending on user needs. The results of the research highlight a number of challenges for HRI in relation to Parkinson's disease: To design a robot capable of adapting to the different routines of PwP; to design systems based on the unique needs of PwP; to involve PwP in the design and development process.

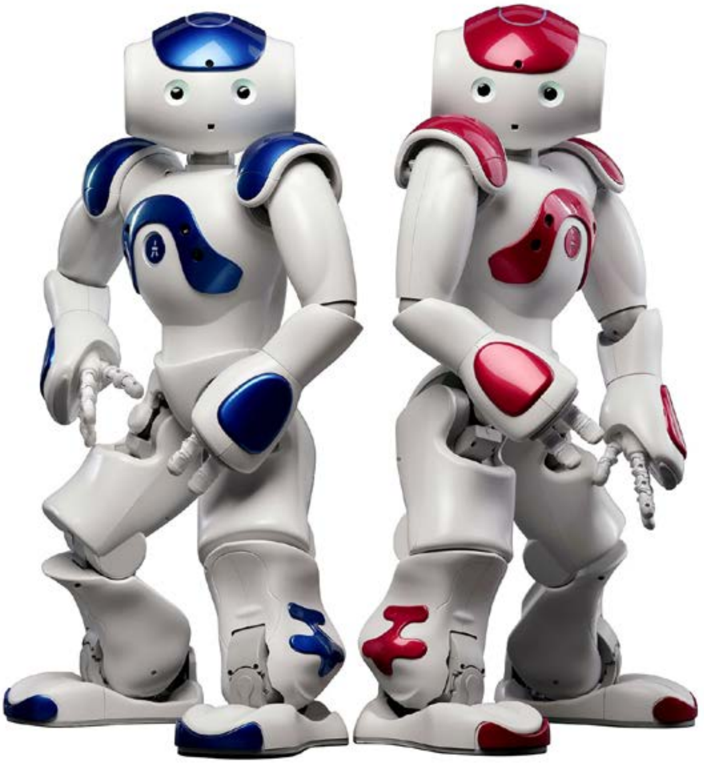

Fig. 7.2 the humanoid robot NAO by Softbank Robotics. Image of Softbank Robotics Europe - own work, CC BY-SA 4.0, https://commons.wikimedia.org/w/index.php?curid=62202564.

7.4 A brief outline of ethical issues for new digital technologies

While the benefits and potential of robotics leave room for countless research directions, they also point to ethical and social issues that experts have been debating for years and pose additional, increasingly complex, and broad ones. Indeed, the growing use of robotic and wearable technologies also brings with it an increase in the ethical issues related to them, both in the scientific and humanistic fields. This topic is so debated that it has generated a vast area of research, Roboethics (Veruggio et al., 2016), with the aim of developing scientific and cultural instruments for the analysis of the ethical implications of assisted robotics, with a view to preventing any abuse against mankind. Ethical issues, especially in relation to the theme of Health Design and technologies for PwP or fragile persons, are extremely sensitive and require detailed guidelines regarding all legal, moral and social aspects. They also concern the reduction of human contact, the loss of personal freedom, the loss of privacy, issues concerning responsibility, infantilisation, emotional deception and attachment (Sharkey & Sharkey, 2012; Veruggio et al., 2016).

However, it is also possible to say that these problems are only one side of the coin. In any negative aspect, in fact, it is possible to find positive feedback, which makes these issues even more complex (Van Maris, 2020).

According to Casey et al. (2016), the most urgent issues, particularly in the case of technology for persons with neurological diseases, include: change or modification in the nature of care; replacement of human care; autonomy of human beings with a view to possible restrictions by the robot concerning safety; negative impact on dignity; emotional attachment of the user and/or excessive dependence on the robot; safety and privacy-related concerns.

Feil-Seifer & Mataric (2011) apply a consolidated medical ethical model to identify some fundamental ethical principles in the field of assistive robotics: They should act in the best interest of the patient; they respond to the principle “first of all, do not harm”, so robots should not harm a patient; they should give the patient the opportunity to make a decision based on informed, non-forced care; fair distribution of scarce health resources.

7.5 The role of Design

Based on what has emerged from the previous paragraphs, the key role of Designers and their design approaches in the development of truly human-centred technologies, which should be built with respect for fundamental human rights and then be adapted flexibly, depending on the different situations, the values, beliefs, expectations and desires of the individual users, supporting their independence and assisting them in improving their well-being and quality of life.

The vision of a Designer can give an important push to inspire new technological advances and translate them into new categories of emerging products, offering unique perspectives both in problem solving, and in problem setting. Indeed, it is no coincidence that the Commission Staff Working Document on “Design as a driver of user-centred innovation” analyses the Design’s contribution to innovation and competitiveness and strongly claims that, although Design is often associated only with the aesthetics of the products, its application is in fact much wider. User needs, aspirations and skills are the starting points and focus of Design activities, with a potential to integrate environmental, safety and accessibility considerations into products, services and systems (Rinaldi, Becchimanzi, Tosi 2018).

Digital technologies are therefore a resource to support caregivers and PwP and present Design and designers with new challenges, different needs and expectations.

From this perspective, the Human-centred Design/HCD approach and the ergonomics for Design (Tosi, 2018) can make an important contribution to identifying and analysing needs that are often silenced, in order to create products centred on people. Moreover, the acceptability of technology is a delicate matter, whose parameters of evaluation offer many challenges to research in Design. PwP want products that can satisfy their aesthetic desires and functional needs but, above all, respect the values of personal identity, dignity and independence.

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8. Micro to macro or macro to micro? The project as production of means of life

by *Adson Eduardo Resende*[1]

Since their appearance on earth, humans have always been busy planning for the future. As a consequence of this occupation, an immense evolution has taken place in all areas of knowledge and technology, giving rise to a wide range of artefacts, buildings, objects, software, as a result of the most varied design methods.

The development of technology has brought with it the creation of countless products applied to the most diverse tasks of our daily lives. Products that do not always, however, meet concretely and/or appropriately to the real needs of final users, and whose shortcomings can be detrimental to both people's quality of life and work productivity. These reasons have driven many researchers, especially those focused on product development, towards studies and research regarding the quality of manufactured goods in the sense of their compliance with the tasks for which they have been designed and the needs of those who use them or will use them in the future.

8.1 Use as project reference

Studies on artefact use situations have highlighted the problems in the interaction that is established (or can be established) between users and artefacts, opening up numerous areas of research aimed at increasing knowledge and, in parallel, methods of investigation and intervention on the interaction between individual and artefact in the different fields. Designing artefacts without taking into account possible user-artefact interaction issues, or considering them superficially, may result in the development of artefacts that are inadequate to meet people's needs. Research, in this sense, also attempts to contribute to the expansion of designers' thinking by leading both to a better understanding of the user to whom the artefact is addressed, and to a deeper understanding of the use for which the artefact is designed.

The use of an artefact is a complex dynamic, determined by a network of variables that concur to achieve a goal. This vast network is made up of actors as well as material and immaterial resources that interact with each other, typically through the creation of artefacts. That is why the artefacts, essential components of this network, are so important and why their quality can contribute to their correct realisation and make them functional and operational units. Therefore, the effort of researchers in the construction of

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methods that consider the activity around artefacts proves to be indispensable in order to guarantee an adequate quality of artefacts concerning activities and everyday life.

New forms of artefact design centred on the evaluation of activities, such as Ergonomic Workplace Analysis (EWA) methodologies and post-occupancy evaluation (POE), have contributed to the identification of usage needs involving artefacts, enriching the information that contributes to their design, including the redefinition of the notion of user participation in the design process.

The user experience is built on long periods of interaction with artefacts and, as previously pointed out, in the structuring defined by a number of other components - tangible and intangible.

At this point, some key terms and concepts should be defined. Delimiting the meaning attributed to these terms in this study does not mean denying other already established meanings, but rather clearly indicating the meaning that will be attributed to them in this text:

- artefact/space, is the result of the design process;
- instrument[2]/environment, is the result of the users' appropriation of the artefact/space and their qualification for the task;
- situated person[3], the person acting in an environment characterised by multiple external and internal conditions (cognitive processes) that stimulate his or her actions;
- conception, the act of conceiving or formulating an original idea, a project, a plan for further realisation.

This chapter focuses on the difficulties that have to be addressed in order to achieve the design objectives concerning the interior spaces of a home and the system of objects, equipment and aids that are used there, meeting the expectations of the users and their most obvious needs.

The design process becomes even more complex when the project is aimed at users with special needs, as in the case of people with Parkinson's disease (PwP). A PwP's home is not just another environment, because personal care and assistance activities, often mediated by healthcare personnel, also take place in that environment.

The intention is to emphasise the responsibility of the "authors of the project", assuming that the interaction with objects and architectural artefacts is an essential aspect of everyone's life, and that these, in turn, are the elements that mediate the actions of the human being in the environment in which he or she lives with the aim of achieving personal fulfilment, through personal satisfaction, sociality and the relationship with the world around him or her and, finally, through the performance of daily activities.

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2 For more on the genesis of the instrument read Beguin (2007), as well as the work of Eastern European psychologists such as Vygotsky (1978) and Leontiev (1956).

3 Site man: The homo situs is to be understood as an interactive entity of all dimensions of the collective and individual context and scales, both an "interpreter" of the immediate situation and its dynamic evolution. He is the social man, who thinks and acts in a given situation. And he encompasses all this, conveying the sense of the moment, of his situation, with all the weight of the past and the change that imposes itself. It is therefore within these multiple contingencies that he exercises his behaviour. He is a man communicating with his environment and concretely ensuring a balance in accordance with his social environment. His room for manoeuvre allows him to appropriately recompose his interest, the usefulness of his action and the social obstacles in his place (Zaoual, 2010).

Human beings always act out of a motivation that is fulfilled/enabled by a reading of the world around them and which subsequently leads to an action. Thus the action is always situated and is the result of the interaction between man and the space/artefact, which always takes place with constant and strong reference to previous experience; the user applies his experience to operate the systems.

8.2 Micro and macro: interfaces as a locus of action for designers

It is important to define what we call macro and micro. It is difficult to start with one definition or the other, because both are self-generating.

The micro is the space of the interface that relates to the user, the space where the action takes place, where the user interacts with objects to produce an effect, a transformation of any situation. For example, when a person walks down the street, he or she has an interaction with the surrounding space that makes it possible to keep the right distance from obstacles and to move between other people. In this sense, the person reads the surrounding space, informs him or herself, plans the actions that will make it possible to adapt to the space. This space generates the macro world.

During the design process, the elements of a building are generally conceived according to the logic of the design process that assumes the adoption of macro and interchangeable solutions amongst the most diverse situations of use, starting from the premise that people interact in a macro form, i.e. distant, and then moving on to the micro solution. That is, the conception and creation of artefacts that have the task of mediating human action in a direct form. In effect, this design logic deals with the conception of the building and then shifts its attention to the interior spaces, and only at the advanced stage of the project does it begin to define the micro elements in detail. This top-down design shift can be related to the difficulties experienced during the performance of everyday tasks within the home environment, and even more so, when dealing with the home-disability relationship, in the case of Parkinson's disease. Difficulties arise when decisions taken at the macro level can translate at the micro level into a barrier to carrying out daily activities.

Developing project solutions without knowing the true needs/necessities of the user or, alternatively, developing theoretical solutions, inevitably generates problems in the user's interaction with his or her home. The underlying principle is that the real needs of people can be discovered and analysed in detail, i.e. on a micro level.

Generally, macro-decisions are made prematurely in the early stages of the design process (preliminary phase), when it is still difficult for the designer to

anticipate the needs of the future users of these spaces. This logic holds designers hostage to their own dynamics and their design choices generally end up being guided by a superficial programme that only develops the project in the macro dimension, without considering the data of the micro world - where individual-artefact interactions take place. For example, defining the dimensions of a bedroom without knowing what the user's needs are and what activities will take place in it, would be a mistake.

To more accurately define the meaning of micro, we start with the concept of interface developed by Bonsiepe in 1998.

8.2.1 Notion of interface

This domain of the project can be defined starting from the principle that, in short, an ontological scheme of the project is composed of the relationship of three areas: firstly, the existence of a user who actually has to perform an action; secondly, the task to be performed; and thirdly, the existence of an artefact that the user needs in order to perform an action. This brings us to the central question of how these three areas can be efficiently and smoothly connected to form a functional unit. It is important to emphasise that these elements are heterogeneous: the human body, the goal of an action, an artefact (Bonsiepe, 1998).

This relationship is ensured through an interface, and one should bear in mind that the interface is not an object, but a space in which interactions between the user, the artefact and the goal of an action are interconnected. And it is in that space that the domain of the designer's design activity must necessarily reside.

Although Bonsiepe introduced the notion of the interface into the design process, his description does not take into account the complexity of this concept. There are other more detailed approaches that help in the perception of the real dimension of what occurs in reality, in detail, and which define the interface as the locus of the design's action. It is therefore the lack of, or poor, detailed knowledge of how the interaction process starts and of its real ability to determine the performance of artefacts/spaces, which prevents designers from developing a design that is truly responsive to people's needs. Having said that, we can introduce a theoretical framework that can better detail how the interaction between people and interface takes place: the theory of activity.

8.2.2 The theory of activity

The theory of activity (see Fig. 8.1) helps us understand the relationship between people and artefacts. This theory holds that in the interaction between people and artefacts, artefacts must respond to specific tasks, the same tasks for which they were designed, and that is when they become productive units, i.e. tools.

To give a simple enough example in order to clarify how site man acts, the theoretical framework of activity is used to understand situated action.

An electrician uses pliers (artefact) for various tasks, the same as those for which they were designed. It may happen during the working day that the electrician needs to hammer in a nail (subject) but does not have a hammer. The electrician (site man), being alone (community), has only one goal: to hammer in the nail to finish the job; so he decides to use the pliers because he cannot waste any more time (division of labour).

This is a small example of situated action, determined by a man who is able to read every possibility and adapt to reality and circumstances.

In this case, an object that has lost its final purpose was taken as an example (the pliers used as a hammer).

However, now let us take the bed as an example, i.e. an artefact made for resting, sleeping. But, in order for this bed to be soft, it was produced with a higher thickness. For a person with physical limitations, it may be very difficult to get in or out of bed, because the designer did not address the problem of the variables related to the different characteristics and capabilities of the users (dynamic structure of the activity) who might use the bed. In this case, a more in-depth analysis would have allowed some design constraints to be defined.

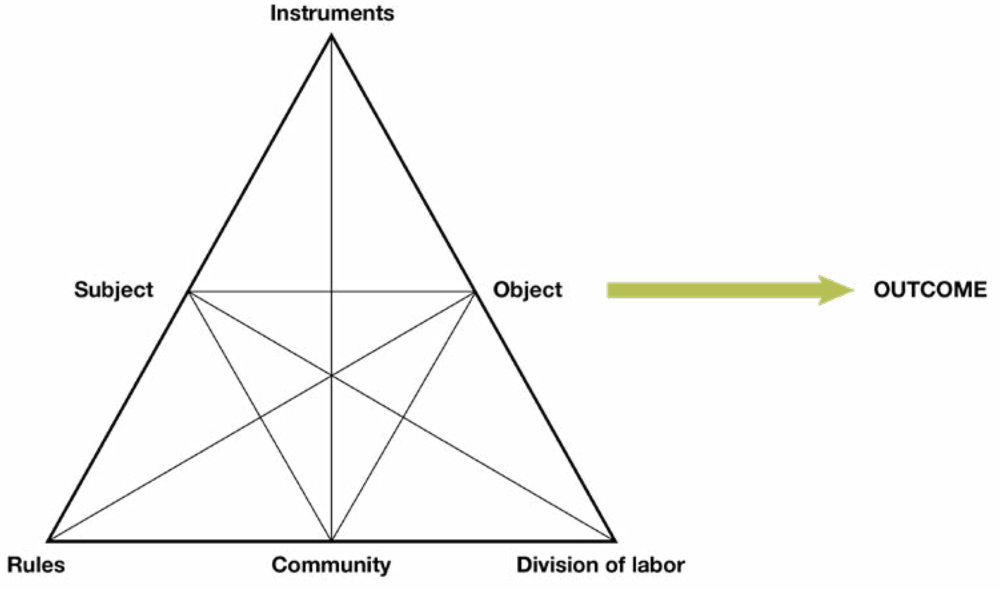

Fig. 8.1 Outline of Activities. Reprocessed image, source: Engestron, 1987.

We can, therefore, point to some possible limitations of design processes that may arise, both in the field of architecture and design, from problem-solving methods based on their breaking down into simpler subproblems and the subsequent definition of solutions.

These methods, by exploiting the subdivision of problems into sub-problems, lead in many cases to solving each of them separately, then bringing together the individual solutions into an overall answer that generates a superficial view of the inter-relationships and inter-dependencies between the various dimensions of the project. This certainly leads to a number of conceptual problems at the level of the design method:

1. traditional design methods do not have tools to understand the complexity of the activity involved in the spaces/objects to be designed;
2. the short time devoted to understanding the problems to be solved;
3. the recovery of users' experience of their interaction with artefacts is only marginal;
4. the view of the human being, which the designer generally assumes, would be a person who does not act in a situated manner and does not transform his actions and does not transform the environment in the process of interaction with spaces/objects, but only reacts to stimuli (i.e. users who will always give a predictable response in the face of a stimulus that is intentional and calculated by the designer);
5. user participation does not imply interference in the decision-making process during the project, nor does it reflect permanent dialogue with the designer;
6. "continuous design" is an important aspect to consider in design - the design continues throughout the process of appropriation by the user and the development from artefact to tool;

7. the designer loses sight of the centrality in the design process, resulting in a management system in which, presumably, the “forces” of the actors involved in the project are equivalent. However, the composition of these forces is not equivalent at all. Balance will be achieved by choosing a new central element for project management, namely the activity.

The activity has certain characteristics that qualify it as a possible design focus: firstly, it establishes as a focus something that should never be lost to designers. Spaces/artefacts are designed to be used as support to achieve a goal.

A second factor is that activity is a common resource for all actors involved in the act of designing spaces/artefacts, but unfortunately some projects do not take this into account. Finally, the third factor refers to the process defined as “from conception to continuous conception”, which occurs in the operation of the activity, its development, and the user-artefact interaction.

At this point, the importance of conducting a detailed analysis of the micro “world” is quite evident, and helps the project team to know the true needs of the real users of the home environment.

The ways of developing new dynamics of design and innovation from the user-designer interaction are determined, on the one hand, by new forms of technical mediation (user trials, 2D and 3D drawings, virtual simulations, etc.) and, on the other, by collective participatory dynamics that allow all the actors involved (researchers, project professionals, users, public managers and health care operators, etc.) to create a constant dialogue that can produce positive effects and bring about and bring about concrete improvement during the design processes of spaces and artefacts as well as provide new approaches to design.

The project, once realised, on a macro level, becomes a condition for the solution on the micro level.

The position of the building, walls, windows, entrances, insulation and natural ventilation are already determined. Complementary designs for electrical wiring, ventilation and artificial/natural lighting are guided by a basic (macro) layout, often discussed at the beginning of the architectural project. However, it is on the micro-scale (micro-world) of the project that the suitability of the elements of use is perceived positively or negatively by the user. The perception of problems easily becomes apparent during the performance of daily activities, when the person’s relationship with the various user interfaces, physical or virtual, is occurring.

In the following section, then, we would like to try to provide possible answers to the question *How to anticipate and identify possible problems in the early stages of the project?*

8.3 Possible answers

In this section we intend to feed into the discussion on how understanding the micro level and its dynamics enables the gathering of indispensable information for the design of macro and micro spaces and artefacts for the domestic environment.

To this end, some of the results achieved by the research programme *Home Care Design for Parkinson's Disease* will be reported, which will be dealt with in more detail in the following chapters, concerning domestic spaces such as bathroom, kitchen, living room, bedroom and other rooms that make up, or could make up, the home for a person with Parkinson's disease.

Although the disciplines of (traditional) design and Ergonomics (of design) contribute to a common goal - designing for use -, the two approaches hold significant differences.

These differences have to be taken into account, as the two approaches are both strongly involved in the field of artefact creation, not being in any way mutually exclusive, but rather different and, at the same time, complementary.

For a better understanding of the two approaches, Table 8.1 is organised in two columns, which describes the aspects that differentiate the two approaches, while when the description appears in a single column, it refers to shared characteristics. Finally, the last eight lines report the result of our personal effort to contribute to the characterisation of the two approaches.

The term "model" appears several times, so it is necessary to describe below what we mean by that. According to Bedny and Karwowski (2007), there are, in general, two types of models in design: design models, which always describe the object of the project, i.e. the future artefact to be built; and ergonomic design models, which refer instead to special requirements of the task. Ergonomic models describe the activity during the performance of a task, its development and possible interactions with artefacts.

When designing, it is important to understand the distinction between the two models, and how crucial their relationship is in the design process. Based on this understanding, the design can be unified and simplified into a single model that considers both artefact and activity aspects.

This unification, this amalgamation of models ends up creating a new model, concerned with both aspects of the artefact and the activity. Indeed, this "new" model will allow designers to consider use in a qualified manner. Since most design methods involve the systematic refinement of a model in response to a previously defined situation/problem, with this "new" model, refinement allows for the inclusion of an evolving view of the activity.

In fact, no model will be able to accurately incorporate all the requirements related to a real object or situation. However, taking into account aspects related to the performance of activities allows one to construct a reasonable approximation of reality (see Tab. 8.1).

Design disciplines (traditional)	**Ergonomics (of design)**
Creative process dependent on the knowledge and skill of the designer.	Creation depends on the knowledge of the ergonomics in relation to the use of the artefact to be designed.
The creation of the artefact relating to future desire is subjective.	
Before experimental models of the artefact, it follows analytical models (simulation, mathematical models, virtual and scale models). These models can also be used in the testing phase.	It conceives an artefact and goes to the test with the real artefact, analysing the obtained results.
Activity models are not used due to the lack of suitable methods for constructing this type of model.	

Symbolic models precede the physical model (presence of analytical methods).	Physical models are used directly (no analytical method).
It creates several proposed artefacts, based on previous models, for a single situation. It experiments with everything and continues by adapting and generating other solutions, based on laboratory tests.	It creates a proposal based on the analysed work situation, i.e. the activity. The proposed solutions are subject to continuous modification until the final solution is reached.
The proposed solution describes a specific and predefined task to be performed.	The proposed solution describes the activity during the execution of the task.
The principles of analysis cannot represent the complexity of the activity.	The method describes in detail the activity for which it is intended.
The interdependent aspects of the task are considered superficially.	The method describes in detail the activity for which the project is intended.
The functional aspect is associated with what one wants to achieve with the system to be designed.	The activity is mediated and composed of a system (of which the user is a part), seen as a whole, where what to achieve is what counts in functional terms.
The model production and analysis phase is at the heart of the design process.	The analysis phase of the activity prior to the production of the model is the main focus.
Each component of the activity is seen as independent in its relationships and tries to simplify them.	The components of the activity are considered interdependent and their interactions complex.
The development time of the design process is short.	The development time of the design process is long.
The result of a need is learnt by the user.	It is the result of a perceived need on the part of the user.
User participation usually takes place in the user's choice from the created solutions. Usually, with the application of a questionary based on scale models.	The participation of the user takes place during the analysis of the activities, with the participation of the user in the definition of requirements and based on full-scale tests, deciding on the evolution of the project. It is during the project that the user validates every single decision.
The result of the project is validated based on the requirements that emerged and were discussed in the initial phase.	The result of the project is validated directly with the users.
The user experience is part of the project data.	The user experience is the basis of the project.
Collective vision of the use of the artefact.	Production for every specific situation.
Lower design cost.	Due to the time spent in the investigation phase, costs are higher.

Tab. 8.1 Comparison of Traditional Design and Design Ergonomics.

Generally speaking, what is proposed by design methods is a sequence: model, analysis, new model, new analysis, and so on, until a satisfactory model is reached, which is usually the result of a process subject to precise time constraints.

In terms of time, there is also another characteristic that does not relate to time constraints, but rather represents a common paradox for both design and Ergonomics (Fig. 8.2): "In the beginning you can do everything, but you know nothing", while at the end "you know everything, but all capacities for action have been exhausted" (Midler, 1996). When the analysis of a situation begins with the aim of designing an artefact to meet a need, little do we know about future activity.

This activity will be subject to interference from decisions made during the design process.

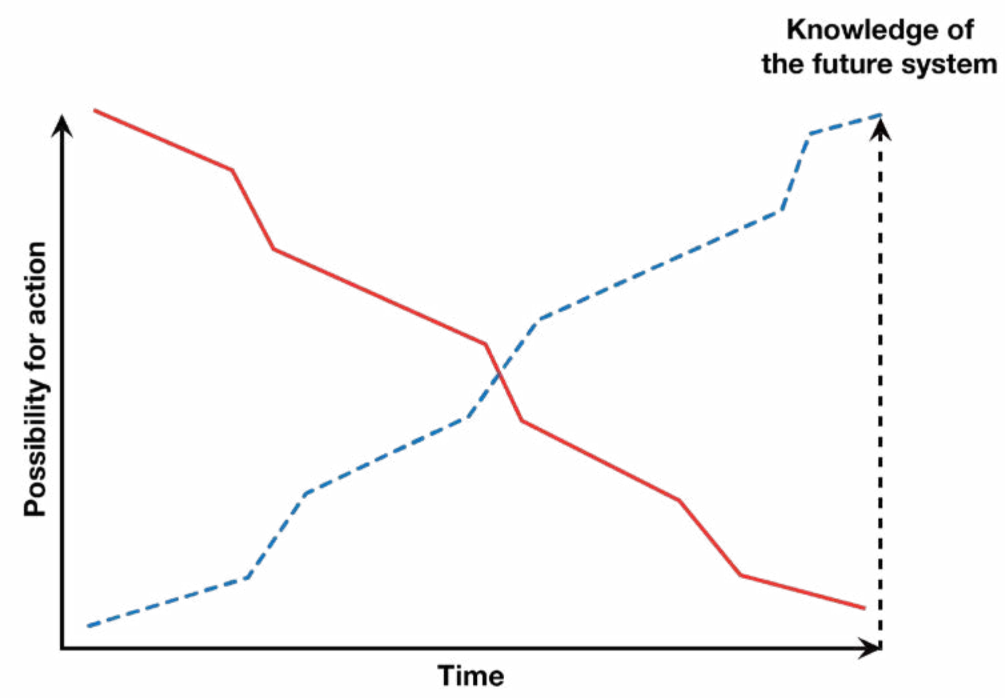

Fig. 8.2 The time factor in the design phase. Reprocessed image, source: Midler, 1996.

It is important to remember that projects can have two purposes: the design of new artefacts and the redesign of existing artefacts, and that these two purposes require separate design processes.

According to Daniellou (1992) and Béguin (2007), for existing artefacts a detailed analysis of the existing must be carried out, whereas, for the design of new systems, the analysis should be focused on the "reference situation aimed at designing certain dimensions of future situations to guide the designers' exploration", and also for characteristic action situations (CAS) which are "a set of determinants whose simultaneous presence conditions the structure of the activity". In the sequence, Daniellou defines CAS as a "unit of task analysis transposed to future situations". With this, the planner does not have a definition of what the future activity involved in the project will be, but rather the construction of possible scenarios. In fact, all these forms of implementation in the project are a form of approaching the objective and the situation the project addresses.

Schön (1983) had already advocated a “dialogue with the situation”, and Alexander (1979), in his work The Timeless Way of Building, also states that people adapt their spaces to their needs, and this process has been going on for centuries.

Daniellou (2007) argues that design processes should generate flexible projects (space for manoeuvre) that enable continuous conception (the design in use).

Another approach concerns distributed design; in this perspective, designers and users contribute to the design process according to their different perspectives and interpretations of problems. According to Béguin, this approach differs from the others in that it defines the project situation as a space for exchange between designers and users, and not only as a means of anticipating future situations or creating a space for manoeuvre. Béguin summarises this approach as follows: “the development of the artefacts and the development of the activity must be considered dialectically during the conduct of the project” (Béguin, 2007, p. 324).

8.4 Final considerations

As already extensively described in the previous pages, tools for human use have two main characteristics: they contain artefact components and user components, i.e. usage patterns. These are the two characteristics that allow tools for human use to become functional. Therefore, designing artefacts means designing future user behaviour in relation to the use of the object or space and in relation to the activities to be performed.

In this respect, the Tool Mediated Activity Theory, which originated from cognitive science, has led to reflections on behaviour and the conception of artefacts.

One of the main points of this theory is the two characteristics peculiar to tools for human use referred to above: they contain components peculiar to artefacts (the result of the design process) and components peculiar to users, i.e. patterns of use (based on experience, usage strategies, adaptation, etc.).

The following are some possible opportunities to modify the design process:

- unifying the (traditional) design model with ergonomics and vice versa;
- exploring the potential offered by reference situations;
- taking as resources the mapping (i.e. surveying and collecting) of characteristic action situations (CAS);
- basing the project on the process of continuous conception and maximum flexibility of the proposed solutions, allowing for an area of creative manoeuvre to meet the user’s needs, and constant attention to the relationship between artefacts and activities.

Recognising the existence of a functional structure of the activity incorporating the artefact, which is the result of the designer’s work, is what helps us to understand the user’s behaviour in his or her interaction during the use of the artefact itself. It is also important to underline that the constraints that condition the design process (time pressure, financial resources, decision-making processes, fragmentation of the project activity, etc.) are present, to a more or less decisive extent, in every project activity, and must in any case be taken into account when evaluating the result of the designer’s activity. However, the conceptual aspects of conception must also be analysed. It is on this level that the paradigm shift can take place and we can focus our efforts to consider usage patterns (user experience and artefact usage strategies). Considering the artefact-instrument genesis can lead to an improvement in design quality and, consequently, in the tools of our life.

In conclusion, we quote a definition of ability proposed by Zaoual (2010): the ability of people to function in a given place in harmony with their conventions, their culture, and their capacity to innovate and promote their "well-being".

Designers must therefore set for themselves the goal of creating solutions that are adequate and/or adaptable to the great human diversity.

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9. The research project *Home Care Design for Parkinson's Disease*

by *Mattia Pistolesi*[1]

The *Home Care Design for Parkinson's Disease* research programme, the results of which are reported in this volume, aimed at defining design guidelines to identify the main and most frequent areas of discomfort and/or difficulty currently experienced by people with Parkinson's disease during their daily life activities and relationships within the private domestic space, and to define the most suitable design solutions to guarantee maximum usability, safety and pleasantness of use of the home environment, its furnishings and equipment.

As already mentioned in the introduction, the research programme, which was carried out in the period 2020-2021, involved different research groups from departments of the University of Florence (Design area), the University of Turin (Medical area) and the Catholic University of Milan (Sociology area), and the Universidade Federal de Minas Gerais, Brazil (Engineering area). Finally, an essential contribution was made by the Confederazione Parkinson Italia, a confederation of 25 voluntary associations involving more than ten thousand people with Parkinson's disease, family members and caregivers, and the Accademia Limpe-Dismov, the Academy for the Study of Parkinson's Disease and Movement Disorders.

The research project was based on the theoretical and methodological approach of the Human-Centred Design (HCD), which made it possible to focus on the specific needs and expectations of people with Parkinson's disease, their families and caregivers, as well as on the specific risk and/or discomfort situations they encounter on a daily basis in their home environment, through their direct involvement in the research activities and direct assessments by the researchers. This chapter describes in detail the methodological approach and the results achieved.

9.1 Methodological approach

As we have seen in chapter three, the theoretical approach and investigation methods of Human-Centred Design (HCD) aim at identifying and interpreting the variables that define the context in which people relate to an environment, a product or a service, to gather their needs and expectations and, in the design context, to guide the development of the project by aiming it at the real needs and desires of its recipients.

Once data on user needs and expectations have been collected, their interpretation and translation in the design phase is the most important step of the HCD process, which develops over three distinct phases: Design considerations, Design requirements and Design specifications (Privitera, Murray, 2009; Tamsin, Bach, 2014).

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[1] Cf. Chap. 4

Design considerations are the elements that can influence the design process, such as “a given percentage of users have no experience in using a given product”. Design requirements are the fundamental elements, because they allow the design process to be finalised according to the needs and desires expressed (consciously or unconsciously) by the users. Therefore, they are the basic project references, which will guide the entire design process, from the development of the initial concept to the final solution.

Design specifications represent the measurable aspects of the project, essential for all interim verification phases up to the final design verification. Design verification ensures that all documented specifications of the new product meet the standards set by current regulations and the requirements defined by the design team.

In the scientific literature (Maguire, 2001; Stanton et al., 2005; George, 2008; Rubin, Chisnell, 2008; Nielsen, 2012; Stanton et al., 2013; Stanton et al., 2014; Tosi, 2020) it is possible to find a large number of investigation methods and intervention tools specifically aimed at the evaluation and design phase of environments, products and services. Usability evaluation methods find wide application in different fields, introducing a “user-centred” approach to design and its needs, which makes it possible to make the investigation phase more structured and to provide comparable and verifiable data on how people interact with the systems they use.

The *Home Care Design for Parkinson’s Disease* research programme, aimed at the definition of guidelines for the design and realisation of a home environment that is fully usable by people with Parkinson’s disease, was based on the application of survey methods and techniques from the HCD approach in order to assess and quantify the experiences the needs and discomforts that people with Parkinson’s disease have to face on a daily basis in their home environment and, at the same time, to collect the needs and expectations of people with Parkinson’s disease, their families and/or their caregivers, who were involved in the survey phase.

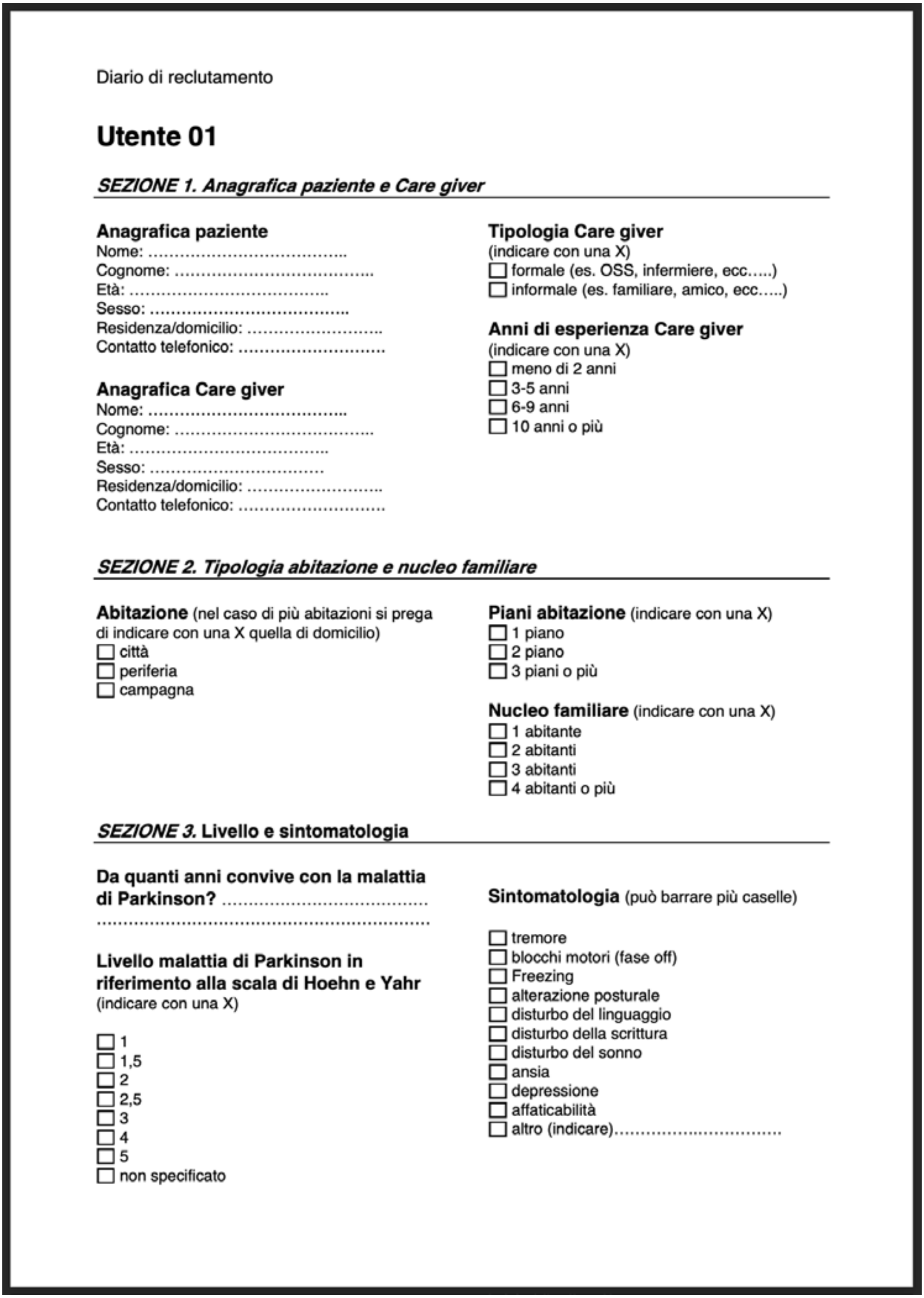
The study envisaged the participation of groups of users in the Tuscany region and, thanks to the fundamental support of Confederazione Parkinson Italia and the Limpe-Dismov Academy, a recruitment campaign of subjects to be involved in the study was launched in collaboration with the Ergonomics & Design Laboratory LED.

The subjects, all resident in Tuscany, and more specifically in the provinces of Florence, Prato, Pisa, Livorno and Grosseto, were involved by telephone in order to receive an initial verbal endorsement of the study from them. Following their accession, they were asked to fill in a recruitment diary comprising three sections:

- section 1: patient and caregiver registry;
- section 2: type of dwelling and household;
- section 3 disease level and symptomatology.

The compilation of the recruitment diary constituted the official participation in the study (see Fig. 9.1). Twenty-five PwP (of varying age, gender and level of symptoms) and 16 caregivers (of varying age, gender and level of experience) participated in the study. In any case, the number of subjects involved represents a scientifically valid sample.

For this specific research project, the LED researchers, after a careful review of the relevant literature and in view of the data to be obtained, decided to use the following methods: Context observation, Semi-structured Interview, Walkthrough (Ornstein, Roméro, 2003), Diagnostic Map, Situation of the Characteristic Action (Daniellou, 2002), and finally Focus group (see tab. 9.1).



Diario di reclutamento

Utente 01

SEZIONE 1. Anagrafica paziente e Care giver

Anagrafica paziente
Nome: ………………………………..
Cognome: ………………………………..
Età: ………………………………..
Sesso: ………………………………..
Residenza/domicilio: ……………………..
Contatto telefonico: ……………………….

Anagrafica Care giver
Nome: ………………………………..
Cognome: ………………………………..
Età: ………………………………..
Sesso: ……………………………
Residenza/domicilio: ……………………..
Contatto telefonico: ……………………….

Tipologia Care giver
(indicare con una X)
☐ formale (es. OSS, infermiere, ecc…..)
☐ informale (es. familiare, amico, ecc…..)

Anni di esperienza Care giver
(indicare con una X)
☐ meno di 2 anni
☐ 3-5 anni
☐ 6-9 anni
☐ 10 anni o più

SEZIONE 2. Tipologia abitazione e nucleo familiare

Abitazione (nel caso di più abitazioni si prega di indicare con una X quella di domicilio)
☐ città
☐ periferia
☐ campagna

Piani abitazione (indicare con una X)
☐ 1 piano
☐ 2 piano
☐ 3 piani o più

Nucleo familiare (indicare con una X)
☐ 1 abitante
☐ 2 abitanti
☐ 3 abitanti
☐ 4 abitanti o più

***SEZIONE 3.* Livello e sintomatologia**

Da quanti anni convive con la malattia di Parkinson? …………………………………
…………………………………………………………

Livello malattia di Parkinson in riferimento alla scala di Hoehn e Yahr
(indicare con una X)

☐ 1
☐ 1,5
☐ 2
☐ 2,5
☐ 3
☐ 4
☐ 5
☐ non specificato

Sintomatologia (può barrare più caselle)

☐ tremore
☐ blocchi motori (fase off)
☐ Freezing
☐ alterazione posturale
☐ disturbo del linguaggio
☐ disturbo della scrittura
☐ disturbo del sonno
☐ ansia
☐ depressione
☐ affaticabilità
☐ altro (indicare)……………………………

Fig. 9.1 Recruitment diary.

Context observation	
Description	This technique is useful for evaluating physical tasks and for assessing usability, as users are not always able to explain in detail how they use the product and may have a distorted perspective of how they behave in various real-life usage situations.
Application	The observation phase will be conducted in the analysis
Execution time	2/4 hours
Instrumentation	• camera/video • audio recorder • notebook
Semi-structured interview	
Description	The interview technique allows the researcher to interview a user by analysing each critical aspect in depth.
Application	The interview phase is conducted in the analysis phase, following the observation of the context.
Execution time	20/40 minutes
Instrumentation	• audio recorder • notebook
Walkthrough	
Description	Evaluation method that enables the descriptive and significant identification of failures, problems and positive aspects of living environments, both from the standpoint oof the actual users and the researcher. It consists of simply walking through the entire building in the company of the users, asking questions in order to become familiar with the domestic environment and the objects contained within it.
Application	The observation phase will be conducted in the analysis phase.
Execution time	40/60 minutes
Instrumentation	• camera/video • audio recorder • notebook
Diagnostic map	
Description	The discovery map or diagnostic map is represented by graphical diagrams necessary to present the results of the evaluation conducted on the everyday life environment. The data previously collected with the different survey methods can be summarised and presented as a summary. These maps contain the most relevant information regarding the assessed points. Through the use of graphic codes, the map presents the main (positive and negative) aspects identified, in order to provide an overall understanding of the situation in the analysed home environment.

Application	The diagnostic map phase will be conducted at the end of the analysis phase.
Execution time	1/2 hours
Instrumentation	• camera/video • audio recorder • notebook
Characteristic action situation	
Description	The “Characteristic action situation” (CAS) is known as the correspondence between the determinants of an activity structure: (i) the objectives of the action; (ii) the persons involved; (iii) the sources of information, means and instruments required; (iv) the elements delimiting the action (time, quality criteria, state of the instruments (e.g. degradation of the object, persons, environment); (v) elements relating to the conditions of the activity, which may have consequences on health and also on the performance of use. The analysis of current activity makes it possible to describe it in a timely manner, formalising the negative and positive experiences of the users in their daily contact with the environments, objects and services used, which in turn contribute to the development of more targeted studies.
Application	The CAS phase will be conducted at the end of the analysis phase
Execution time	This phase is conducted directly by the researchers and does not involve the participation of users.
Instrumentation	n/a
Focus group	
Description	The focus group method consists of collective interviews with previously selected groups of users (nurses, doctors, carers, family members, etc.). In these interviews, the researcher plays the role of animator, stimulating and keeping the group focused on the topics to be discussed. This approach is interesting because it enables the exchange of various experiences (memories, stories, everyday problems, personal strategies, etc.) between people with Parkinson’s disease.
Application	The focus group phase will be conducted at the end of the analysis and debriefing phase. On that occasion, the participants are shown images, renderings, concept maps in draft form, of possible design solutions that are useful for triggering a qualitative discussion with the real users.
Execution time	2/4 hours
Instrumentation	• camera/video • audio recorder • notebook

Tab. 9.1 Methodological approach before the Covid-19 global pandemic emergency.

Due to the spread of the global Covid-19 pandemic emergency, and in view of the limitations imposed by the virus, the previously defined methodological approach had to undergo a major change, both organisationally and in terms of time.

In order to obtain scientific data that could subsequently guide the researchers towards drafting the guidelines, the following methods were chosen:

(i) Exploratory semi-structured interview. This first interview, conducted by telephone, aimed at investigating certain aspects of PwP and, if present, of one's caregiver (formal and informal). The following areas of investigation were part of the interview: Parkisnon disease, home, aids and assistive technology, work and public services. More specifically, in relation to Parkinson's disease, the PwP and then the caregiver, if present, were asked to describe their typical day, explaining which activities require assistance, which are performed with ease and which with difficulty. They were asked to give an overall assessment of the dwelling, indicating which spaces create discomfort and which create well-being. From the standpoint of aids and assistive technologies, it was asked whether they are used and how they were rated, who has recommended buying them and which are the best ones. On the other hand, with regard to public services close to the dwelling, they were asked which are present, how far away they are, how they are reached and what difficulties they experience in accessing them. Finally, the last area of investigation concerns work. Participants were asked about the type of work they do and how Parkinson's influences or has influenced their work.

(ii) Specific structured interview. This second interview was conducted with a selected group of users (18), previously involved in the semi-structured interview. The reason for the selection was dictated by the level of PwP symptoms. With the aim of receiving more interesting data, the researchers decided to interview PwPs with a medium to severe level of symptomatology (level 2.5 to 5 with reference to the Hoehn and Yahr scale). More specifically, the following six questions were asked: (i) *How many rooms does your home have?* (ii) *In view of Parkinson's disease, what features should your ideal home have?*(iii) *On a scale of 1 to 5, with 1 being the lowest and 5 the highest, how satisfied are you with your home?* (iv) *In your opinion, what could be improved in your house?* (v) *From your point of view, do you believe that technology can improve your life? If yes, what kind of technology can you think of?;* (vi) *What do you think of a house that can change a space depending on a need to be met? Do you think a flexible/mutable house might be right for you?*

9.2 Results

9.2.1 Recruitment diary

With regard to section 1: patient and caregiver data and as already mentioned in the previous section, 25 PwP, of varying age, gender and level of symptoms, and 16 caregivers, of varying age, gender and level of experience, participated in the study.

All recruited subjects live in Tuscany, more specifically in the following provinces: Florence, Prato, Pisa, Livorno and Grosseto. Of the 25 PwP, 18 are men and the remaining part are women (7). As for caregivers, 13 are women and 3 are men. All caregivers are informal, i.e. they are represented by the spouse (husband or wife) or son/daughter.

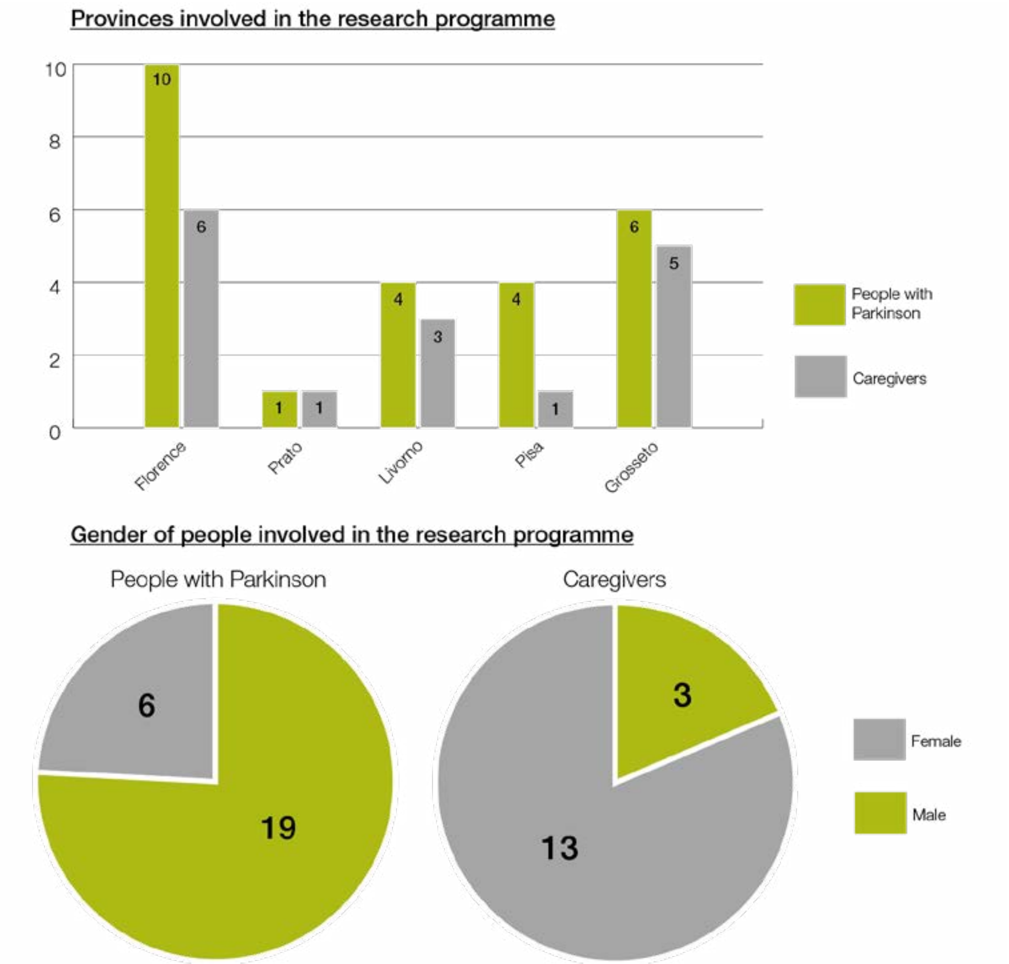


Fig. 9.2 Provinces involved in the research programme (top) and Gender of people involved in the research programme (bottom).

Regarding the age of the participants:

- for PwP: 2 subjects are aged between 40 and 50, 3 subjects are aged between 51 and 60, 11 subjects are aged between 61 and 70, and finally 9 subjects are aged between 71 and 80;
- for caregivers: 1 subject is aged between 40 and 50, 6 subjects are aged between 51 and 60, 4 subjects are aged between 61 and 70 and, finally, 3 subjects are aged between 71 and 80.

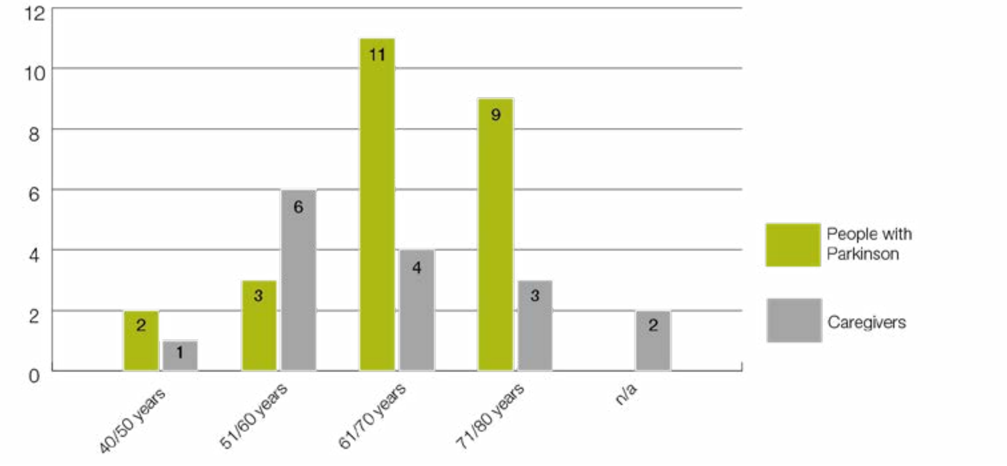


Fig. 9.3 Age by persons involved.

Concerning section 2: type of dwelling and household, a large proportion of the study subjects live between the city (11) and the suburbs (9), while a small portion of the recruited sample lives in the countryside (5). This categorisation by type of dwelling is crucial because it allows us to relate the size of the rooms in the dwelling to the day-to-day experiences of the PwP and their caregiver.

Those who live in the city can obviously enjoy services and conveniences "at their fingertips", but may have limitations in terms of the size of the rooms in the house and the presence or absence of outdoor space (private garden or terrace), unlike those who live in the suburbs or in the countryside, who can generally enjoy larger internal environments than those in the city, and often the presence of outdoor space, to the detriment of the proximity of services (transport, public offices, shops, etc.) (see Fig. 9.4).

As far as the floor of the house is concerned, most of the houses of those involved are developed on one floor (20). Only 3 out of 25 subjects stated that they live in a multi-storey house. As far as the household is concerned, most of the respondents stated that they live in a two-person household (16), whereas the remaining sample stated that they either live alone (2) or live with two (4) or three other people (3) (see Fig. 9.4).

To conclude the recruitment diary part, Section 3: Level and Symptomatology, this section focuses on three key aspects, namely the years of living with PD, the current level of PD and finally the symptomatology of PD.

As already described in section 2, PD is heterogeneous and the data collected show that the years of living with PD, the level of the disease and its symptomatology are highly variable aspects depending on the subject.

In order to have a clear reading of the emerged results, the symptom-related data were grouped into macro-categories.

As far as years of living with PD are concerned, the data is almost uniform across all categories, whereas when it comes to PD level, with reference to the Hoehn and Yahr scale, a large majority of the subjects stated that their PD level ranged from 2.5 to 5.

Approximately 7 out of 25 subjects, on the other hand, stated that they were not aware of their level of Parkinson's disease (see Fig. 9.5).

Furthermore, as shown in figure 9.5, with regard to symptomatology, 16 out of 25 subjects stated that they suffered from fatigability, while 14 subjects suffered from sleep disturbance.

13 out of 25 subjects stated to experience motor blocks, freezing, postural changes and writing disorders, while 12 out of 25 subjects suffer from tremor (the recruitment diary did not reveal whether the tremor is localised to a limb or to the lower or upper limbs). Finally, a small portion composed of eight subjects reported suffering from speech disorder, anxiety and depression (See Fig. 9.5).

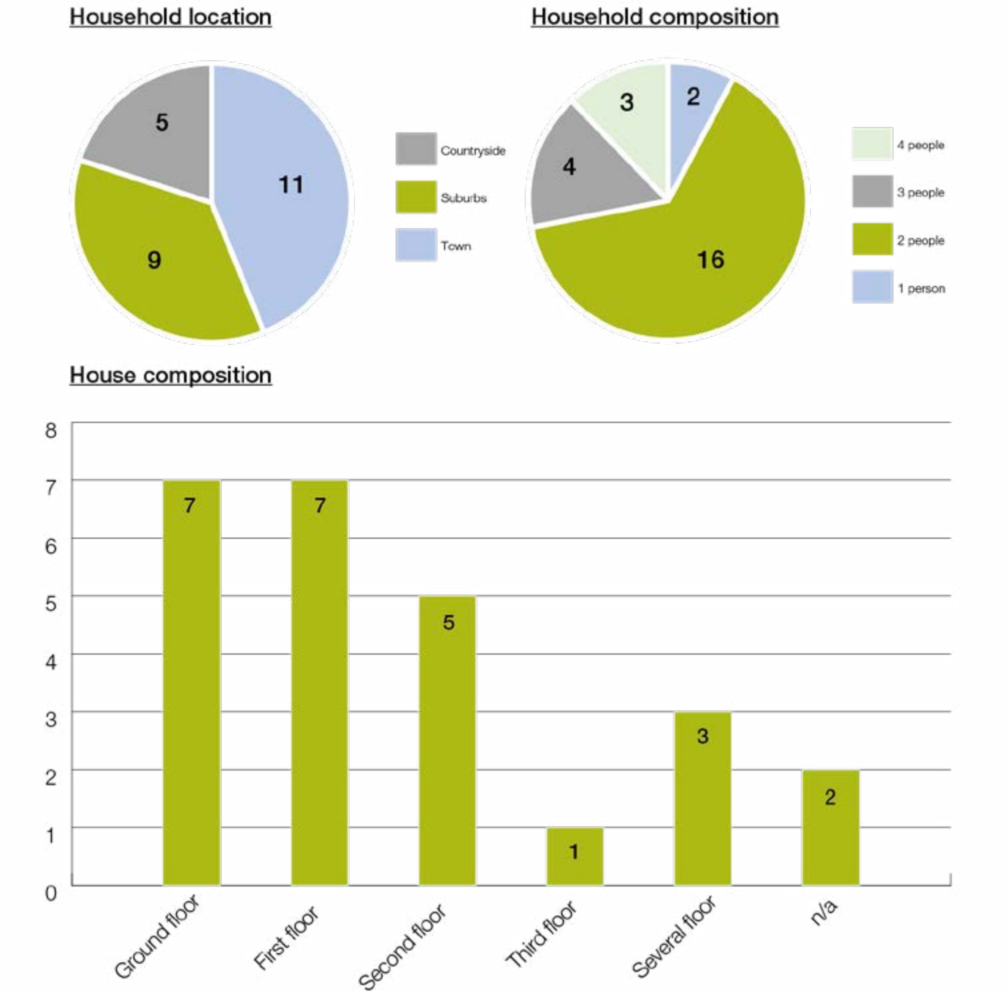


Fig. 9.4 Household location (top left), household composition involved in the research programme (top right) and house composition (bottom).

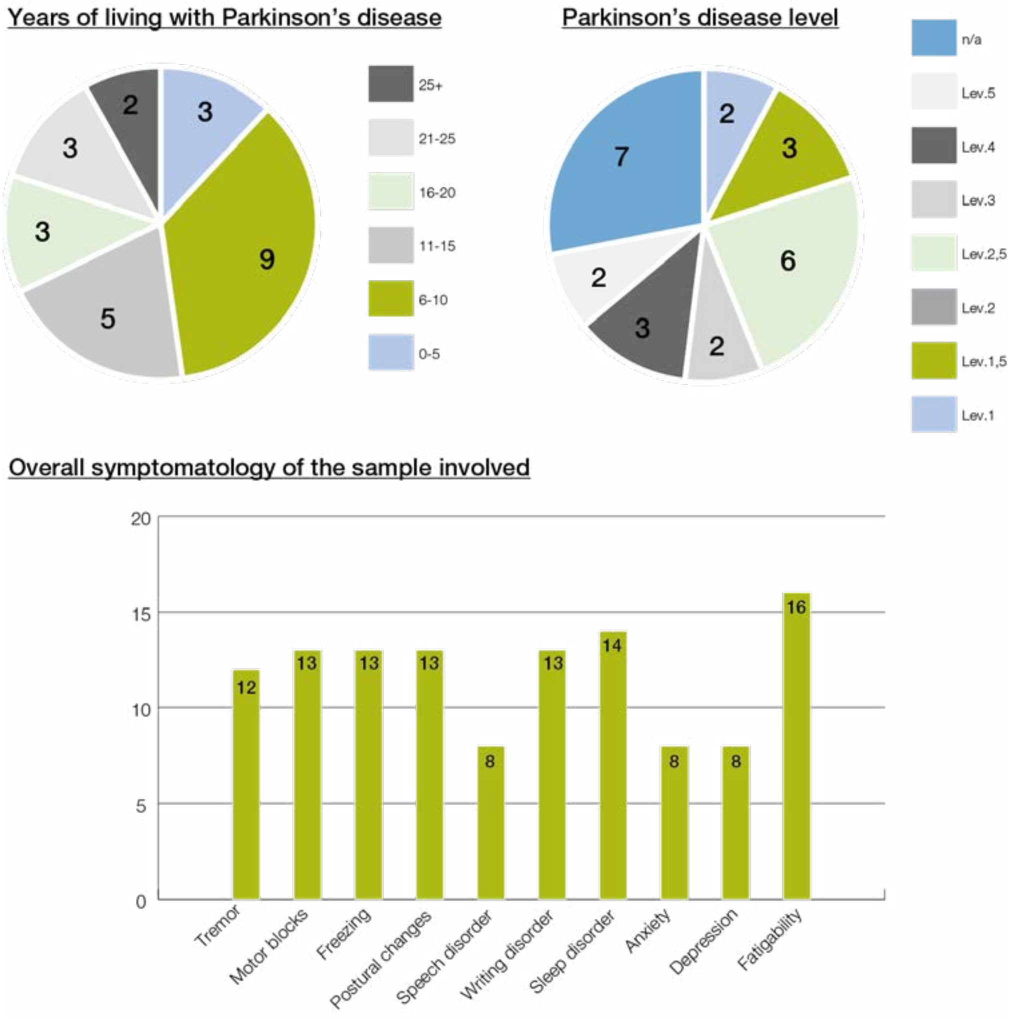


Fig. 9.5 Years of living with Parkinson's disease (left), level of Parkinson's disease (right) and overall symptomatology of the sample involved (bottom).

9.2.2 Exploratory semi-structured interview

Once the recruitment of users was completed, phase 1 of the study involved an exploratory semi-structured interview conducted via telephone.

The users involved took between 30 minutes and 60 minutes to complete the interview. Certainly important aspects, which emerged for most of those involved, were the enthusiasm and participation shown towards the objectives of the study.

With regard to PwP (n=25), the following emerged:

- Area of investigation Parkinson's disease. As a rule, the day of each PwP starts very early with the administration of a first dose of medication, usually Levodopa. Afterwards, most of the respondents engage in physical activities (a small portion of these subjects continued to do physical activities at home), go for a walk and pursue hobbies. A smaller part of the interviewed sample, on the other hand, devotes itself to carrying out their work. To the question What problems do you encounter when you have to perform common daily tasks? Can you tell me what you feel, how you feel and what you do when you have to perform a complicated task?, the answers received are very different from each other, and it is assumed that this depends on the heterogeneity of PD, which influences to varying degrees the daily experiences of PwP.

In this regard, depending on the symptomatology, the effect of the medicine and the time of day, the interviewed users stated to experience variable difficulty in performing common activities, such as holding a glass of water, rolling spaghetti, pressing a button on the computer keyboard and going to the toilet. This latter activity for some users turns into a stimulus to try to complete the task independently, whereas for the majority of respondents it results in anger and depression. A very interesting fact is that, at the time of the interview, 7 out of 25 users were still independent, whereas 13 out of 25 users needed partial assistance during the day and 5 out of 25 users needed prolonged and continuous assistance. Finally, when asked To what extent has Parkinson's influenced (or is influencing) your life? 20 out of 25 subjects (80%) stated that Parkinson's has disrupted their life and the life of their family;

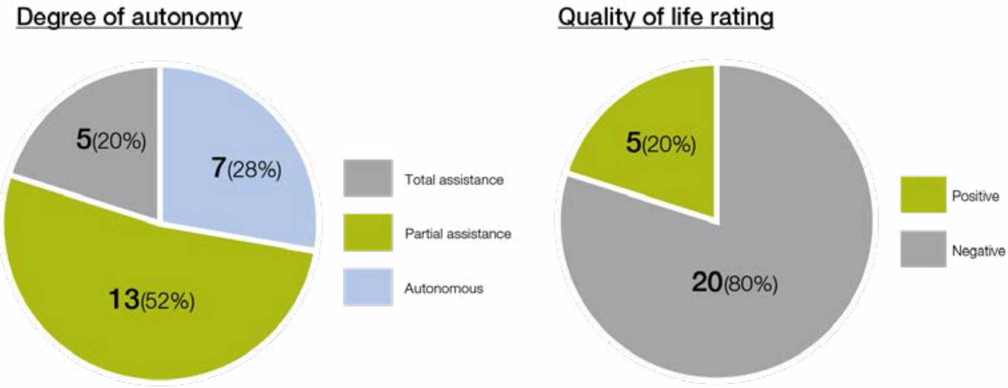


Fig. 9.6 Degree of autonomy (left) and quality of life rating for PwP (right).

- Area of investigation The home. The interview revealed that 16 out of 25 users are satisfied with the house they live in, as they have plenty of space. While the remaining portion (9) attributes a negative value to the house they live in. The rooms and parts of the house that create the most discomfort/problems are the bathroom, particularly because of its size and/or organisation, the presence and size of stairs, and finally the presence of small spaces such as storage rooms. 2 users stated, on the other hand, that due to Parkinson's they had to look for a new home that was as accessible as possible, while 7 out of 25 users stated that they had renovated some rooms in their home over time. Finally, 2 users plan to renovate their homes in the future to make them more accessible to the needs of PwP;

- Area of investigation Aids and assistive technologies. 14 out of 25 subjects use aids and/or assistive technologies, while the remainder (11) do not need them for the time being. Listed below, in no particular order, are the assistive aids and assistive technologies that are currently used throughout the day by the sample recruited for the study: toilet handles, shower seat, cane, folding cane, sock-wearing tool, indoor and outdoor walker, wheelchair, motorised chair, adaptable bed, anti-decubitus mattress, crutches, bed rail, and, finally, codivilla spring;
- Area of investigation Generic services. The interview showed that, for 18 out of 25 subjects, general services (rubbish bins, medicines, tobacco, newsagents, bars, supermarkets, shops, pharmacies, hospitals, public gardens, clinics) are close or fairly close to their homes (within walking distance). While for the remaining 7 subjects, they have to take their car or a means of transport to reach the services;
- Area of investigation Work. Finally, with regard to work, 12 out of 25 subjects retired regularly, while 10 subjects retired early and 3 of them chose to stop working for personal reasons. 3 out of 25 subjects stated at the time of the interview that they were still working.

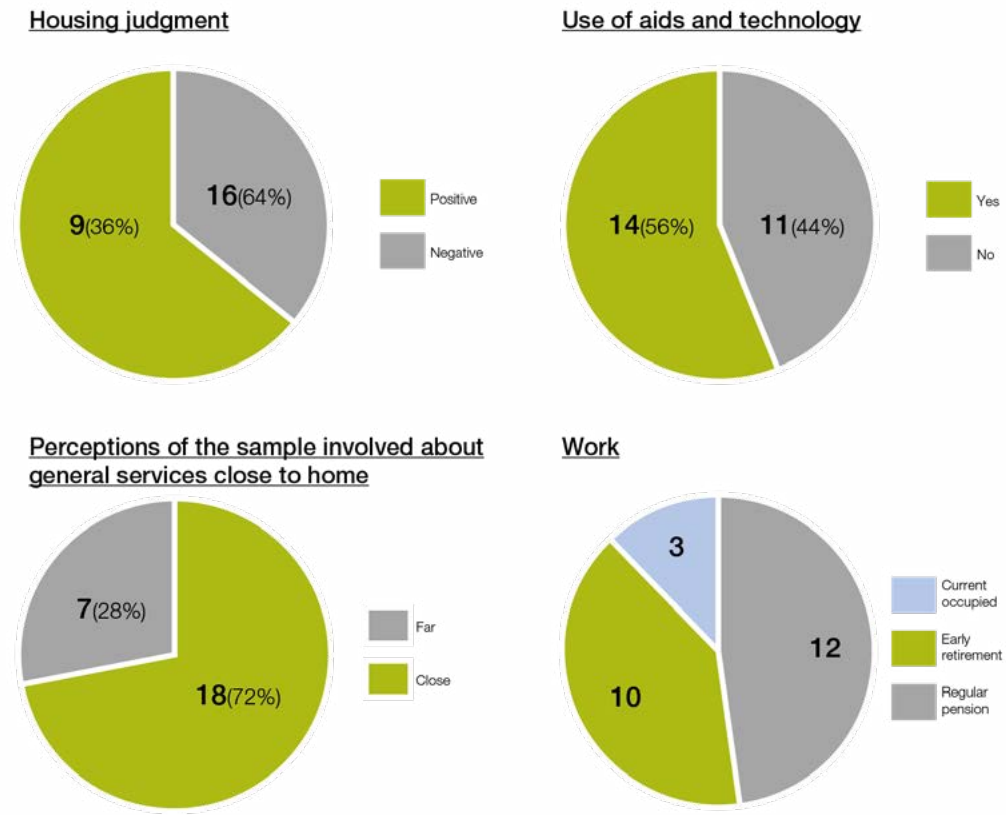


Fig. 9.7 Housing judgment (top left), use of aids and technology (top right), perceptions of the sample involved about general services close to home (bottom left) and, finally, work (bottom right).

The following emerged with regard to caregivers (16):

- 10 out of 16 caregivers stated that PD had negatively changed their quality of life both practically and psychologically. While the remaining 6 caregivers stated that in view of the slightly advanced level of Parkinson's disease, at the time of the interview, they did not have to change their way of living or relating to PwP (see Fig. 9.8).
- The changes imposed by PD also largely reflect on the work of caregivers. Indeed, 7 out of 16 caregivers were forced to organise work to provide care for their spouse/parent. 4 users had to apply for part-time work, 1 user had to retire early, 1 person has never been able to work and finally only 1 out of 6 caregivers stated at the time of the interview that they take advantage of the benefits of law 104.

Of the remaining 9 caregivers, however, 8 had retired regularly, while only 1 person stated at the time of the interview that he or she continued to work regularly.

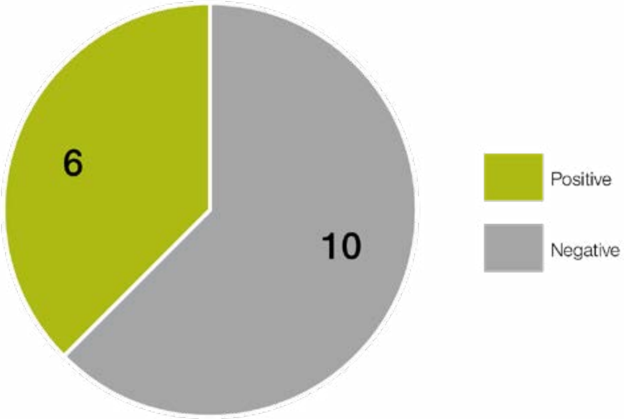


Fig. 9.8 Caregiver's quality of life judgement.

9.2.3 Structured specialised interview and context observation

Once the semi-structured interview had been completed, the working team, having analysed the results, agreed to proceed to the second phase with users presenting a medium to severe level of symptomatology (level 2.5-5 on the Hoehn and Yahr scale).

This exclusion criterion allowed the researchers to receive more interesting data for research purposes, which were subsequently jointly analysed and used for the drafting of the guidelines (see Chapter 10).

Consequently, the interview continued for 18 subjects.

The specific structured interview was conducted exclusively with PwP, and the participation of the caregiver was ensured for those subjects with speech disorders. This phase followed two modes of participation, through the telephone or through video call platforms.

9 users preferred to use the telephone as an interview tool, while the remaining 9 preferred to use video call platforms (see Fig.9.9).

During this phase, six specialised questions were asked, as well as the subsequent request to the participants to document the interior and exterior spaces of their home through photos. The results are given below.

Regarding *Question 1. How many rooms does your home consist of?* 7 out of 18 subjects live in a 5-room home, while 4 subjects live in a 4-room home, 6 subjects live in a 4-, 6- and 10-room home respectively, and finally 1 subject lives in an 8-room home.

With regard to outdoor space, 7 out of 18 subjects have one or more terraces, some of them on several floors of the residence, while 4 out of 18 subjects have a garden and, finally, 6 out of 18 subjects stated that they have a garage serving the home (see Fig. 9.10).

Regarding *Question 2. In view of Parkinson's what features should your ideal home have?* the wide range of data that emerged from this response shows that 13 out of 18 people would like housing solutions with bathrooms of a suitable size to ensure access and turning space for a wheelchair as well as the space required to install grab bars and a shower seat.

10 of the interviewees attach great importance to stairs. Although they know that stairs, depending on the PD's level of symptomatology, can be an incentive to reduce freezing, they prefer single-storey housing solutions without internal stairs.

Furthermore, 7 out of 18 subjects stated that they would like more accessibility within the kitchen environment for those who have to sit in a wheelchair or use a walker. The biggest problems can be traced back to the use of wall and base units in the kitchen, but also to the appliances provided.

5 out of 18 subjects attach great importance to outdoor space (terrace or garden) and home usability/accessibility for walkers and wheelchairs.

Finally, 4 out of the 18 respondents stated that they needed rooms of a suitable size for wheelchair access, open space solutions (at least guarantee this between the kitchen and living room) and spaces within the home where physical activity could also be performed (see Fig. 9.10).

For *Question 3. On a scale of 1 to 5, where 1 represents the lowest value and 5 the highest, how satisfied are you with your home?* it can be seen from figure 9.10 "overall opinion of the home" that 5 out of 18 subjects gave an overall value of 4, therefore positive, while 2 users gave a value of 3 and, finally, only 1 user gave a value of 2.

The remaining 10 out of 18 users did not give an overall rating to the house they live in. Similar results can be found in the table "overall living space rating". If we do not consider the n/a, value, i.e. not applicable, a good percentage of the users give an average positive value, and thus it is assumed that they are satisfied with the rooms in each individual house even if everyone would like to make

some modification (see Fig. 9.10 and Fig. 9.11).

Turning to *Question 4. In your opinion, what could be improved in your home?* as can be seen from the characteristics shown in Figure 9.11, a large majority of users say they would like to change the bathroom (10).

Subsequently, 6 out of 18 subjects would like to have suitable means of overcoming height differences (footboards, hoists, lifts), 5 subjects would like a space where they could do physical activities, 2 subjects would like to have grab bars or handles placed at strategic points in the house, in addition to the bathroom, while 1 subject needed an outdoor space and rooms and a kitchen of a size suitable for a wheelchair (see Fig. 9.12).

The answers to *Question 5. From your point of view, do you believe that technology can improve your life? If so, what kind of technology can you think of?* are very positive. Indeed, 12 out of 18 users are convinced that some new technologies can improve the quality of life and the degree of autonomy of PwP.

While three users are not convinced that technology can contribute to improving the quality of life, they believe that love and constant help from a caregiver are the key elements in coping with PD on a daily basis. Finally, the remaining 3 subjects did not answer the question (see Fig. 9.13).

In conclusion, the answers to *Question 6. What do you think of a house that can change the organisation of its interior spaces depending on a need to be met? Do you think a flexible/adaptable house might be right for you?* are extremely positive. 16 out of 18 users state that flexibility and versatility can be a viable alternative to meet the changing needs of PwP and not be forced to renovate their home or relocate (see Fig. 9.14).

Once the interview was completed, the subjects were asked to document, by means of a video call or alternatively with photos, the environments in their homes. The most interesting images are shown below (see Fig. 9.15, Fig. 9.16 and Fig. 9.17).

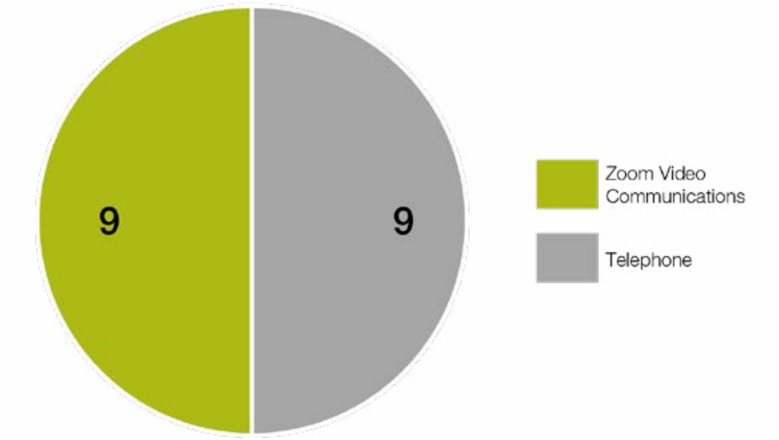
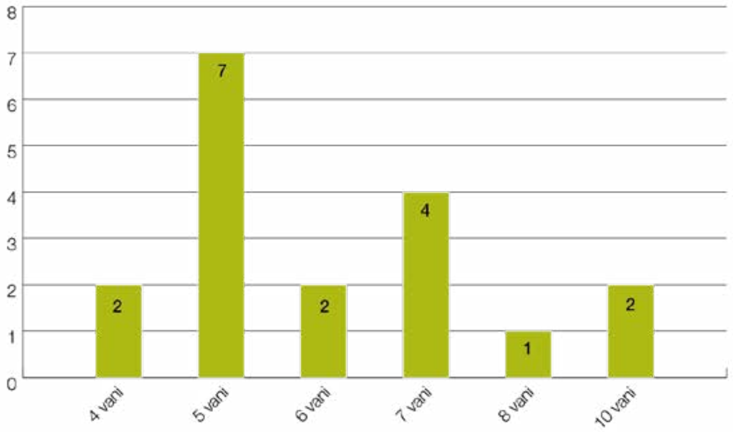
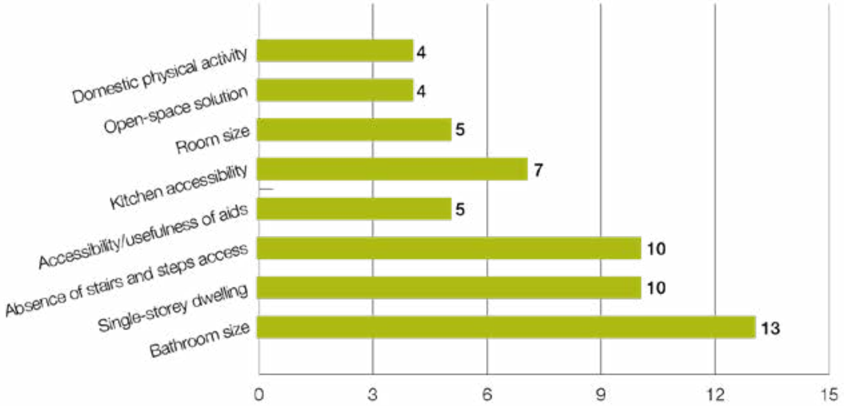


Fig. 9.9 Tools used for the specific structured interview.

Question 1



Question 2



Question 3

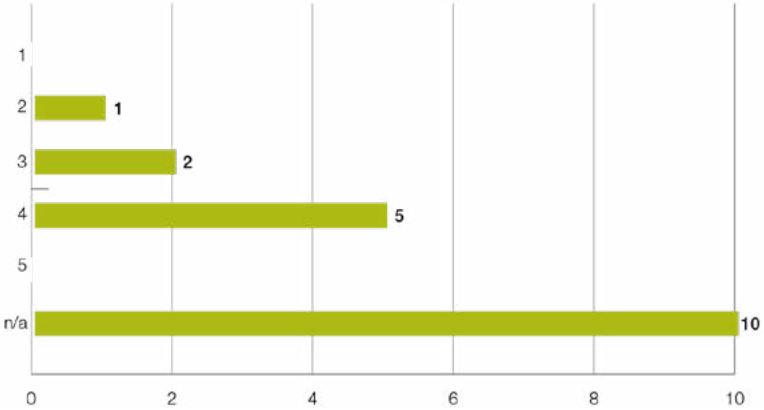


Fig. 9.10 Results of Question 1 (top), Question 2 (middle) and Question 3 (bottom).

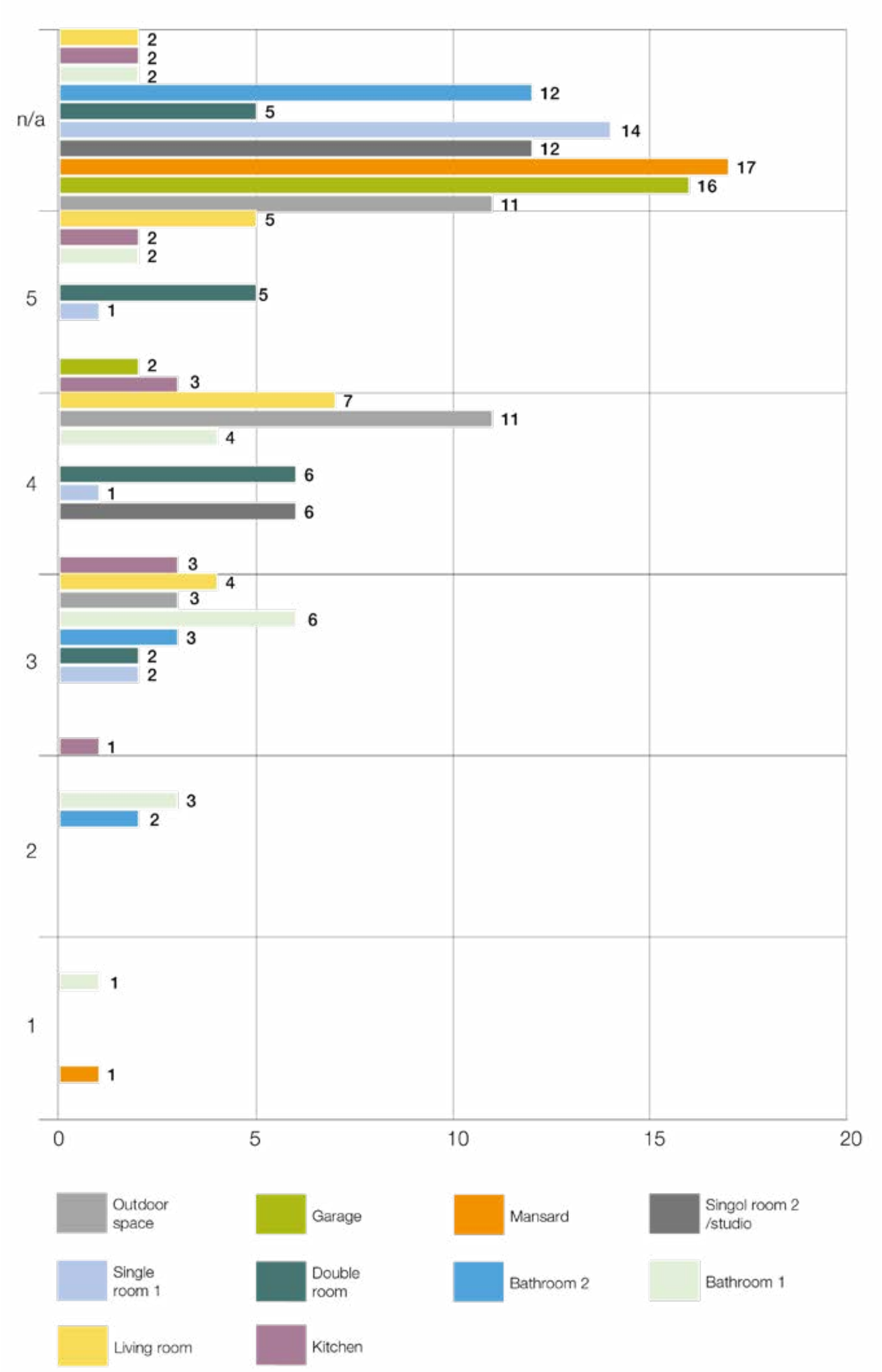


Fig. 9.11 Overall assessment of the rooms that make up the home of the sample involved.

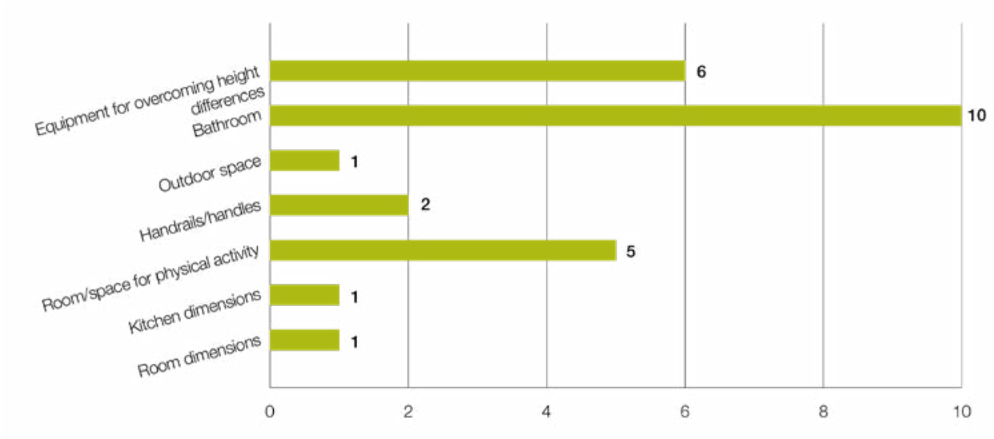


Fig. 9.12 Desires and needs stated by the sample involved in the research programme.

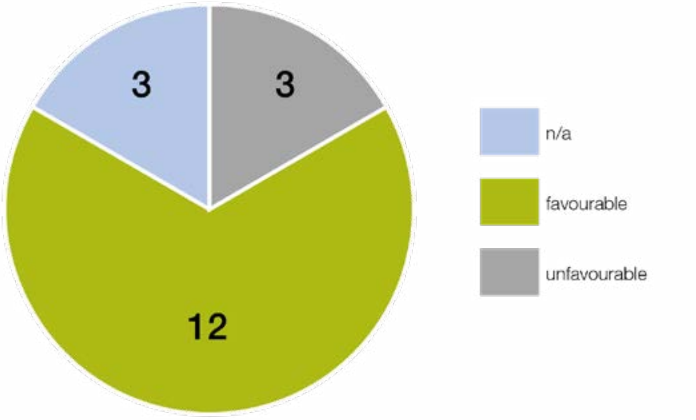


Fig. 9.13 Judgement regarding “home technology”.

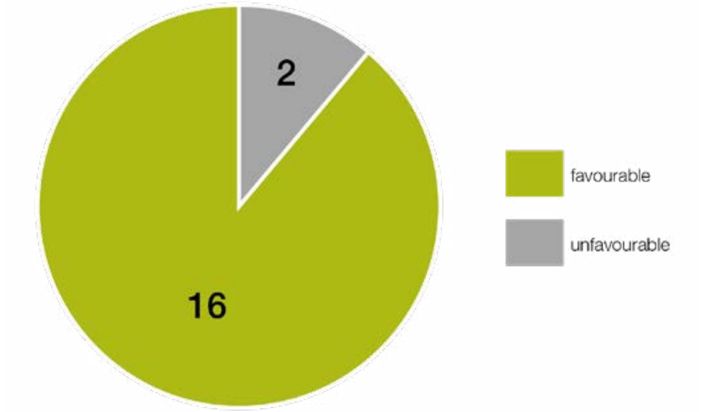


Fig. 9.14 Judgement regarding “domestic flexibility”.

Fig. 9.15 Photos of the spaces in the homes of the sample involved in the research programme.

Fig. 9.16 Photos of the spaces in the homes of the sample involved in the research programme.

Fig. 9.17 Photos of the spaces in the homes of the sample involved in the research programme.

9.2.4 Problem mapping and conceptual matrix

Below is the overall mapping of the problems and demands that emerged during the semi-structured interview, the structured interview and the context observation.

The table below shows the major areas of focus.

Domestic environment	Description
Vertical routes	• some users complain about the presence of steps or flights of stairs;
Horizontal routes	• lack of ample space to ensure the passage and turning of the walker or wheelchair to ensure home accessibility and to limit freezing; • lack, or inadequacy, of space for movement between the elements of furniture in the home: e.g. table-chair; chair-sofa; table-lounge-kitchen; etc; • lack of space to enable wheelchair rotation in certain rooms of the house; • difficulties in passing through narrow doors or narrow spaces (e.g. corridors); • difficulty in walking due to the presence of obstacles in the horizontal routes (sofa, armchair, bed, furniture, etc.); • presence of unevenness in the outdoor space (terrace, garden, etc.);
Room dimensions	• lack of space, within bathrooms and bedrooms, to allow access to the caregiver during hygiene and cleaning of the PwP; • lack of sufficient space for physical activity, physiotherapy and/or recreational activities;
Access	• difficulty opening and closing doors and windows;
Furnishing, aids and assistive technology	• lack of grab bars and/or support elements at the most critical points of the home (change of stride) for fall prevention; • lack of space to install grab bars in the bathroom; • difficulty in reaching low furniture. Some users complain about the difficulty of bending down to reach objects placed in the kitchen base units or on lower shelves or cabinets; • difficulty getting out of bed or armchair (beds, armchairs and static sofas). Many PwP are in favour of having motorised beds, armchairs and sofas; • lack of knowledge of aids or assistive technologies for Parkinson’s or other motor impairments;
Other	• some users have problems with body thermoregulation; • and finally, some users complain about a low/poor participation of the sectoral associations in relation to PwP and their caregivers.

Tab. 9.2 Areas of intervention.

Once the global problem mapping was completed, and prior to the definition of the conceptual matrix, a summary table was produced relating typical household activities to the 5 Parkinson's levels (see Tab. 9.3).

This categorisation (Hoehn, Yahr, 1967; KNFG, 2004; EPDA, 2009; Perillo, 2013) made it possible to identify which domestic activities could be carried out independently, for which ones an aid must be used and, finally, which activities must be carried out by the caregiver.

This information was used to define the minimum spaces to be ensured within each domestic environment (see Chapter 10).

Next, the conceptual matrix was produced (see Tab. 9.4), i.e. an outline organisational scheme, in which the two columns on the left indicate the spaces that generally make up or may make up a dwelling, and the conceptual principle, i.e. the expected and conceivable requirements that define the activities to be conducted within each room.

While the two header rows at the top show the numbers of the 18 users (identified by a sequence number) and 3 letters summarising the rating given by each user to each home environment. Each letter represents:

- I, indispensable. Representing the prerequisites for PwP to be able to access and use the living spaces;
- N, necessary. Representing the necessary prerequisites for PwP to be able to access and use the dwelling spaces;
- D, desirable. Representing the desirable requirements, which emerged during the observation phase, useful for PwP to be able to access and use the living space.

	MOTOR SYMPTOMS											
DOMESTIC ACTIVITIES TYPE	Level 1 - 1.5 (mild symptomatology)				Level 2 - 2.5 (mild to moderate symptomatology)				Level 3 (moderate symptomatology)			
	Tremor	Motor Blocks	Postural Alteration	Muscle Rigidity	Tremor	Motor Blocks	Postural Alteration	Muscle Rigidity	Tremor	Motor Blocks	Postural Alteration	Muscle Rigidity
Stow-away material containers/cabinets/high drawers												
Stowing/removing low containers/cabinets/drawers material												
Opening/closing doors/windows												
Switching lights on/off												
Turning on/off/adjusting temperature												
Use small appliances												
Use large appliances												
Sitting/standing up chair/sofa/armchair												
Lie down/stand up in bed												
Move around in bed												
Use table												
Dressing/undressing												
Washing/drying												
Eating/drinking												
Prepare food												
Use hob												
Use sink (kitchen)	●	●	●	●	✣	✣	✣	✣	✣/■	✣/■	✣/■	✣/■
Use shower												
Use WC												
Use bidet												
Use sink (bathroom)												
Use mixer tap/faucet (kitchen/bathroom)												
Walk indoor environment												
Walk outdoor environment												
Use remote control												
Use book												
Use PC/tablet/mobile phone												
Exercise												
Use sports equipment												
Do physiotherapy or similar												
Work (telecommuting)												
Bringing in groceries/taking out the rubbish												
Cleaning objects/environments												
Using a means of transport (car, scooter, bike)												

Level 4 (moderate to severe symptoms)				Level 5 (severe symptomatology)				DOMESTIC ACTIVITIES TYPE
Tremor	Motor Blocks	Postural Alteration	Muscle Rigidity	Tremor	Motor Blocks	Postural Alteration	Muscle Rigidity	
■/✶	■/✶	■/✶	■/✶	✶	✶	✶	✶	Stow-away material containers/ cabinets/high drawers
■/✶	■/✶	■/✶	■/✶	✶	✶	✶	✶	Stowing/removing low containers/ cabinets/drawers material
■	■	■	■	✶	✶	✶	✶	Opening/closing doors/windows
■	■	■	■	✶	✶	✶	✶	Switching lights on/off
■	■	■	■	✶	✶	✶	✶	Turning on/off/adjusting temperature
■/✶	■/✶	■/✶	■/✶	⊗	⊗	⊗	⊗	Use small appliances
■/✶	■/✶	■/✶	■/✶	⊗	⊗	⊗	⊗	Use large appliances
■	■	■	■	■/✶	■/✶	■/✶	■/✶	Sitting/standing up chair/sofa/ armchair
■	■	■	■	■/✶	■/✶	■/✶	■/✶	Lie down/stand up in bed
✣/■	✣/■	✣/■	✣/■	■/✶	■/✶	■/✶	■/✶	Move around in bed
✣/■	✣/■	✣/■	✣/■	■/✶	■/✶	■/✶	■/✶	Use table
■	■	■	■	✶	✶	✶	✶	Dressing/undressing
■	■	■	■	✶	✶	✶	✶	Washing/drying
■	■	-	■	■/✶	■/✶	-	■/✶	Eating/drinking
■/✶	■/✶	■/✶	■/✶	⊗	⊗	⊗	⊗	Prepare food
■/✶	■/✶	■/✶	■/✶	⊗	⊗	⊗	⊗	Use hob
■/✶	■/✶	■/✶	■/✶	✶	✶	✶	✶	Use sink (kitchen)
■	■	■	■	■/✶	■/✶	■/✶	■/✶	Use shower
■	■	■	■	■/✶	■/✶	■/✶	■/✶	Use WC
⊗	⊗	⊗	⊗	⊗	⊗	⊗	⊗	Use bidet
■/✶	■/✶	■/✶	■/✶	■/✶	■/✶	■/✶	■/✶	Use sink (bathroom)
■/✶	■/✶	■/✶	■/✶	■/✶	■/✶	■/✶	■/✶	Use mixer tap/faucet (kitchen/ bathroom)
■	■	■	■	■/✶	■/✶	■/✶	■/✶	Walk indoor environment
■	■	■	■	■/✶	■/✶	■/✶	■/✶	Walk outdoor environment
■	■	-	■	✶	✶	-	✶	Use remote control
■	■	-	■	■/✶	■/✶	-	■/✶	Use book
■	■	-	■	■/✶	■/✶	-	■/✶	Use PC/tablet/mobile phone
■	■	■	■	■/✶	■/✶	■/✶	■/✶	Exercise
■	■	■	■	■/✶	■/✶	■/✶	■/✶	Use sports equipment
✶	✶	✶	✶	✶	✶	✶	✶	Do physiotherapy or similar
⊗	⊗	⊗	⊗	⊗	⊗	⊗	⊗	Work (telecommuting)
■	■	■	■	⊗	⊗	⊗	⊗	Bringing in groceries/taking out the rubbish
■	■	■	■	⊗	⊗	⊗	⊗	Cleaning objects/environments
⊗	⊗	⊗	⊗	⊗	⊗	⊗	⊗	Using a means of transport (car, scooter, bike)

Tab. 9.3. The 4 cardinal symptoms. The following symptoms are considered motor blocks: akinesia, bradykinesia, facial mimicry, dysarthria (speech disorder), scialorrhoea, freezing, micrografia (writing disorder), dysphagia (difficulty in swallowing). The symptoms of PD can be divided into motor and non-motor symptoms. For the purposes of this research project, this table does not consider non-motor symptoms such as dementia, depression, anxiety, sexual disorders, pain and fatigability. Legend:

- ● The subject has difficulty performing the action;
- ✣ The subject could perform the action with difficulty without needing aids or assistance from a caregiver;
- ■ The subject performs the action with difficulty and needs assistive aids/technologies;
- ✶ The subject needs continuous assistance to perform the action;
- ⊗ The subject is no longer able to perform the action. These actions are to be considered dangerous for PwP.

CONCEPTUAL MATRIX

Domestic space	Conceptual principle	Users																																
		1			2			3			4			6			9			10			11			12			13			15		
		I	N	D	I	N	D	I	N	D	I	N	D	I	N	D	I	N	D	I	N	D	I	N	D	I	N	D	I	N	D	I	N	D
KITCHEN	Kitchen use																								x									
	Manoeuvring space			x		x				x									x		x										x			x
	Manoeuvring space with assistive aids			x						x									x		x					x								x
	Presence of walking aids						x													x						x								x
	Space between kitchen-table-seating		x				x			x																								
	Use of worktop																																	
	Use of wall cabinets												x						x															
	Use of base units																		x		x						x							
	Opening and closing doors					x			x			x						x													x			x
	Opening and closing windows								x			x						x													x			x
LIVING ROOM	Living room use																																	
	Manoeuvring space			x		x				x									x		x										x			x
	Manoeuvring space with assistive aids			x						x									x		x					x								x
	Presence of walking aids						x													x						x								x
	Space between table-couch/armchair-mobile (TV)		x				x			x																								
	Use of armchair/sofa																				x								x					
	Use of furniture																		x		x						x							
	Opening and closing doors					x			x			x						x													x			x
	Opening and closing windows								x			x						x													x			x
BATHROOM	Bathroom use																				x													
	Manoeuvring space				x					x		x							x		x				x									x
	Manoeuvring space with assistive aids			x						x									x		x					x								x
	Presence of walking aids	x					x								x				x	x				x		x								x
	Space between washbasin-shower-wc-bidet		x							x		x																						
	Use of WC																																	
	Use of bidet								x																x				x					
	Use of shower					x			x						x											x				x			x	
	Use of washbasin								x																									
	Opening and closing doors					x			x			x						x													x			x
	Opening and closing windows								x			x						x													x			x
BEDROOM	Bedroom use																																	
	Manoeuvring space					x				x		x							x		x													x
	Manoeuvring space with assistive aids									x									x		x					x								x
	Presence of walking aids						x													x						x								x
	Space between bed and wardrobe		x				x			x																								
	Use of bed															x			x	x						x			x					
	Use of wardrobe																		x														x	
	Opening and closing doors					x			x			x						x													x			x
	Opening and closing windows								x			x						x													x			x
AUXILIARY SPACE	Auxiliary space use																				x													
	Dedicated space for physical activity		x			x				x		x			x									x									x	
	Space dedicated to work activities																		x						x									
	Space dedicated to relaxation/resting activities	x				x									x					X														
	Space dedicated to domestic activities (cleaning clothes; ironing clothes; etc.)																																	
	Manoeuvring space									x									x															x
	Manoeuvring space with assistive aids									x									x															x
	Presence of walking aids																																	x
	Opening and closing doors					x			x									x													x			x
	Opening and closing windows					x			x									x													x			x
OUTDOOR SPACE	Use of outdoor space (courtyard and/or terrace)																		x															
	Manoeuvring space					x													x		x													x
	Manoeuvring space with assistive aids																		x		x													x
	Presence of walking aids																																	x
	Space between furnishings					x																												
	Proximity to entrance																																	
	Opening and closing doors					x			x									x													x			x
	Opening and closing windows								x									x													x			x
OTHER	Other																																	
	Lift					x														x				x				x			x			x
	(space for) Stair lift			x		x				x			x			x				x				x				x			x			x
	Proximity to citizen services					x				x		x				x					x						x			x				
	Assistive aids/assistive technologies		x			x												x		x						x							x	
	Physical activity		x		x				x		x				x						x													
	Involvement in associations											x			x			x																
	Suitable door dimensions >90cm																		x															

Domestic space	Conceptual principle	17			18			20			21			22			23			24		
		I	N	D	I	N	D	I	N	D	I	N	D	I	N	D	I	N	D	I	N	D
KITCHEN	Kitchen use																					
	Manoeuvring space									x												
	Manoeuvring space with assistive aids	x											x			x		x				
	Presence of walking aids		x							x			x			x		x				
	Space between kitchen-table-seating									x			x									
	Use of worktop						x			x			x									
	Use of wall cabinets						x			x			x									
	Use of base units						x			x			x									
	Opening and closing doors												x						x			
	Opening and closing windows												x						x			
LIVING ROOM	Living room use																					
	Manoeuvring space																					
	Manoeuvring space with assistive aids	x											x			x		x				
	Presence of walking aids		x							x			x			x		x				
	Space between table-couch/armchair-mobile (TV)												x									
	Use of armchair/sofa																					x
	Use of furniture									x												
	Opening and closing doors												x						x			
	Opening and closing windows												x						x			
BATHROOM	Bathroom use																					
	Manoeuvring space					x																
	Manoeuvring space with assistive aids	x									x					x		x				x
	Presence of walking aids		x							x	x			x				x				x
	Space between washbasin-shower-wc-bidet																					
	Use of WC							x														
	Use of bidet							x														
	Use of shower							x						x				x				
	Use of washbasin																		x			
	Opening and closing doors												x						x			
	Opening and closing windows												x						x			
BEDROOM	Bedroom use																					
	Manoeuvring space																					
	Manoeuvring space with assistive aids	x									x					x		x				
	Presence of walking aids		x							x	x					x		x				
	Space between bed and wardrobe															x						
	Use of bed	x				x			x		x			x						x		
	Use of wardrobe																					
	Opening and closing doors												x						x			
	Opening and closing windows												x						x			
AUXILIARY SPACE	Auxiliary space use	x																				
	Dedicated space for physical activity	x					x	x					x									
	Space dedicated to work activities						x															x
	Space dedicated to relaxation/resting activities								x		x											
	Space dedicated to domestic activities (cleaning clothes; ironing clothes; etc.)	x																				
	Manoeuvring space																					
	Manoeuvring space with assistive aids	x														x						
	Presence of walking aids		x							x						x						
	Opening and closing doors												x									
	Opening and closing windows												x									
OUTDOOR SPACE	Use of outdoor space (courtyard and/or terrace)		x				x											x				
	Manoeuvring space									x												
	Manoeuvring space with assistive aids	x									x			x								
	Presence of walking aids		x							x	x			x								
	Space between furnishings																					
	Proximity to entrance			x					x													
	Opening and closing doors												x									
	Opening and closing windows												x									
OTHER	Other																					
	Lift			x																		x
	(space for) Stair lift			x																		x
	Proximity to citizen services		x															x				
	Assistive aids/assistive technologies	x									x			x				x				
	Physical activity											x			x							
	Involvement in associations	x				x			x			x			x							
	Suitable door dimensions >90cm												x									

Tab. 9.4. Conceptual matrix.

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10. Guidelines for the design of usable home environments for people with Parkinson’s disease

by *Francesca Tosi, Mattia Pistolesi*[1]

This last chapter presents the Design Guidelines resulting from the *Home Care Design for Parkinson’s Disease* research, describing its objectives and approach.

The guidelines are a set of recommendations and/or operational indications, aimed at guiding actions, types of behaviour or a *modus operandi*, within a given context, or at proposing a structured set of good practices and possible alternatives for the development of project solutions addressed to specific sectors.

As reported in Chapter 4, the Guidelines are widely used in the design disciplines, since they represent a fundamental tool to support, direct and make designers aware of the most suitable design choices referred to a specific sector of intervention (e.g.: hospital furniture, working environments, pedestrian paths, products of use, etc.) and/or to a design objective (e.g.: safety of workplaces; accessibility of pedestrian paths; or in our case, maximum usability and flexibility over time of the home environment for people with disabilities).

The aim of the Guidelines for *the design of home environments usable by people with Parkinson’s disease* is to define flexible and adaptable design solutions over time, capable of meeting the needs and expectations shared by different user profiles within a home environment.

In other words, the aim was to move from a design specifically aimed at people with disabilities, and in particular people with Parkinson’s disease, to an inclusive design, aimed at ensuring the accessibility and usability of environments and the simplicity, comprehensibility and manageability of products, not only for PwP but for all those who live or spend time in their home environment, and therefore for their family and friends, formal/informal caregivers and healthcare professionals and, more generally, for all the people to whom the proposed solutions can bring a concrete improvement in their quality of life.

All the solutions are in fact potentially applicable, with appropriate adjustments and additions, to other areas of intervention that aim at guaranteeing maximum levels of usability and adaptability of everyday living environments over time.

Before going into the details of the Guidelines, it is certainly useful to introduce their structure, which is designed to address as broad and heterogeneous an audience as possible, comprising current and future professionals, but also people directly affected by the disease, their families and healthcare professionals.

To this end, the sheets contained in the Guidelines, dedicated to each individual room in the home, are composed of four parts, one dependent on the other, providing different graphic and descriptive levels:

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[1] Authors of Chap. 10: Francesca Tosi p. 165 to p. 257; Mattia Pistolesi p. 258 to p. 343.

1. Dimensioned 2d drawings with the minimum dimensions to be respected, called *2d plans*.

2. Description of the technical aspects to be taken into account, called *description*.

3. 3D representations produced using the rendering technique, called *virtual environments*.

4. Finally, indications regarding products, aids and assistive technologies on the national and international market, called *references*.

Furthermore, each individual environment has been represented in its possible evolutions in relation to the evolution of the person's needs over time, demonstrating the fact that if PD changes, in severity and intensity, and in a different way from person to person, then the environment in which he or she lives may also change over time to meet the new needs of the PwP.

For this reason, the environments are represented with three levels of evolution: mild, moderate and severe symptoms. The first, referring to the mild level of symptomatology, considers PwP to still be able to perform all, or almost all, common household activities independently. The technical tables show the person without any aids or assistive technology. The second, referring to the moderate level of symptomatology, considers that the PwP suffers from postural instability but is still physically independent. The technical tables show the person using the walker, and grab bars are placed at strategic points in the room, such as corners, where the change of stride is expected to take place. Finally, the third, referring to the level of severe symptomatology, considers the PwP to have difficulty walking and performing household activities independently. For the latter development, the technical tables show a person using the wheelchair, both grab bars and other aids for movement are present, and the constant presence of the formal/ informal caregiver is envisaged.

The environments and elements represented in the guidelines are as follows: (i) bathroom (ii) bedroom (iii) kitchen (iv) auxiliary space, to be understood as a single bedroom for a child or caregiver, or an auxiliary space in the home where physical activity or teleworking can take place (v) living room (vi) utility room and laundry room (vii) garage (viii) outdoor space (ix) doors and windows (x) floors (xi) vertical routes (xii) management and control systems.

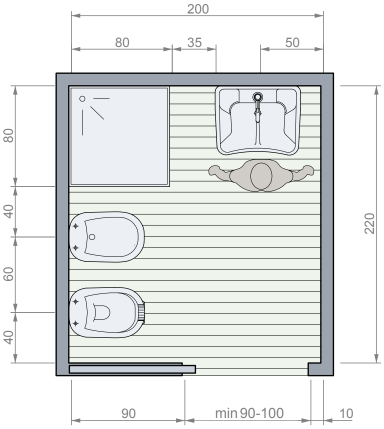
Since this is a research project that lies somewhere between two areas of design - Interior Design and Product Design - specifically focused in this case to the health and care sector, some areas of the project were deliberately not dealt with and, in particular, the systems, lighting, and architectural and structural aspects of the building, in order to focus on the interior environments, furniture, objects of use and aids, most suitable for PwP and their caregivers.

To conclude, the Guidelines end with design hypotheses for the home environment, which aim at indicating how each individual space can be used and put in relation with the other spaces in the home to form 3 solutions for households of 2, 3 or 4 people respectively.

Bathroom

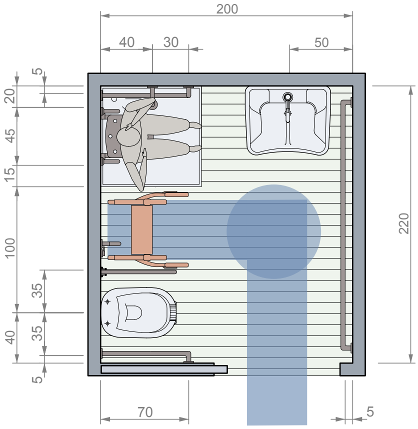
Dimension
2.00m X 2.20m = 4.40mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bathroom may be equipped with a bidet. In order to provide more space in the bathroom right from the start, however, we recommend the use of a multifunctional toilet that integrates the functionality of a bidet.

MODERATE level of symptomatology

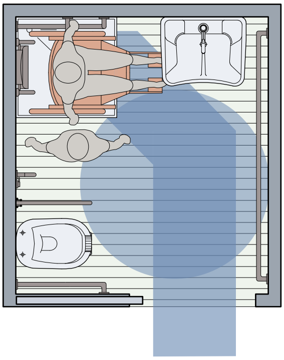


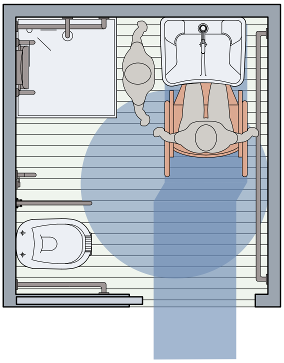
NOTE:
In the case of PD at the MODERATE stage, the bidet should be replaced with a bidet hand shower. The space between the shower and the toilet will be able to accommodate the aids. In addition, the shower must be equipped with a folding seat. Handrails should be provided at strategic points.

Bathroom

Dimension
2.00m X 2.20m = 4.40mq

SEVERE level of symptomatology



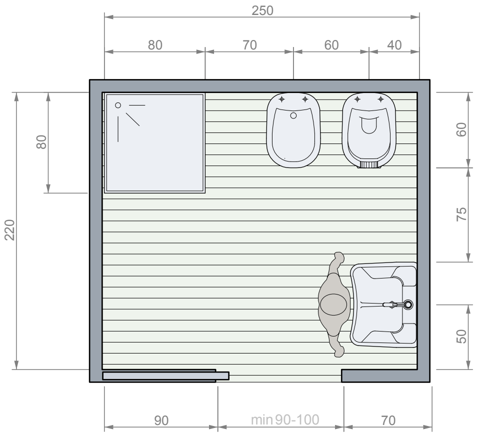


NOTE:
In the case of PD at the SEVERE stage, the bidet should be replaced with a bidet hand shower. The space between the shower and the toilet will be able to accommodate the aids. In addition, the shower must be equipped with a folding seat. Handrails should be provided at strategic points. For this level of symptomatology, the presence of the formal/informal caregiver is also expected.

Bathroom

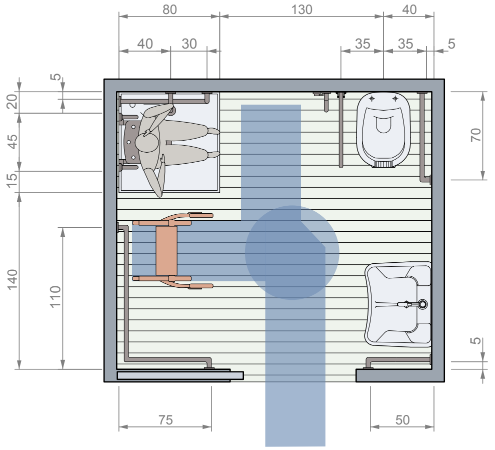
Dimension
2.20m X 2.50m = 5.50mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bathroom may be equipped with a bidet. In order to provide more space in the bathroom right from the start, however, we recommend the use of a multifunctional toilet that integrates the functionality of a bidet.

MODERATE level of symptomatology



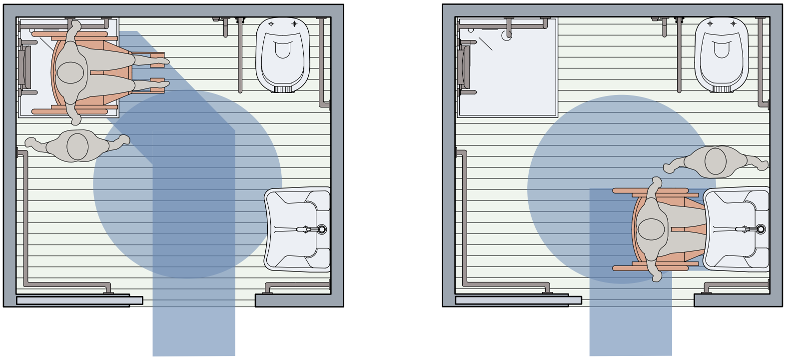
NOTE:
In the case of PD at the MODERATE stage, the bidet should be replaced with a bidet hand shower. The space between the shower and the toilet will be able to accommodate the aids. In addition, the shower must be equipped with a folding seat. Handrails should be provided at strategic points.

2D plans Sheet **1.02**

Bathroom

Dimension
2.20m X 2.50m = 5.50mq

SEVERE level of symptomatology

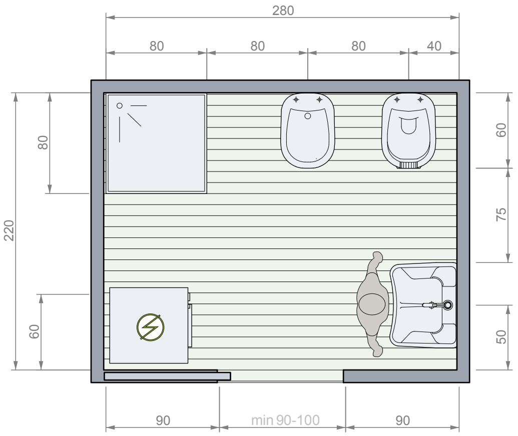


NOTE:
In the case of PD at the SEVERE stage, the bidet should be replaced with a bidet hand shower. The space between the shower and the toilet will be able to accommodate the aids. In addition, the shower must be equipped with a folding seat. Handrails should be provided at strategic points. For this level of symptomatology, the presence of the formal/informal caregiver is also expected.

Bathroom

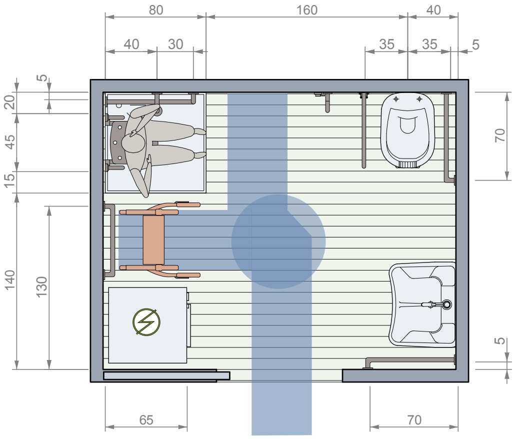
Dimension
2.80m X 2.20m = 6.16mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bathroom may be equipped with a bidet. In order to provide more space in the bathroom right from the start, however, we recommend the use of a multifunctional toilet that integrates the functionality of a bidet.

MODERATE level of symptomatology



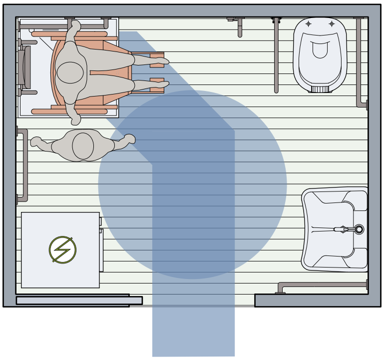
NOTE:
In the case of PD at the MODERATE stage, the bidet should be replaced with a bidet hand shower. The space between the shower and the toilet will be able to accommodate the aids. In addition, the shower must be equipped with a folding seat. Handrails should be provided at strategic points.

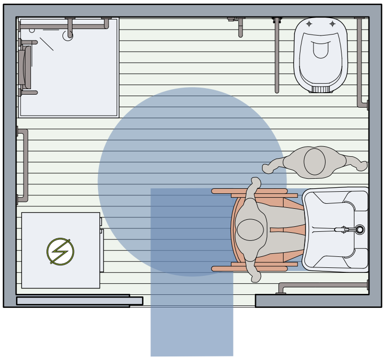
⚡ Washing machine/Tumble dryer

Bathroom

Dimension
2.80m X 2.20m = 6.16mq

SEVERE level of symptomatology





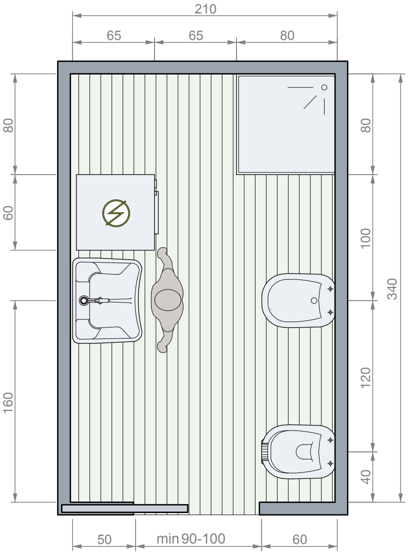
NOTA:
In the case of PD at the SEVERE stage, the bidet should be replaced with a bidet hand shower. The space between the shower and the toilet will be able to accommodate the aids. In addition, the shower must be equipped with a folding seat. Handrails should be provided at strategic points. For this level of symptomatology, the presence of the formal/informal caregiver is also expected.

⚡ Washing machine/Tumble dryer

Bathroom

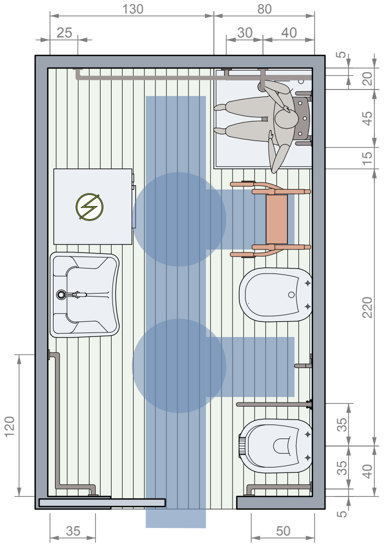
Dimension
2.10m X 3.40m = 7.14mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bathroom may be equipped with a bidet. In order to provide more space in the bathroom right from the start, however, we recommend the use of a multifunctional toilet that integrates the functionality of a bidet.

MODERATE level of symptomatology



NOTE:
In the case of PD at the MODERATE-SEVERE stage, the bidet should be replaced with a bidet hand shower. The space between the shower and the toilet will be able to accommodate the aids. In addition, the shower must be equipped with a folding seat. Handrails should be provided at strategic points.

⚡ Washing machine/Tumble dryer

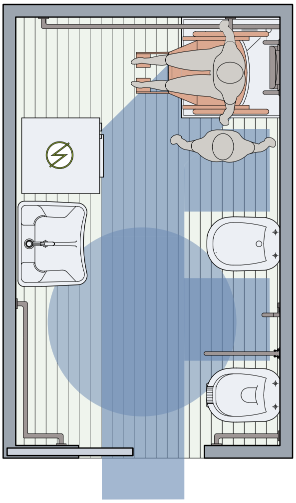
2D plans

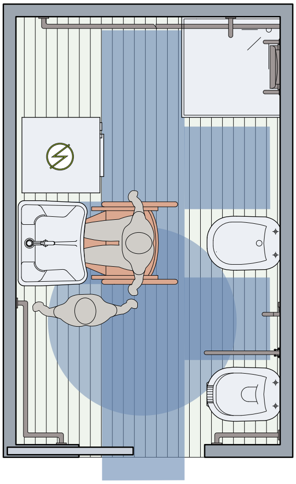
Sheet **1.04**

Bathroom

Dimension
2.10m X 3.40m = 7.14mq

SEVERE level of symptomatology





NOTE:
In the case of PD at the SEVERE stage, the bidet should be replaced with a bidet hand shower. The space between the shower and the toilet will be able to accommodate the aids. In addition, the shower must be equipped with a folding seat. Handrails should be provided at strategic points. For this level of symptomatology, the presence of the formal/informal caregiver is also expected ..

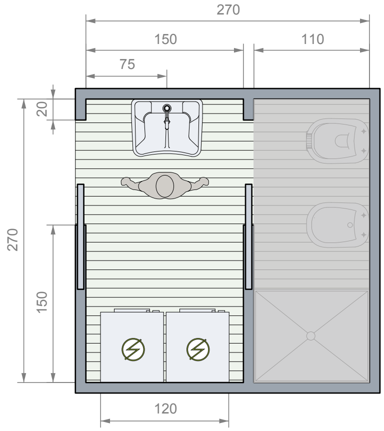
⚡ Washing machine/Tumble dryer

2D plans Sheet **1.04**

Service bathroom and laundry room

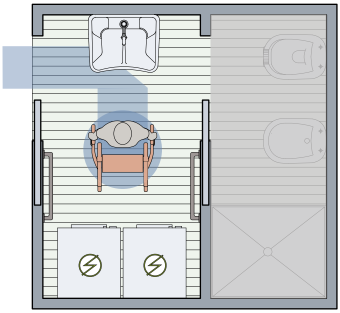
Dimension
2.70m X 2.70m = 7.29mq

MILD level of symptomatology



NOTE:
Current legislation prescribes that at least one bathroom in the dwelling must meet the requirements of Law 13/89. In the case of additional bathrooms, or service bathrooms, wheelchair accessibility should be ensured in the anteroom.
As can be seen in this solution, it is ensured that PwP, with varying degrees of symptomatology, can make use of the space, which is used to place the washbasin and the laundry area (consisting of a washing machine and dryer). As far as the wash basin is concerned, please refer to sheet 1. description, while as far as the washer/dryer is concerned, the following applies:
- purchase appliances equipped with control buttons and door opening/closing systems at a height of between 40 cm and 140 cm (maximum reachable area for a wheelchair user);
- if this height is not guaranteed, place appliances on a raised floor.

MODERATE level of symptomatology

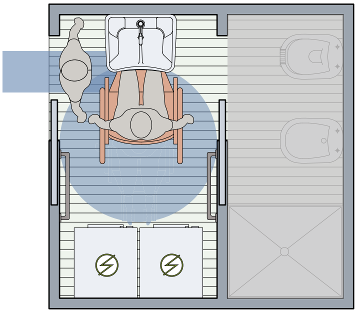


Washing machine/Tumble dryer

Service bathroom and laundry room

Dimension
2.70m X 2.70m = 7.29mq

SEVERE level of symptomatology



⚡ Washing machine/Tumble dryer

2D plans

Sheet **1.05**

Bathroom

From sheet 1.01 to 1.05

(a) Position and sizing:

- the bathroom should be located next to the bedrooms or alternatively in the bedroom. This makes it possible, in some cases, to ensure the transport of dependent persons from the bed to the bathroom by means of overhead or mobile lifts;
- the dimensions of the bathroom (as reported in the previous sheets) should ensure easy access to the PwP using crutches, a walker, wheelchair or lift. In addition, access to the caregiver should be ensured in the case of moderate-to-severe symptom levels in order to provide care for PwP;
- the size of the bathroom should ensure flexibility in terms of the provision of grab bars or other assistive aids;
- it is possible to envisage placing the washing machine/dryer inside the bathroom. The important thing is to ensure easy access to the PwP and its caregiver;
- the access door and window should be of the sliding type, equipped with handles that are easy to use by those with tremor, muscle rigidity and/or motor blocks. In an emergency, the door should also be opened from the outside;
- the dimensions of the door should be between 90 and 100 cm, so as to ensure passage by the PwP using crutches, a walker and/or wheelchair, or a lift.

(b) Sanitary ware:

- the bathroom should be equipped with the following sanitary ware: WC, bidet, walk-in shower and washbasin. It is possible to replace the bidet with a multifunctional WC (see references - tab 1) or with a bidet hand shower. Multifunctional toilets are a viable alternative solution to the bidet hand shower, because they allow those with limited upper limb skills to use them with little effort;
- the WC and bidet should be of the wall-hung type placed at least 50 cm from the floor level. The WC and bidet placed at a height of more than 50 cm enable easy sitting and standing up. Both WC and bidet must be placed at a minimum distance of 40 cm from the side wall, with the front edge varying from 50 to 75-80 cm from the rear wall. Space must be left on one side for a walker and wheelchair;
- the WC and bidet should provide the possibility of installing, even at a later date, supports to facilitate sitting and standing up;

continues on the other page >

Description: design consideration

Sheet **1**

Bathroom

From sheet 1.01 to 1.05

- the water drain must be easily accessible;
- the washbasin should be column-free, placed at a height of 80 cm from the floor level for easy access to the wheelchair user. A washbasin model with side supports for the forearms is recommended. The front edge should preferably be concave so that the trunk can be securely supported during washing operations;
- taps and mixers should be of the “lever” type or equipped with a photocell;
- the shower faucet should be equipped with an up-and-down bar and possibly have two faucets, one fixed at the top for washing the entire body, and one placed at the bottom for washing specific areas of the body;
- the shower must be on the floor, free of unevenness that could create a risk of tripping or falling. In addition, the shower should have the dimensions to ensure the installation of a folding seat, where this is not possible, space must be provided for the positioning of a wheelchair;
- the bathroom should have handrails installed at strategic points to ensure safety, usability and best use of the sanitary facilities;
- the bathroom floor, including the shower tray, must be made of non-slip material;
- appliances should be purchased with control buttons and door opening/closing systems at a height of between 40 cm and 140 cm (maximum reach zone for a wheelchair user). If this height is not guaranteed, place the appliances on a raised floor;
- the mirror must be reclining, placed above the washbasin in an area between 90 cm and 170 cm high;
- it is also useful to provide wheeled cabinets next to the washbasin that allow objects to be easily approached and, if necessary, free up space for the wheelchair. Very important, the cabinets must have wheel locking systems;
- any wall cabinets should be equipped with up-and-down shelves to enable the wheelchair user to reach higher levels as well. Avoid retractable solutions that may increase the risk of the PwP falling.

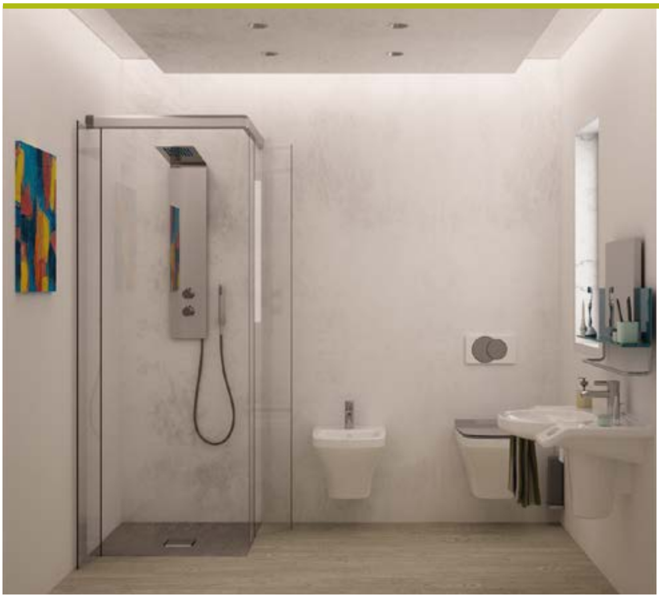
Description: design consideration

Sheet **1**

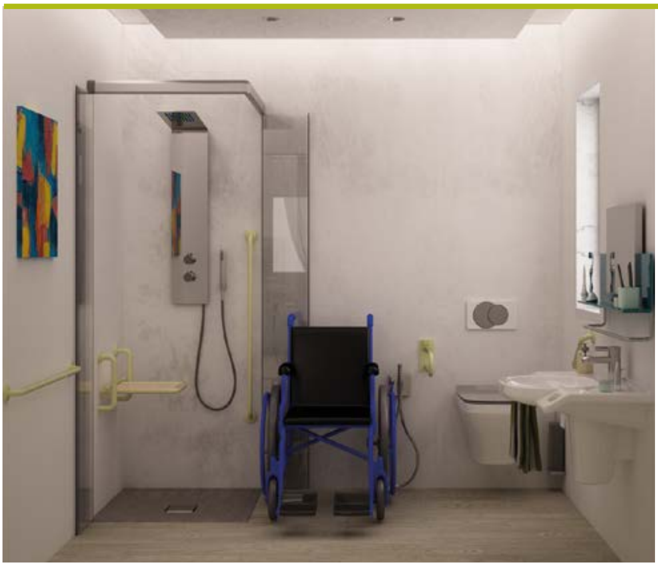
Bathroom

From sheet 1.01 to 1.05

MILD level of symptomatology



MODERATE-SEVERE level of symptomatology



Virtual environments

Sheet **1**

Bathroom

From sheet 1.01 to 1.05

MILD level of symptomatology

MODERATE-SEVERE level of symptomatology

Virtual environments

Sheet **1**

Bathroom

From sheet 1.01 to 1.05

MILD level of symptomatology

MODERATE-SEVERE level of symptomatology

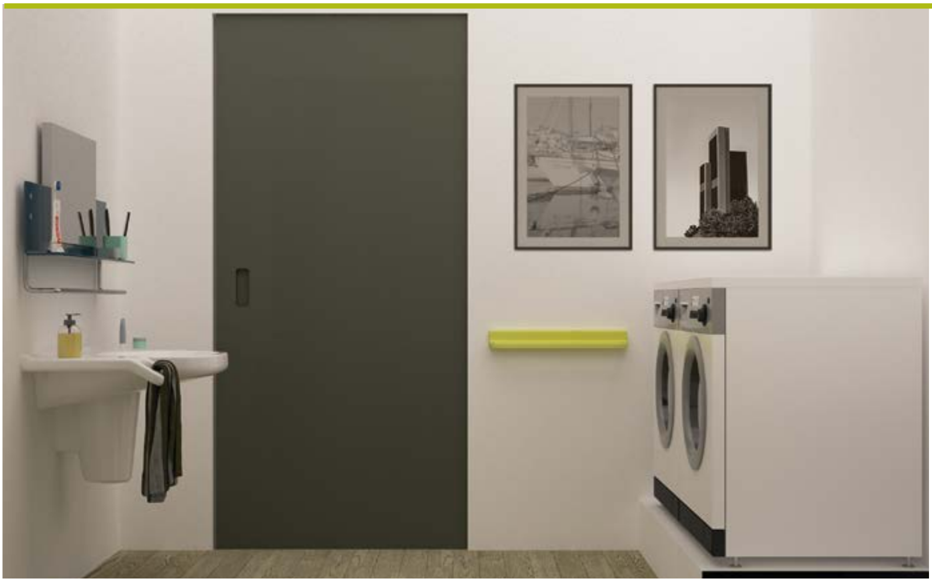
Virtual environments

Sheet **1**

Service bathroom and laundry room

From sheet 1.01 to 1.05

MILD level of symptomatology



MODERATE-SEVERE level of symptomatology

Virtual environments

Sheet **1**

Aquaclean multifunctional toilet (Geberit AG) (top), www.geberit.it/prodotti/per-il-bagno/-geberit-aquaclean/.
Toilet Lifter (Ropox) (bottom), https://ropox.com/products/toilet-lifter/.

Hi-Loo Fixed WC Holder (Etac AB), https://www.etac.com/products/bathroom-aids/toileting/etac-hi-loo-fixed/.

Bathroom

From sheet 1.01 to 1.05

Life Care Design washbasin (Pontegiulio spa) (top left), www.pontegiulio.com/it-IT/SK_XB43CMS02/Lavamani.
Flight washbasin (Goman s.r.l) (top right), www.goman.it/lavabo-universale-flight.php.
Swingline washbasin (Ropox) (bottom), www.ropox.com/products/swingline-washbasin/.

References: Washbasin

Sheet **1**

Bathroom

From sheet 1.01 to 1.05

Olona shower tray (Geberit AG) (top), www.geberit.it/prodotti/per-il-bagno/docce-a-filo-pavimento/.
Setaplano shower tray (Geberit AG) (bottom), www.geberit.it/prodotti/per-il-bagno/docce-a-filo-pavimento/.

References: Shower

Sheet **1**

Bathroom

From sheet 1.01 to 1.05

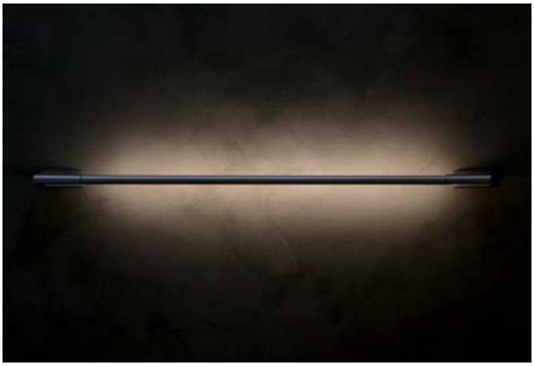
Bathroom accessories (Ponte Giulio) (top left), www.pontegiulio.com/it-IT/PK/prodotti.html.
Bathroom accessories (Goman s.r.l.) (top right), www.goman.it/bagni-per-disabili.php.
Bathroom accessories (Goman s.r.l.) (bottom), www.goman.it/bagni-per-disabili.php.

References: Accessories

Sheet **1**

Bathroom

From sheet 1.01 to 1.05




Shine handle (Ever Life Design by Thermomat Saniline s.r.l.) (left), https://www.everlifedesign.it/shine-barra-lumino- sa/.
Feel handle (Ever Life Design by Thermomat Saniline s.r.l.) (right), www.everlifedesign.it/porta-asciugamani-desi- gn-in-legno-feel/.


Tuck seat (Ever Life Design by Thermomat Saniline s.r.l.) (left), www.everlifedesign.it/tuck/.
Life Care Design seat (Pontegiulio spa) (right), www.pontegiulio.com/it-IT/PK/prodotti.html.

References: Accessories

Sheet **1**

Bathroom

From sheet 1.01 to 1.05

Reclining mirror (Goman s.r.l) (top), www.goman.it/specchi-bagno-disabili/specchio-classic-anti-batterico.
Rail/ceiling lifts (Chinesport spa) (bottom left), www.sollevati.it/tipologia/sollevatori/sollevatori-a-binario-soffitto/.
Kompass motorised lift (Moretti spa) (bottom right), www.morettispa.com/categoria-prodotto/mopedia/sollevamala- ti-e-verticalizzatori/.

References: Accessories

Sheet **1**

Bathroom

From sheet 1.01 to 1.05

Cosmopolitan electronic tap (Grohe) (top left), www.grohe.it/it_it/servizi/cataloghi-brochure.html.
Electronic tap One (Idral spa) (top right), www.idral.it/categorie-prodotto/rubinetteria/rubinetti-elettronici/.
Elbow control tap (Idral spa) (bottom), www.idral.it/cat/rubinetteria/rubinetti-leva-clinica/.

References: Accessories

Sheet **1**

Bathroom

From sheet 1.01 to 1.05

Long-handled sponges (Fanwer) (top), https://www.fanwer.com/collections/bathroom.
Long-handled brush and comb (Fanwer) (bottom left), https://www.fanwer.com/collections/bathroom.
Comb and brush with long handle (Officina Ortopedica Ferrero s.r.l) (bottom right), http://ferreromed.it/products/view/spazzole-e-pettini.

References: Accessories

Sheet **1**

Bathroom

From sheet 1.01 to 1.05

Inflatable washbasin (Fanwer) (top), https://www.fanwer.com/collections/bathroom.
Nail clippers (Officina Ortopedica Ferrero s.r.l) (bottom), http://ferreromed.it/products/-view/spazzole-e-pettini.

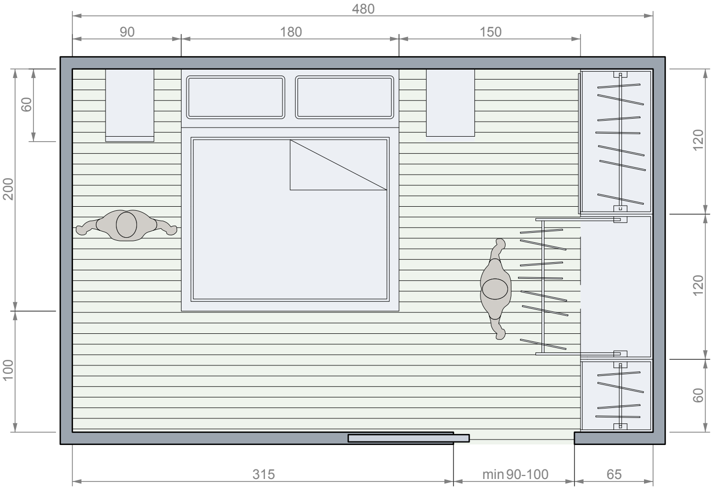
References: Accessories

Sheet **1**

Bedroom

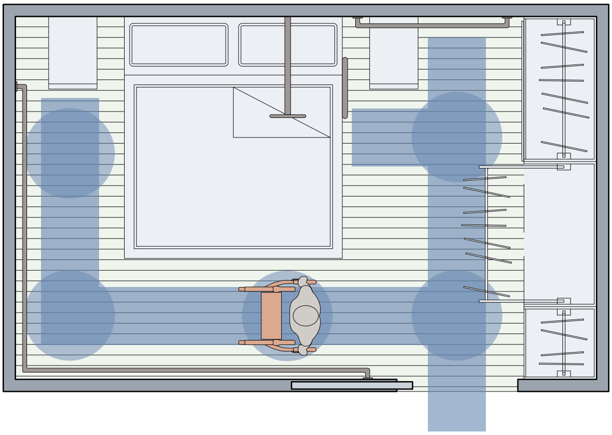
Dimension
4.80m X 3.00m = 14.40mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bedroom may be without any assistance aids. It is recommended, however, to keep the space between the bed and the wardrobe at least 150 cm on one side.

MODERATE level of symptomatology

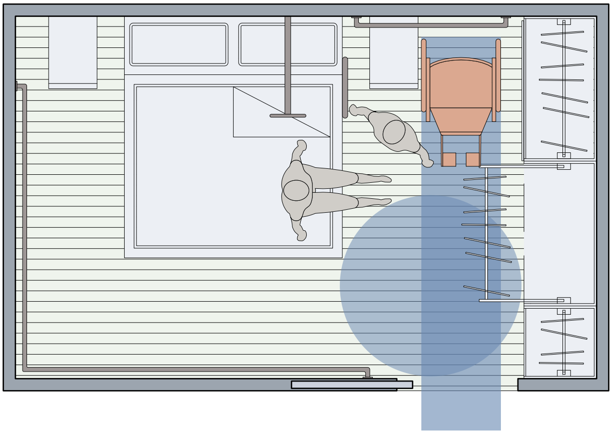


NOTE:
In the case of PD at the MODERATE stage, grab bars and assistive aids (side rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

Bedroom

Dimension
4.80m X 3.00m = 14.40mq

SEVERE level of symptomatology

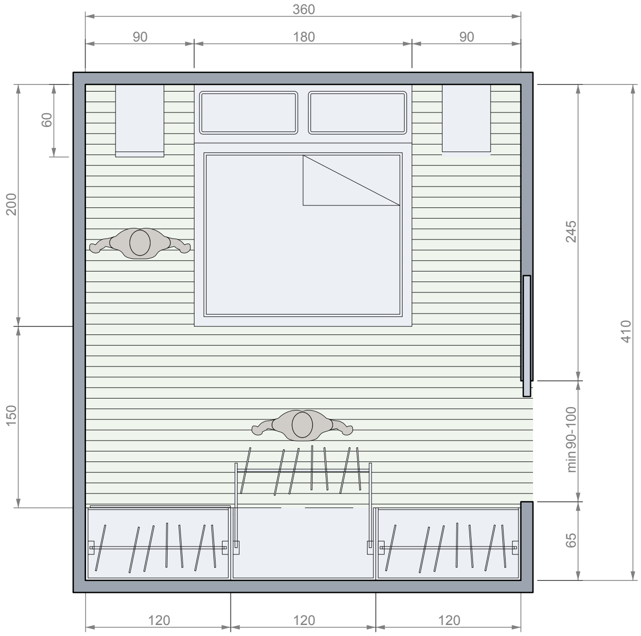


NOTE:
In the case of PD at the SEVERE stage, grab bars and assistive aids (rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

Bedroom

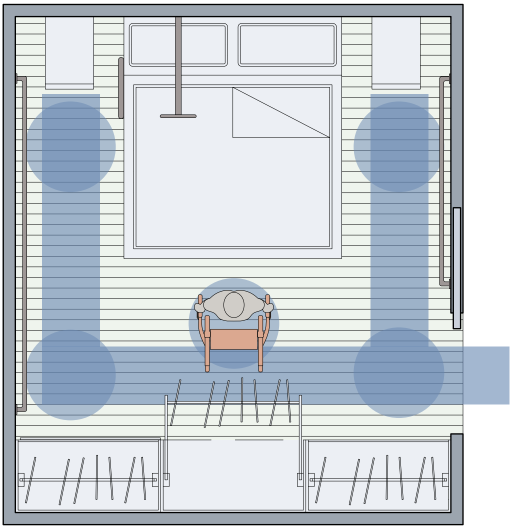
Dimension
3.60m X 4.10m = 14.76mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bedroom may be devoid of any assistive aids. It is recommended, however, to keep the space between the bed and the wardrobe at least 150 cm on one side.

MODERATE level of symptomatology



NOTE:
In the case of PD at the MODERATE stage, grab bars and assistive aids (side rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

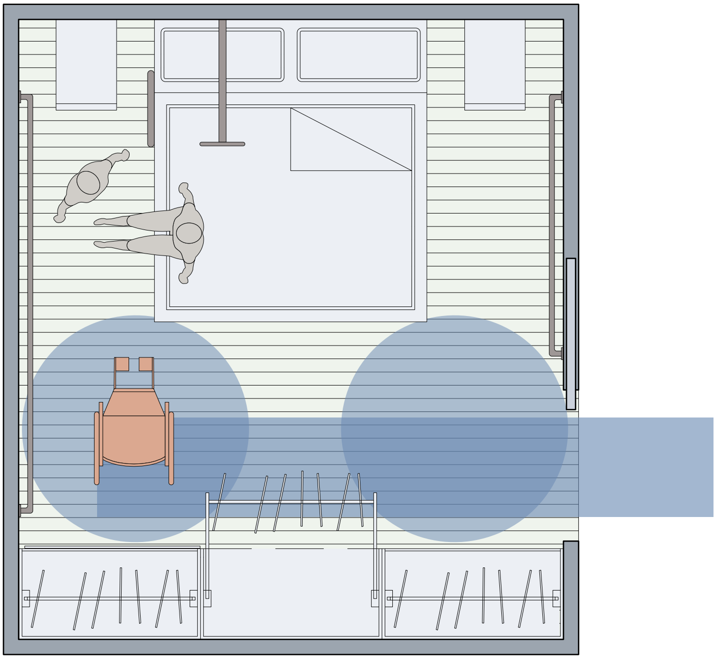
2D plans

Sheet **2.02**

Bedroom

Dimension
3.60m X 4.10m = 14.76mq

SEVERE level of symptomatology

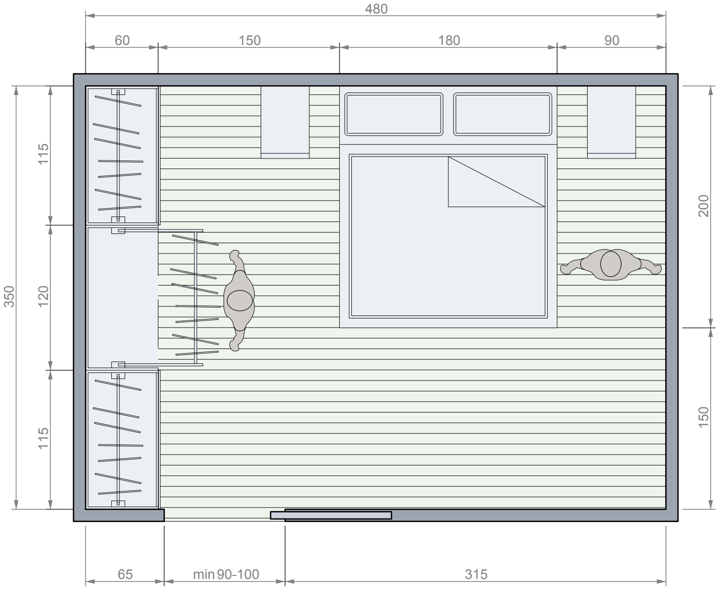


NOTE:
In the case of PD at the SEVERE stage, grab bars and assistive aids (rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

Bedroom

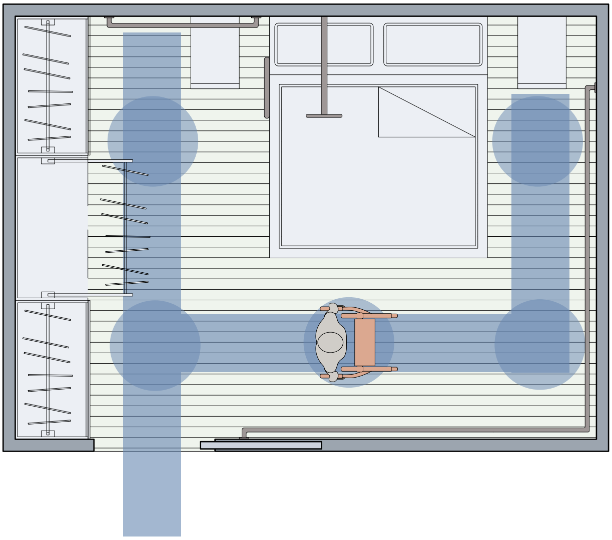
Dimension
4.80m X 3.50m = 16.80mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bedroom may be devoid of any assistive aids. It is recommended, however, to keep the space between the bed and the wardrobe at least 150 cm on one side.

MODERATE level of symptomatology



NOTE:
In the case of PD at the MODERATE stage, grab bars and assistive aids (side rails and handles) should be installed in the room.
The 150 cm space is now necessary to enable the caregiver to help the PwP.

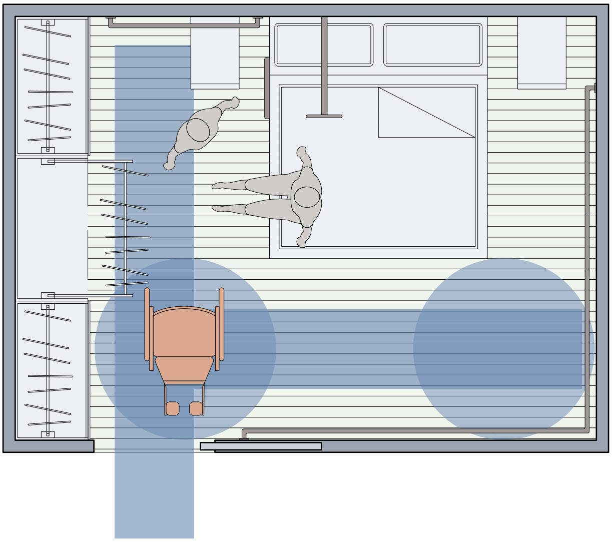
2D plans

Sheet 2.03

Bedroom

Dimension
4.80m X 3.50m = 16.80mq

SEVERE level of symptomatology

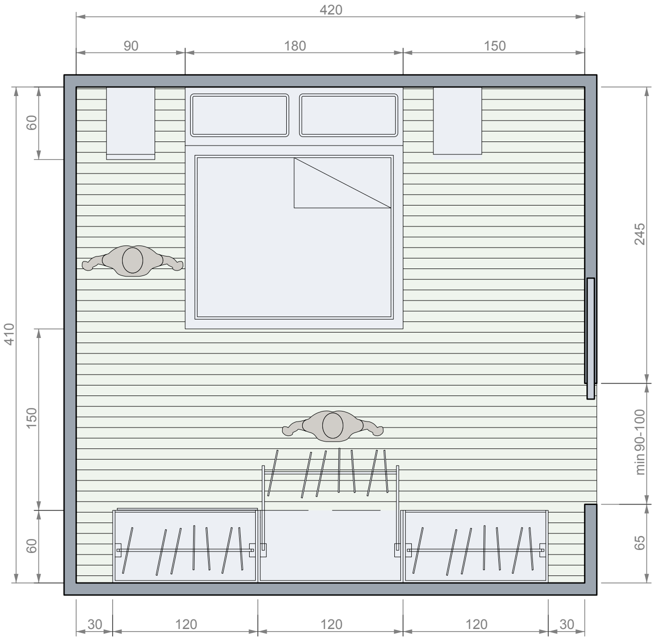


NOTE:
In the case of PD at the SEVERE stage, grab bars and assistive aids (rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

Bedroom

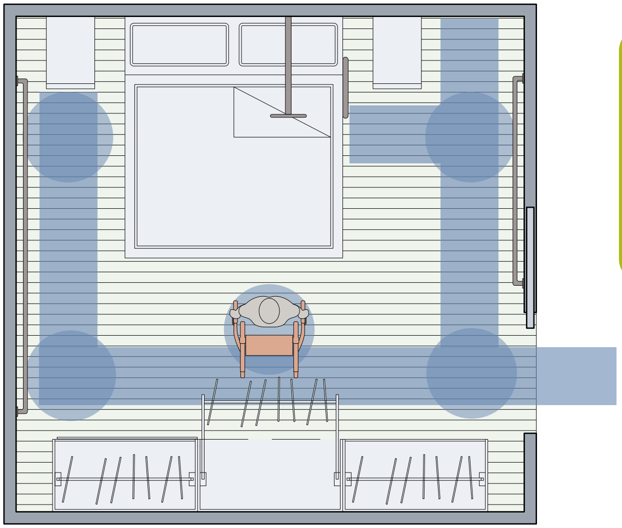
Dimension
4.20m X 4.10m = 17.22mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bedroom may be devoid of any assistive aids. It is recommended, however, to keep the space between the bed and the wardrobe at least 150 cm on one side.

MODERATE level of symptomatology



NOTE:
In the case of PD at the MODERATE stage, grab bars and assistive aids (side rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

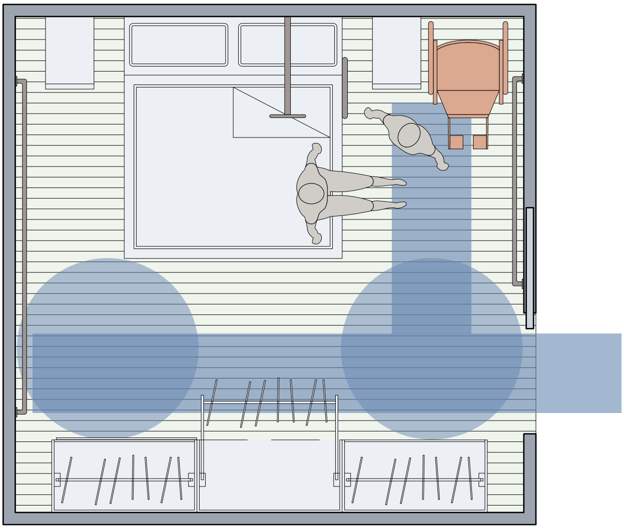
2D plans Sheet **2.04**

Bedroom

Dimension

4.20m X 4.10m = 17.22mq

SEVERE level of symptomatology

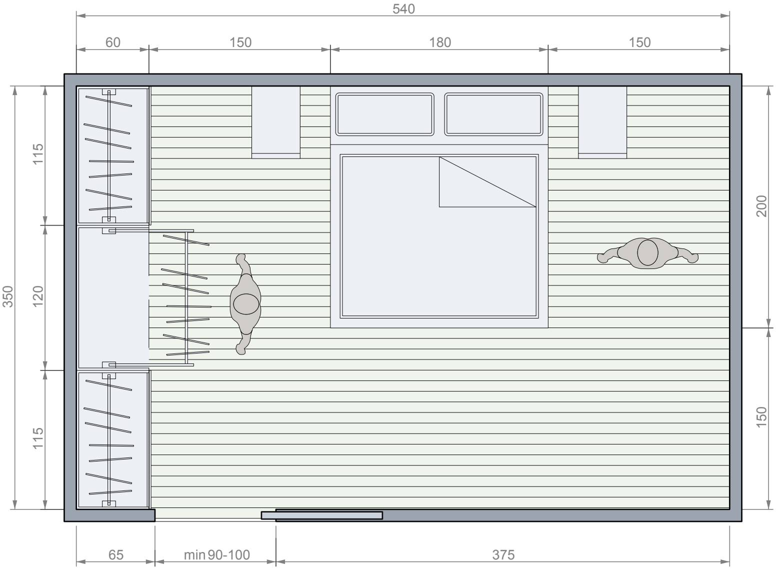


NOTA:
In the case of PD at the SEVERE stage, grab bars and assistive aids (rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

Bedroom

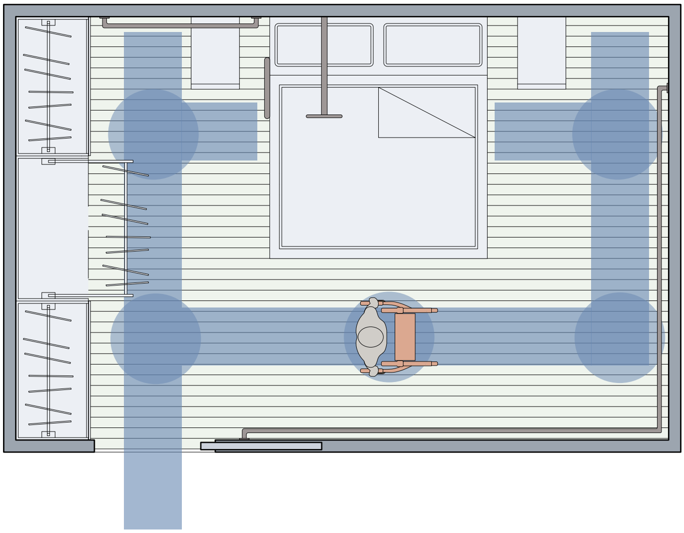
Dimension
5.40m X 3.50m = 18.90mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bedroom may be devoid of any assistive aids. It is recommended, however, to keep the space between the bedroom and the wardrobe at least 150 cm on one side.

MODERATE level of symptomatology

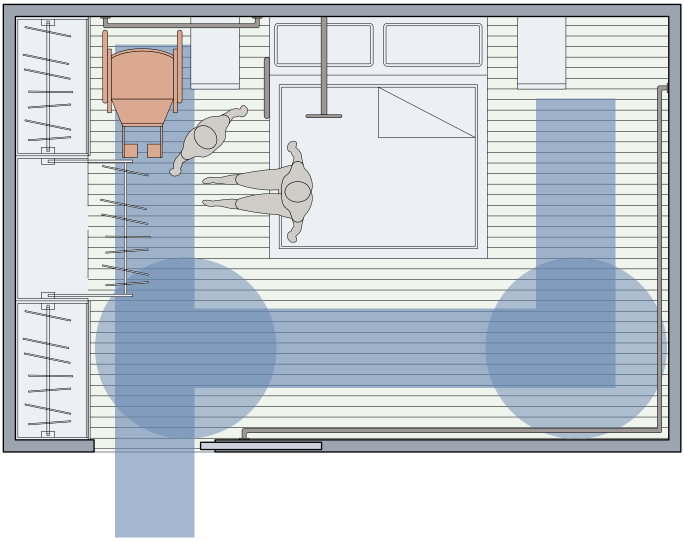


NOTE:
In the case of PD at the MODERATE stage, grab bars and assistive aids (side rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

Bedroom

Dimension
5.40m X 3.50m = 18.90mq

SEVERE level of symptomatology

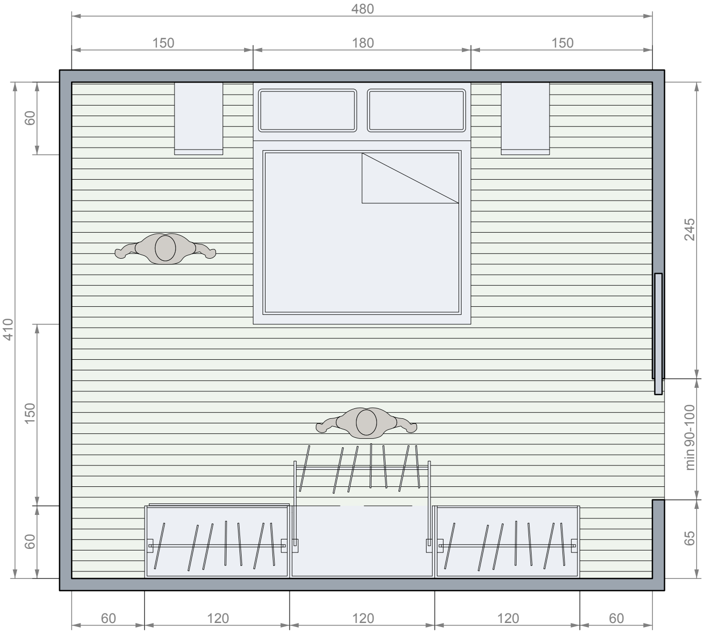


NOTE:
In the case of PD at the SEVERE stage, grab bars and assistive aids (rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

Bedroom

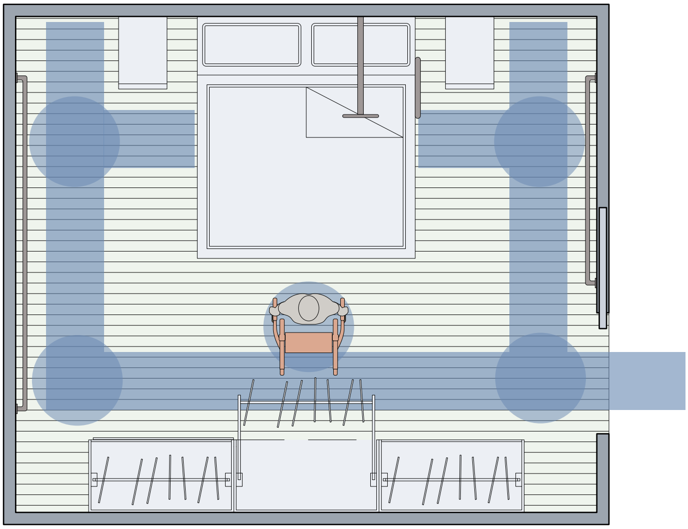
Dimension
4.10m X 4.80m = 19.68mq

MILD level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bedroom may be devoid of any assistive aids. It is recommended, however, to keep the space between the bed and the wardrobe at least 150 cm on one side.

MODERATE level of symptomatology



NOTE:
In the case of PD at the MILD stage, the bedroom may be devoid of any assistive aids. It is recommended, however, to keep the space between the bed and the wardrobe at least 150 cm on one side.

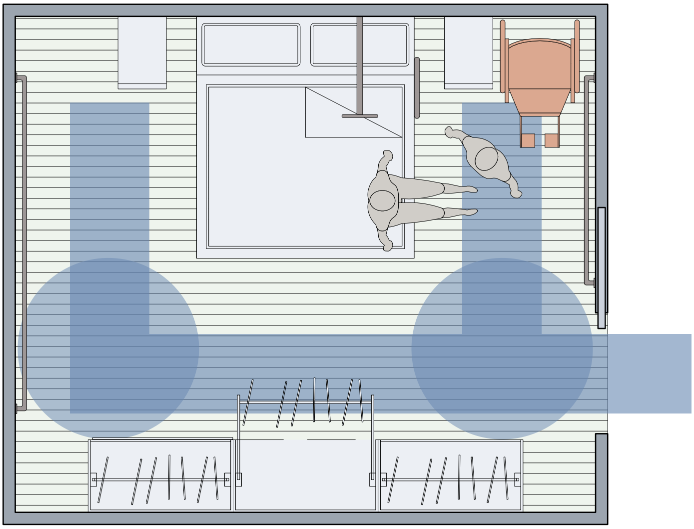
2D plans

Sheet **2.06**

Bedroom

Dimension
4.10m X 4.80m = 19.68mq

SEVERE level of symptomatology



NOTE:
In the case of PD at the SEVERE stage, grab bars and assistive aids (rails and handles) should be installed in the room. The 150 cm space is now necessary to enable the caregiver to help the PwP.

2D plans

Sheet **2.06**

Bedroom

From sheet 2.01 to 2.06

(a) Position and sizing:

- the study of the dimensions of the bedroom and the relative positioning of the furniture components is based on the principle of arranging the bed, wardrobe, chest of drawers and bedside tables in such a way as to guarantee the possibility of access and use of the space even by a person with reduced or impeded mobility, with the aim of guaranteeing: entry to the room, transfer to the bed, use of the other furniture elements, use of switches and controls, and finally, the possibility of manoeuvring the window;
- the dimensions of the bedroom (as listed in the previous sheets) should ensure easy access to the PwP using crutches, a walker, wheelchair or lift. In addition, access to the caregiver should be ensured in the case of moderate-to-severe symptom levels in order to provide care for PwP;
- the size of the bedroom should ensure flexibility over time in terms of providing grab bars or other assistive devices;
- more specifically, the bedroom for one person must be 9 square metres (minimum surface area) and for two people it must be 14 square metres (minimum surface area);
- the access door and window should be of the sliding type, equipped with handles that are easy to use by those with tremor, muscle rigidity and/or motor blocks. In an emergency, the door should also be opened from the outside;
- the dimensions of the door should be between 90 cm and 100 cm, so as to ensure passage by the PwP using crutches, walker and/or wheelchair, or lift.

(b) Equipment:

- the minimum spaces to be ensured between equipment and walls should be 90 cm. In the case of the use of crutches, walkers, wheelchairs and/or lifts, at least 150 cm of usable space should be ensured. For greater accessibility, also over time, it is recommended to maintain the space of 150 cm on at least three sides of the bed (sheets 2.05 and 2.06), sufficient for moving and manoeuvring;
- the bedroom should have handrails installed at strategic points to ensure safety, usability and access;

continues on the other page >

Description: design consideration

Sheet **2**

Bedroom

From sheet 2.01 to 2.06

- the bed frame (standard mattress size 160x200 - 180x200) should be made high enough to ensure easy sitting/standing for the PwP. In addition, the same structure should ensure, even subsequently, that there are rails and/or handles to facilitate getting out of bed, help in turning around, and protection. In addition, the bed frame should be at least 20 cm raised from the ground, in order to facilitate the insertion of the lift later on;
- it is recommended to purchase a bed (double or single) of the swivelling and electrically motorised type;
- the wardrobe should be equipped with up-and-down hangers so that even wheelchair users can reach the top levels of the wardrobe;
- in view of the symptoms of PwP and in order to limit falls caused by opening hinged doors, it is advisable to purchase cabinets with sliding doors equipped with handles/grips that can be easily used by those suffering from tremor, muscle rigidity and/or motor blocks;
- place at least one bedside cabinet next to the bed that can be used by the PwP to store breakfast foods to be taken before the daily therapeutic cycle. Bedside tables should also have a rotatable top and be easily placed next to the bed, possibly turning into a side table.

Description: design consideration

Sheet **2**

Bedroom

From sheet 2.01 to 2.06

MILD level of symptomatology

MODERATE-SEVERE level of symptomatology

Virtual environments

Sheet **2**

MILD level of symptomatology

MODERATE-SEVERE level of symptomatology

Bedroom

From sheet 2.01 to 2.06

MILD level of symptomatology

MODERATE-SEVERE level of symptomatology

Virtual environments

Sheet **2**

Bedroom

From sheet 2.01 to 2.06

MILD level of symptomatology

MODERATE-SEVERE level of symptomatology

Virtual environments

Sheet **2**

Bedroom

From sheet 2.01 to 2.06

Motorised folding bedstead (Trapuntificio C.A.T) (left), www.trapuntificiocat.it/negozio-materassi-trento/.
Folding and revolving mattress (Wimed divisione MOVI spa) (right), https://www.wimed.it/prodotti/letti/.
Universal and movable safety rails (Allmobility Trading) (bottom), www.allmobility.it/trasferimenti.html.

References: Mattress

Sheet **2**

Bedroom

From sheet 2.01 to 2.06

Bed lift (Moretti spa) (top), www.morettispa.com/prodotti/assistenza-alla-persona/.
Lift easy up 200 (Chinesport spa) (bottom), https://www.chinesport.it/catalogo/stabilizzatori-in-postura-eretta/easy-up/AV3121B3452G-standing-av3-sup-mob-fx-s-l-f-.

References: Mattress

Sheet **2**

Bedroom

From sheet 2.01 to 2.06

Bedside lift (Wimed divisione MOVI spa) (top), www.wimed.it/prodotti/letti/.
Bedside table (Wimed divisione MOVI spa) (bottom), www.wimed.it/prodotti/letti/.

References: Accessories

Sheet **2**

Bedroom

From sheet 2.01 to 2.06

Servetto® wardrobe (Servetto s.r.l) (top), www.servetto.it/it/prodotti/saliscendi.html.
Shine handle (Ever Life Design by Thermomat Saniline s.r.l.) (bottom left), https://www.everlifedesign.it/shine-barra-luminosa./.
Nylon handle (Thermomat Saniline s.r.l.) (bottom right), https://thermomat.com/prodotto/saniline-accessori-bagni-disabili/maniglioni-e-corrimano/serie-nylon/maniglione-lineare-mm-300-2/.

References: Accessories

Sheet **2**

Motorised lifts (Moretti spa) (top), www.morettispa.com/categoria-prodotto/mopedia/sollevamala- ti-e-verticalizzatori/.
Rail/ceiling lifts (Chinesport spa) (bottom), www.sollevati.it/tipologia/sollevatori/sollevatori-a-binario-soffitto/.

References: Accessories | Sheet **2**

Bedroom

From sheet 2.01 to 2.06

Clothing aids and supports (Fanwer) (top), www.fanwer.com/collections.
Button hook (Fanwer) (bottom), www.fanwer.com/collections.

References: Accessories

Sheet **2**

Bedroom

From sheet 2.01 to 2.06

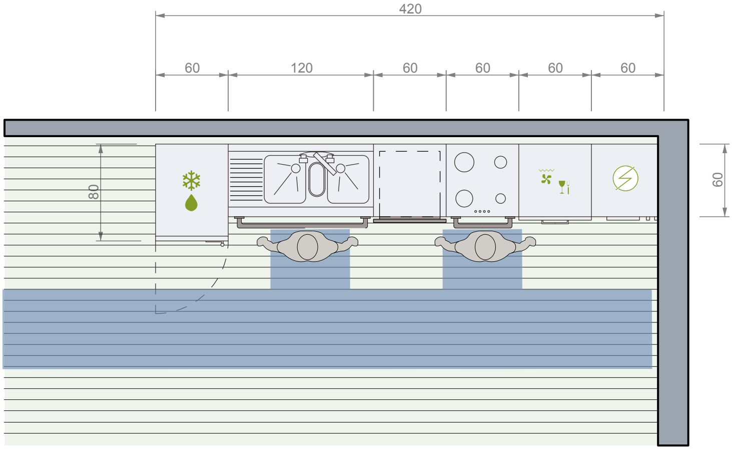
Shoehorn (Fanwer) (top), www.fanwer.com/collections.
Garments with buttons and Velcro fasteners (Lydda Wear) (bottom), www.lyddawear.com/component/virtuemart/results,1-52?keywordvelcro&option=com_virtuemart&view=category&limitstart=0&virtuemart_category_id=0).

References: Accessories | Sheet **2**

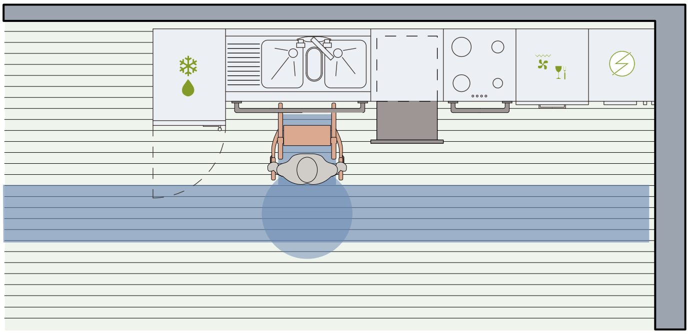
Linear kitchen

Dimension
4.20m X 0.60m

MILD level of symptomatology



MODERATE level of symptomatology



NOTE:
It is recommended to purchase a kitchen with handles/supports arranged along the perimeter of the kitchen.
In this linear kitchen solution, the oven is placed above the dishwasher, as well as the refrigerator and washing machine.

Fridge

Dishwasher

Washing machine
Tumble dryer

Oven

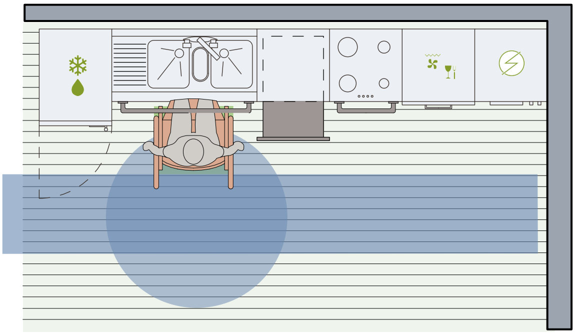
2D plans

Sheet **3.01**

Linear kitchen

Dimension
4.20m X 0.60m

SEVERE level of symptomatology



Fridge

Washing machine
Tumble dryer

Dishwasher

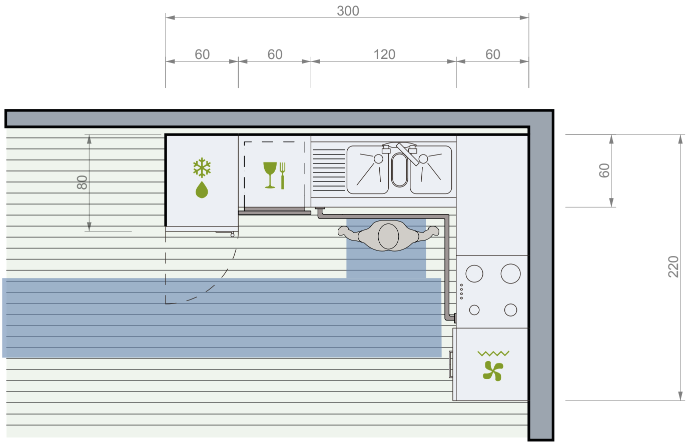
Oven

2D plans Sheet **3.01**

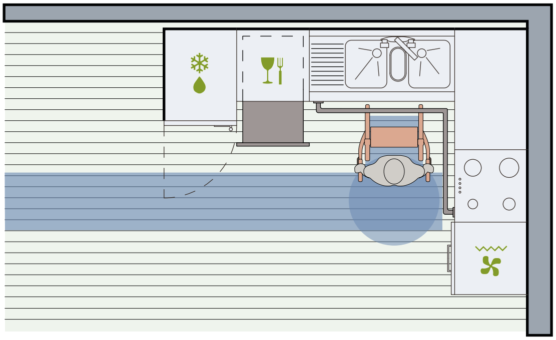
Angular kitchen (L-shaped kitchen)

Dimension
3.00m X 2.20m X 0.60m

MILD level of symptomatology



MODERATE level of symptomatology



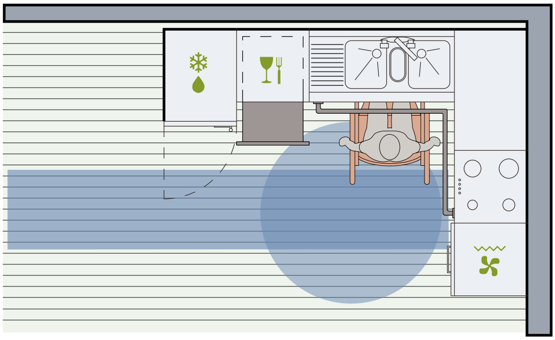
NOTE:
It is recommended to purchase a kitchen with handles/supports arranged along the perimeter of the kitchen.
In this L-shaped kitchen solution, the oven, dishwasher and refrigerator are arranged following the development of the kitchen.

❄ Fridge
Dishwasher
Washing machine
Tumble dryer
Oven

Angular kitchen (L-shaped kitchen)

Dimension
3.00m X 2.20m X 0.60m

SEVERE level of symptomatology



Fridge

Dishwasher

Washing machine

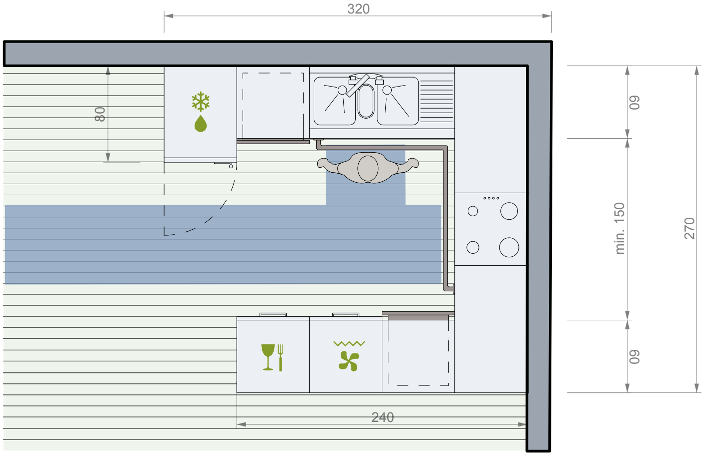
Tumble dryer

Oven

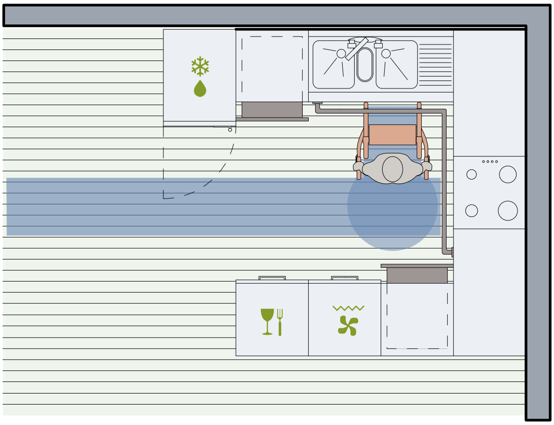
U-shaped kitchen

Dimension
3.00m X 2.70m X 2.20m

MILD level of symptomatology



MODERATE level of symptomatology



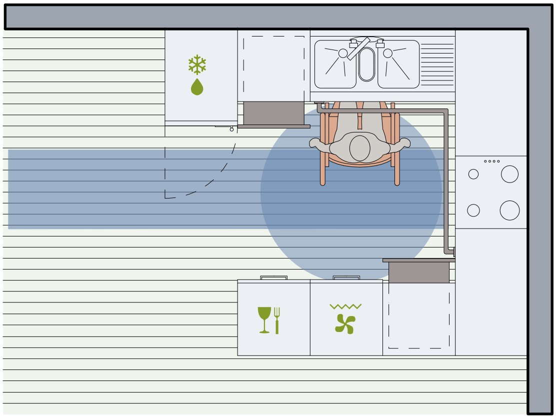
NOTE:
It is recommended to purchase a kitchen with handles/supports arranged along the perimeter of the kitchen.
In this U-shaped kitchen solution, the oven, dishwasher and refrigerator are arranged following the development of the kitchen.

Fridge
Washing machine
Tumble dryer
Dishwasher
Oven

U-shaped kitchen

Dimension
3.00m X 2.70m X 2.20m

SEVERE level of symptomatology



Fridge

Washing machine
Tumble dryer

Dishwasher

Oven

Kitchen

From sheet 3.01 to 3.03

(a) Position and sizing:

- organise the development and sizing of the kitchen in a rational and functional manner. The minimum size of the kitchen to accommodate the dimensional standards of furniture and equipment is 240 cm;
- the kitchen, appliances and related outlets should be placed on the same wall. Alternatively, they should be arranged on adjoining walls (L-shaped kitchen and U-shaped kitchen). The kitchen should have no edges, the edges should be bevelled;
- the ideal solution for a fully accessible kitchen is to design a suspended worktop, with a space below that can be accessed with a wheelchair, and include mobile drawers;
- crockery, small appliances, kitchen linen and foodstuffs should be within easy reach. It is therefore a good idea to place everything that is generally used more frequently in plain sight (in cupboards, on shelves). Arranging work surfaces in a coordinated manner also helps the PwP to minimise movement while carrying out household tasks.

(b) Equipment:

- the kitchen worktop should be placed at a height of 70-80 cm from the floor. Variable height solutions controlled by push buttons or similar systems are preferable;
- an empty space must be provided underneath the main appliances and the worktop to allow easy access also by a wheelchair user;
- wall cabinets should be equipped with up-and-down shelves to enable wheelchair users to reach the top levels. Avoid retractable solutions that may increase the risk of the PwP falling;
- wall cabinets and draining racks must be easy to reach, so the former must be placed at a suitable height, while the latter can be a countertop model;
- in view of the symptoms of PwP and to limit falls caused by opening hinged doors, it is advisable to purchase wall cabinets with sliding or hinged doors equipped with handles that are easy to use for those suffering from tremor, muscle rigidity and/or motor blocks;

continues on the other page >

Description: design consideration

Sheet **3**

Kitchen

From sheet 3.01 to 3.03

- in order to limit falls, the kitchen should have grab bars arranged along the worktop;
- purchase appliances with control buttons and door opening/closing systems at a height between 40 cm and 140 cm (maximum reachable area for a wheelchair user). If this height is not guaranteed, place the appliances on a raised floor. The oven and dishwasher should be positioned in such a way that they can be used while seated. Pillar installation is therefore recommended;
- for the hob, it is preferable to have a model with induction hobs and not gas hobs. Indeed, the induction hob allows pans to be moved by dragging them, rather than by lifting them. The ignition knobs must also be placed in the front position;
- the sink must be wide and shallow (no more than 15 cm) with a space underneath of at least 65 cm in height from the floor and 40 cm in depth. The tap should be of the “lever” type or equipped with a photocell;
- (possibly) consider home automation solutions capable of managing and controlling electronic equipment via a dedicated digital interface;
- it is also useful to have cabinets on wheels next to the washbasin that allow objects to be easily approached and, if necessary, free up space for a wheelchair. Very important, the cabinets must have wheel locking systems.

Description: design consideration

Sheet **3**

Kitchen

From sheet 3.01 to 3.03

VARIABLE level of symptomatology

VARIABLE level of symptomatology

Virtual environments

Sheet **3**

VARIABLE level of symptomatology

VARIABLE level of symptomatology

Kitchen

From sheet 3.01 to 3.03

VARIABLE level of symptomatology

VARIABLE level of symptomatology

Virtual environments

Sheet **3**

Kitchen

From sheet 3.01 to 3.03

Artematica kitchen (Valcucine spa), www.valcucine.com/collezioni/artematica/.

References: Kitchen models

Sheet **3**

Kitchen

From sheet 3.01 to 3.03

Vertiinside kitchen (Ropox), www.ropox.com/products/vertiinside/.

References: Kitchen models

Sheet **3**

Kitchen for disabled people (Viem snc), https://www.viemcucine.it/cucine-per-disabili.php.

References: Kitchen models

Kitchen

From sheet 3.01 to 3.03

Multifunctional Table (Ropox) (top), www.ropox.com/products/4single-complete/.
Tac Tee aids (Functionable s.r.l) (bottom), www.tactee.it.

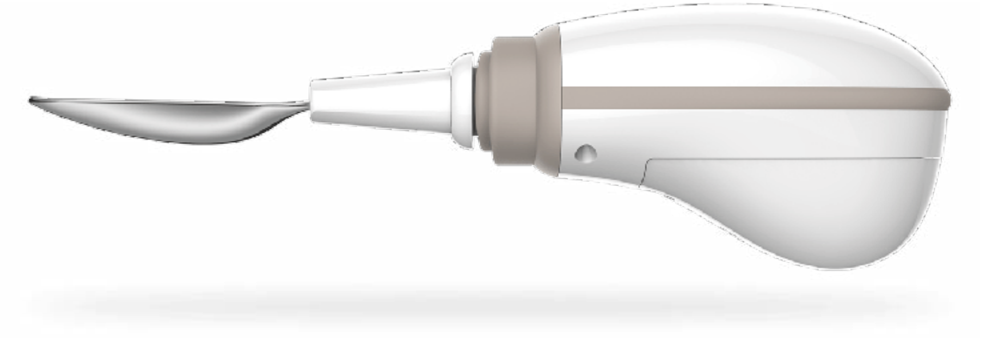
References: Accessories

Sheet **3**

Kitchen

From sheet 3.01 to 3.03

Cutlery, plates and glasses set (Eat Well), www.eatwellset.com/product-page /copy-of-8-piece-eatwell-assistive-tableware-set188.



Non-Spill cup (Officina Ortopedica Ferrero s.r.l) (top left), www.ferreromed.it/products/-view/bicchiere-non-spill.
Deluxe nosey cup (Officina Ortopedica Ferrero s.r.l) (top right), www.ferreromed.it/products/view/bicchiere-nosey-deluxe.
Gyenno anti-tremor spoon (Gyenno Technologies CO.) (bottom), https://www.gyenno.com/spoon-en Sistema di ausili magnetici per gli oggetti.

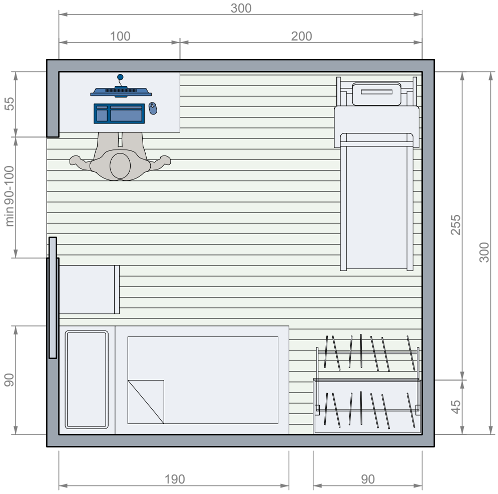
Stainless steel cut protection for fingers (Fanwer) (top), https://www.fanwer.com/collections/personal-care.
Ultra-light angled cutlery (Officina Ortopedica Ferrero s.r.l) (bottom), http://ferreromed.it/products/view/posate-ultraleggere-ergonomiche-in-foam.

References: Accessories Sheet **3**

Auxiliary space

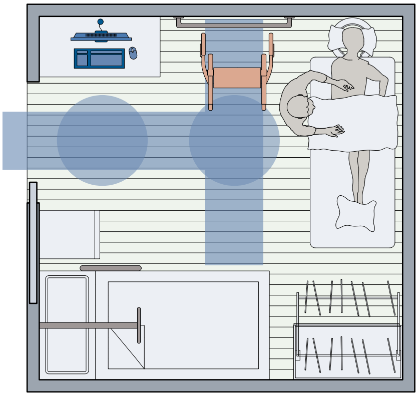
Dimension
3.00m X 3.00m = 9.00mq

MILD level of symptomatology



NOTE:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and physical activity. It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space. It is also advisable to provide space to allow for the passage and rotation of a walker, a wheelchair and access for a lift.

MODERATE level of symptomatology



NOTE:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and rehabilitation. It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space. It is also advisable to provide space to allow for the passage and rotation of a walker, a wheelchair and access for a lift.

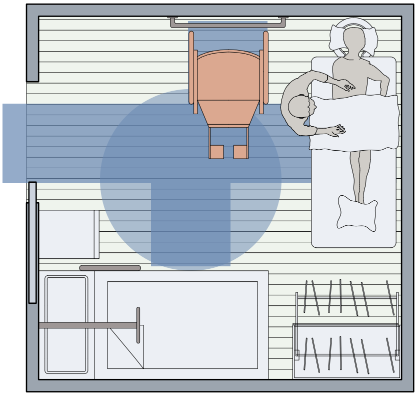
2D plans

Sheet **4.01**

Auxiliary space

Dimension
3.00m X 3.00m = 9.00mq

SEVERE level of symptomatology

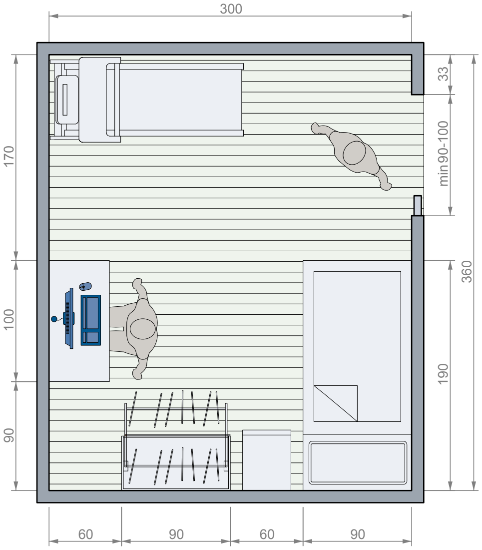


NOTE:
This space is designed for rehabilitation. It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space. It is also advisable to provide space to allow for the passage and rotation of a walker, a wheelchair and access for a lift.

Auxiliary space

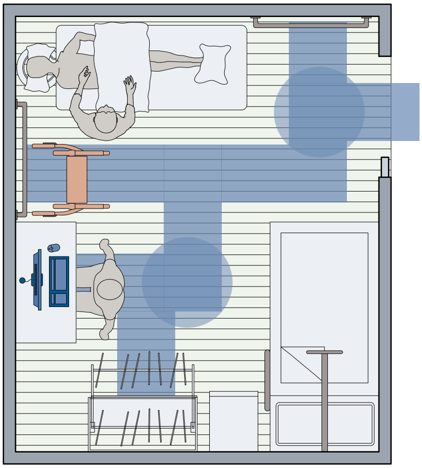
Dimension
3.00m X 3.60m = 10.80mq

MILD level of symptomatology



NOTE:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and physical activity. It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space. It is also advisable to provide space to allow for the passage and rotation of a walker, a wheelchair and access for a lift.

MODERATE level of symptomatology



NOTE:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and rehabilitation.
It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space. It is also advisable to provide space to allow for the passage and rotation of a walker, a wheelchair and access for a lift.
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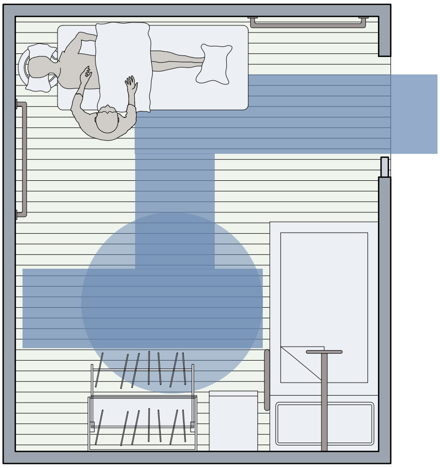
2D plans Sheet **4.02**

Auxiliary space

3.00m X 3.60m = 10.80mq

SEVERE level of symptomatology

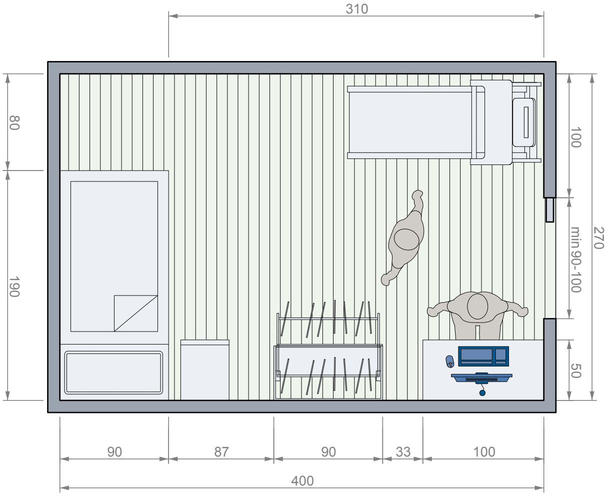


NOTE:
This space is designed for rehabilitation.
It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space. It is also advisable to provide space to allow for the passage and rotation of a walker, a wheelchair and access for a lift.

Auxiliary space

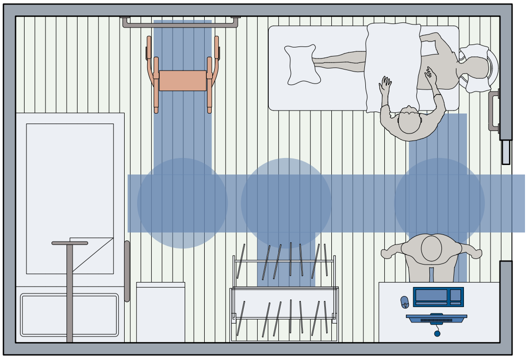
Dimension
2.70m X 4.10m = 11.07mq

MILD level of symptomatology



NOTE:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and physical activity. It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space.
It is also advisable to provide space for passage and rotation of a walker, a wheelchair and access for a lift.

MODERATE level of symptomatology

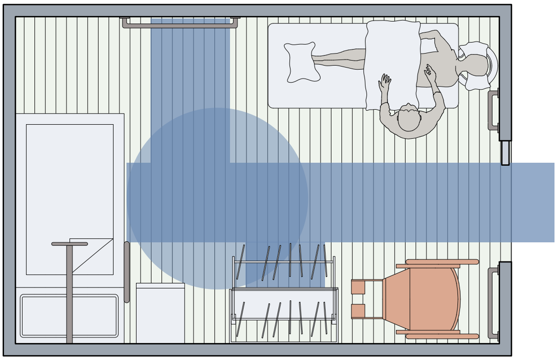


NOTE:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and rehabilitation.
It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space.
It is also advisable to provide space to allow for the passage and rotation of a walker, a wheelchair and access for a lift.

Auxiliary space

Dimension
2.70m X 4.10m = 11.07mq

SEVERE level of symptomatology

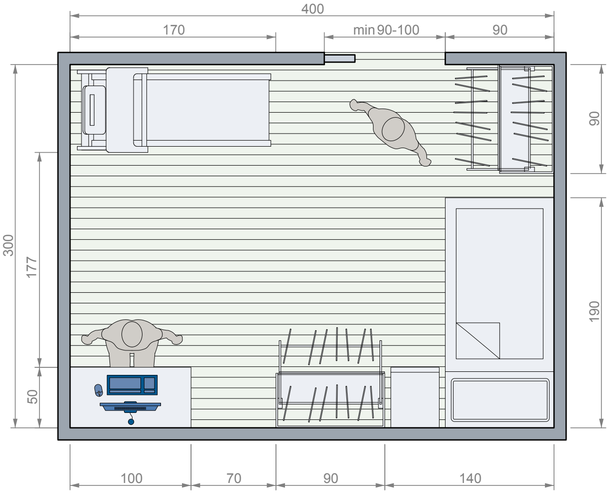


NOTE:
This space is designed for rehabilitation. It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space. It is also advisable to provide space for passage and rotation of a walker, a wheelchair and access for a lift.

Auxiliary space

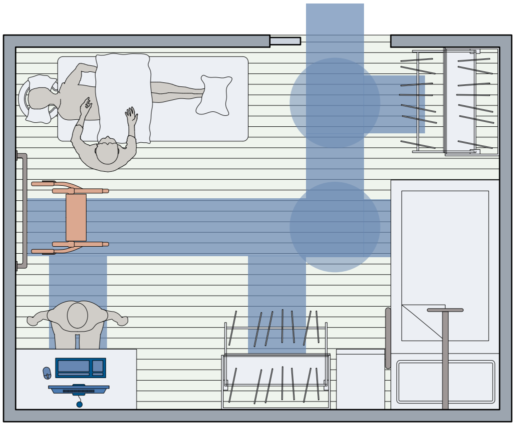
Dimension
4.00m X 3.00m = 12.00mq

MILD level of symptomatology



NOTE:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and physical activity. It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space.
It is also advisable to provide space for passage and rotation of a walker, a wheelchair and access for a lift.

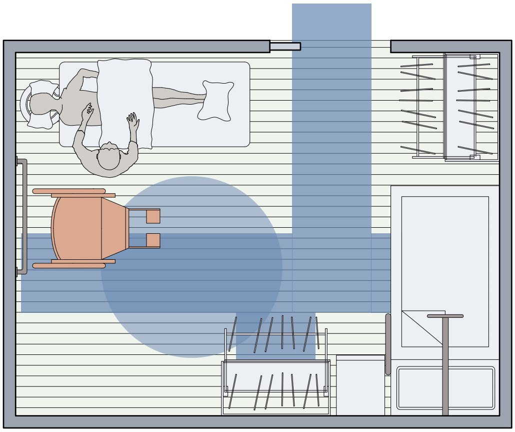
MODERATE level of symptomatology



NOTE:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and rehabilitation. It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space.
It is also advisable to provide space to allow for the passage and rotation of a walker, a wheelchair and access for a lift.

Dimension
4.00m X 3.00m = 12.00mq

SEVERE level of symptomatology



NOTE:
This space is designed for rehabilitation. It will however be at the discretion of the PwP to choose how to organise and use the auxiliary space. It is also advisable to provide space to allow for the passage and rotation of a walker, a wheelchair and access for a lift.

Auxiliary space

From sheet 4.01 to 4.04

As described in the notes, this space is designed to be used in a variety of ways, depending on the needs of the PwP and the family.

It can be used as a single room (able to accommodate a son/daughter or a formal caregiver. The minimum surface area refers to what is indicated in the current regulations, i.e. 9 square metres (minimum size) or to be able to carry out teleworking, physical activity and rehabilitation activities.

The previous sheets (sheet 4.01 to sheet 4.04 - 2D plan) show how the auxiliary space can be used. However, it will be at the discretion of the PwP to choose how to organise and use the auxiliary space.

(a) Position and sizing:

- the study of the dimensions of the bedroom and the positioning of the furniture components is based on the principle of arranging the equipment (e.g. bed, wardrobe, bedside tables, desk, physical activity/rehabilitation equipment) in such a way that it can be accessed and used by persons with reduced or impaired mobility, in order to ensure: entry to the room, transfer to the bed, use of the other furniture elements, use of switches and controls, and finally the possibility of operating the window;
- the dimensions of the assistive space (as listed in the previous sheets) should ensure easy access to the PwP using crutches, walker, wheelchair or lift. In addition, access to the caregiver should be ensured in the case of moderate-to-severe symptom levels in order to provide care for the PwP;
- the size of the assistive space should ensure flexibility over time in terms of the provision of grab bars or other assistive devices;
- the access door and window should be of the sliding type, equipped with handles that are easy to use by those with tremor, muscle rigidity and/or motor blocks. In an emergency, the door should also be opened from the outside;
- the dimensions of the door should be between 90 cm and 100 cm, so as to ensure passage by the PwP using crutches, a walker and/or wheelchair, or a lift;
- the minimum spaces to be ensured between equipment and walls should be 90 cm. In the case of the use of crutches, walkers, wheelchairs and/or lifts, at least 150 cm of usable space should be ensured to allow for the rotation of a wheelchair.

continues on the other page >

Auxiliary space

From sheet 4.01 to 4.04

(b) Equipments:

- the auxiliary space should have handrails installed at strategic points to ensure safety, usability and access;
- the bed frame (standard mattress size 80x200 - 90x200) should be made high enough to ensure easy seating/raising for the PwP. In addition, the same structure should also subsequently guarantee the provision of rails and/or handles to facilitate getting out of bed, help in turning around, and protection;
- it is recommended to purchase a bed (double or single) of the swivelling and electrically motorised type or similar systems;
- the standard size of a desk is 80x160, although many models varying in size and finish can be found on the market;
- as far as sports equipment is concerned, standard measurements are given below:
    - exercise bike 50x120 (folding type is recommended);
    - treadmill 70x155 (folding type is recommended);
    - elliptical 70x130 (folding type is recommended);
    - yoga mat 65x190 (folding type is recommended).

It will, however, be at the discretion of PwP to purchase the best equipment to carry out the physical activity. Space must therefore be left for both the PwP and the caregiver to enter the auxiliary space;

- with regard to rehabilitation, the standard dimensions of the couch are 75x180. Space must therefore be left for both the PwP and the physiotherapist (or other similar health professionals) to enter the auxiliary space;
- the wardrobe should be equipped with up-and-down hangers so that even wheelchair users can reach the top levels of the wardrobe;
- in view of the symptoms of PwP and in order to limit falls caused by opening hinged doors, it is advisable to purchase cabinets with sliding doors equipped with handles/grips that can be easily used by those suffering from tremor, muscle rigidity and/or motor blocks;
- place at least one bedside cabinet next to the bed that can be used by the PwP to store breakfast foods to be taken before daily medication. Bedside tables should also have a rotatable top that can easily be placed next to the bed, possibly turning into a side table.

Description: design consideration

Sheet **4**

Auxiliary space

From sheet 4.01 to 4.04

SMART WORKING

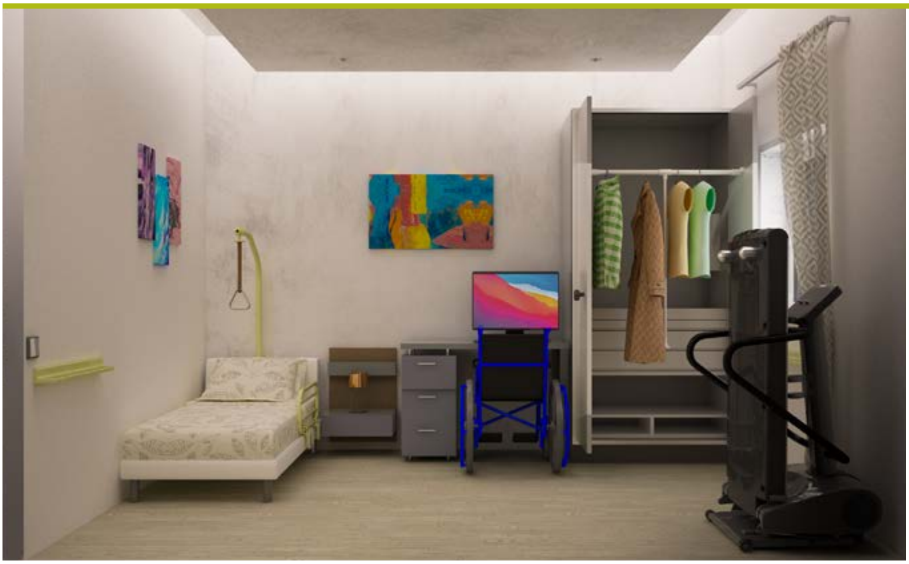
SMART WORKING and PHYSICAL ACTIVITY

Virtual environments

Sheet **4**

SMART WORKING

SMART WORKING and PHYSICAL ACTIVITY



Auxiliary space

From sheet 4.01 to 4.04

SMART WORKING and PHYSICAL ACTIVITY

PHYSICAL ACTIVITY

Virtual environments

Sheet **4**

Auxiliary space

From sheet 4.01 to 4.04

Motorised folding bedstead (Trapuntificio C.A.T) (left), www.trapuntificiocat.it/negozio-materassi-trento/.
Folding and revolving mattress (Wimed divisione MOVI spa) (right), https://www.wimed.it/prodotti/letti/.
Universal and movable safety rails (Allmobility Trading) (bottom), www.allmobility.it/trasferimenti.html.

References: Mattress

Sheet **4**

Bed lift (Moretti spa) (top), www.morettispa.com/prodotti/assistenza-alla-persona/.
Lift easy up 200 (Chinesport spa) (bottom), https://www.chinesport.it/catalogo/stabilizzatori-in-postura-eretta/easy-up/AV3121B3452G-standing-av3-sup-mob-fx-s-l-f-.

Auxiliary space

From sheet 4.01 to 4.04

Bedside lift (Wimed divisione MOVI spa) (top), www.wimed.it/prodotti/letti/.
Bedside table (Wimed divisione MOVI spa) (bottom), www.wimed.it/prodotti/letti/.

References: Accessories

Sheet **4**

Servetto® wardrobe (Servetto s.r.l) (top), www.servetto.it/it/prodotti/saliscendi.html.
Shine handle (Ever Life Design by Thermomat Saniline s.r.l.) (bottom left), https://www.e-verlifedesign.it/shine-barra-luminosa./.
Nylon handle (Thermomat Saniline s.r.l.) (bottom right), https://thermomat.com/prodotto/saniline-accessori-bagni-disabili/maniglioni-e-corrimano/serie-nylon/maniglione-lineare-mm-300-2/.

Auxiliary space

From sheet 4.01 to 4.04

Welly-M pedalboard (Chinesport spa) (top left), https://www.chinesport.it/catalogo/riabilitazione/pedalatori/XGA012-pedaliera-welly-m.
Welly-Combi pedalboard (Chinesport spa) (top right), https://www.chinesport.it/catalogo/riabilitazione/pedalatori/XGA015-pedaliera-welly-e-combi.
Nirvana immersive neuromotor rehabilitation system (BTS spa) (bottom), www.btsbioengineering.com/nirvana/it/.

References: Accessories

Sheet **4**

Auxiliary space

From sheet 4.01 to 4.04

Digital high-tech fitness rehab mirror D-Wall (Tecnobody) (top), https://www.tecnobody.com/it/prodotti/dettaglio/d-wall-elite&source=gmail-imap&ust=1644489344000000&usg=AOvVaw1rVDQVw85HgstA2esdGi2m.
Exercise mat (Chinesport spa) (bottom), https://www.chinesport.it/catalogo/ginnastica-medica/materassini-gommapiuma-colorati.

References: Accessories

Sheet **4**

Auxiliary space

From sheet 4.01 to 4.04

Tapis roulant (Chinesport spa) (top), https://www.chinesport.it/catalogo/camminatori/camminatori-reharunner-02/XRU049-camminatore-reharunner-02-51-pc/.
Cyclette (Chinesport spa) (bottom), https://www.chinesport.it/DB_files/repository/F/9/X-GA0021_1.jpg.

References: Accessories

Sheet **4**

Auxiliary space

From sheet 4.01 to 4.04

Teletyping aids, trackballs, joysticks and keyboards (Helpicare), www.helpicare.com/ausili-e-soluzioni/.

References: Accessories

Sheet **4**

Auxiliary space

From sheet 4.01 to 4.04

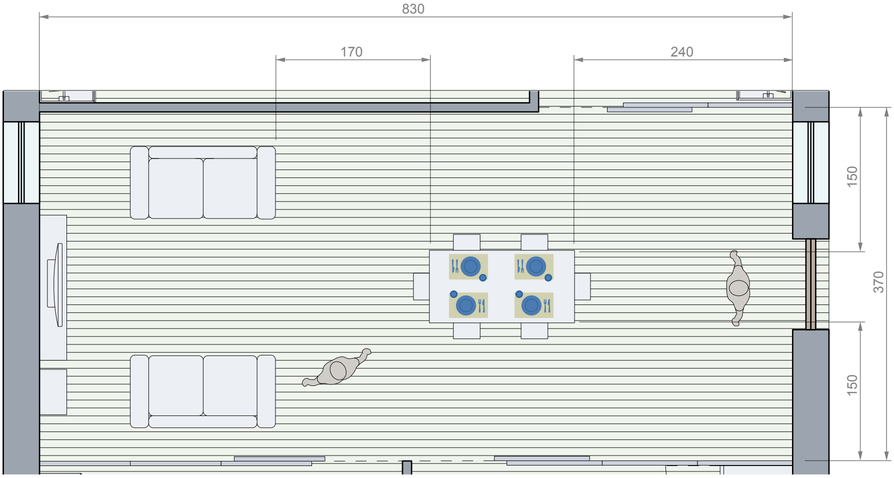
Manual or electric reclining table (Ropox) (top), www.ropox.com/product-category/vision-table-series/.
Writing aids (Officina Ortopedica Ferrero s.r.l) (bottom), www.ferreromed.it/products /cat/ausili-per-lautonomia/ausiliper-leggere-scrivere-e-disegnare/ausili-per-scrivere-e-disegnare.

References: Accessories | Sheet **4**

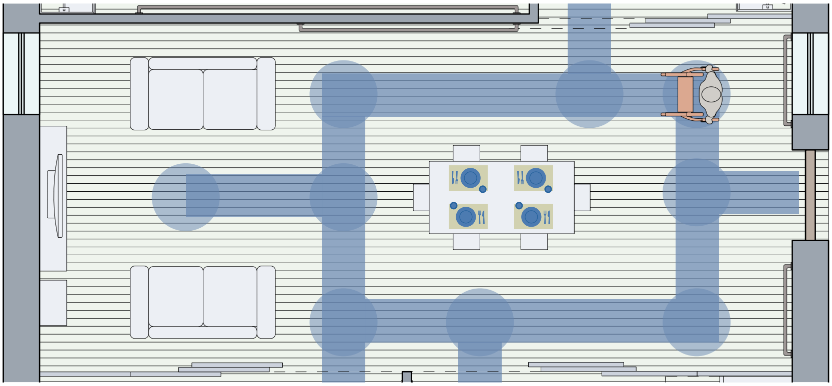
Living room

Dimension
approx. 31.00 mq.

MILD level of symptomatology



MODERATE level of symptomatology



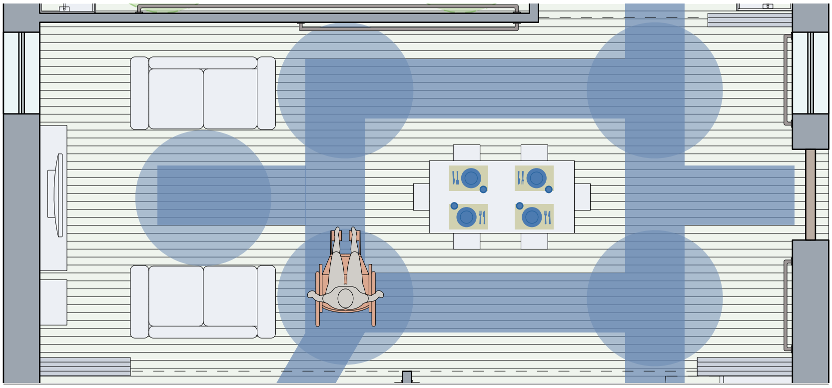
2D plans

Sheet **5.01**

Living room

Dimension
approx. 31.00 mq.

SEVERE level of symptomatology



NOTE:
The living room can be used as a dining area, a relaxation area and an area for teleworking/physical activity/rehabilitation.
MILD symptom level:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and physical activity.
MODERATE symptom level:
This space was designed to be able to carry out 2 activities at the same time, such as teleworking and rehabilitation.
SEVERE symptom level:
This space is designed for rehabilitation.
Whatever the level of PD symptomatology, it will still be at the discretion of the PwP to choose how to organise and use the auxiliary space.

Living room

Dimension
approx. 36.00 mq.

MILD level of symptomatology

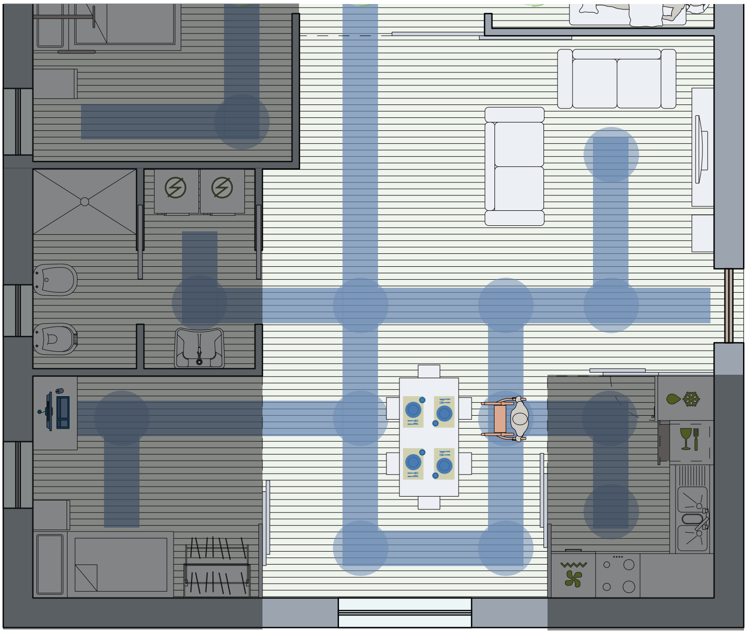
2D plans

Sheet **5.02**

Living room

Dimension
approx. 36.00 mq.

MODERATE level of symptomatology



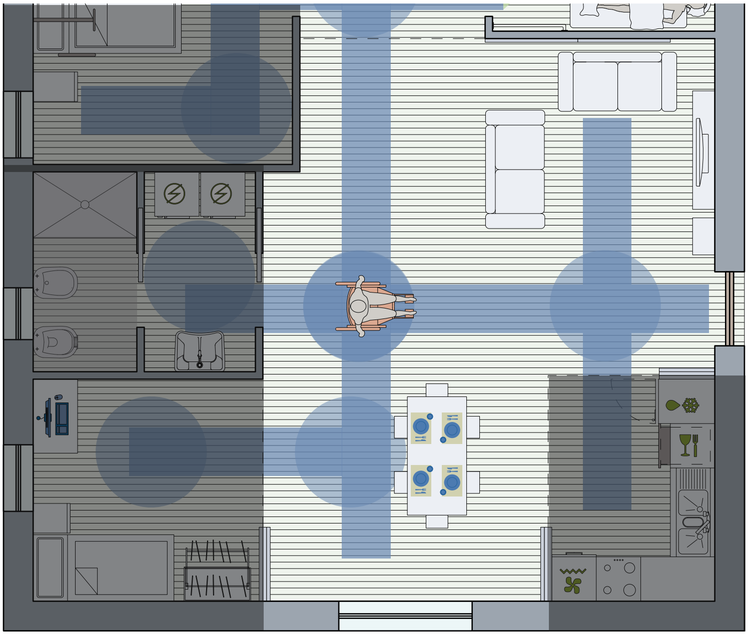
2D plans

Sheet **5.02**

Living room

Dimension
approx. 36.00 mq.

SEVERE level of symptomatology



NOTE:
The living room can be used as a dining area, a relaxation area and an area for teleworking/physical activity/rehabilitation.
MILD symptom level:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and physical activity.
MODERATE symptom level:
This space was designed to be able to carry out 2 activities at the same time, such as teleworking and rehabilitation.
SEVERE symptom level:
This space is designed for rehabilitation.
Whatever the level of PD symptomatology, it will still be at the discretion of the PwP to choose how to organise and use the auxiliary space.

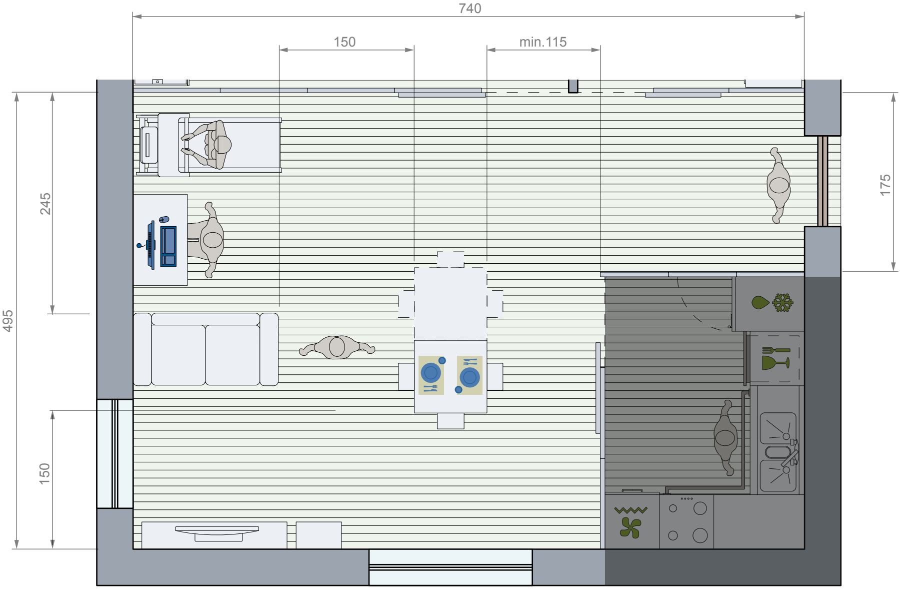
2D plans

Sheet **5.02**

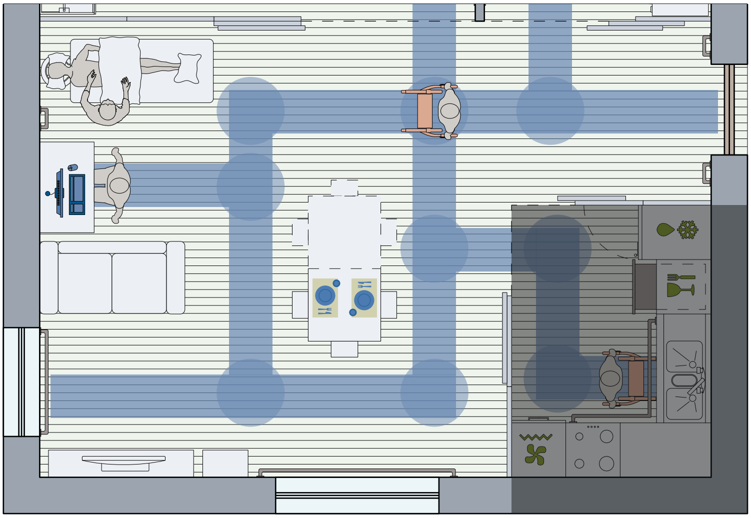
Living room

Dimension
approx. 37.00 mq.

MILD level of symptomatology



MODERATE level of symptomatology



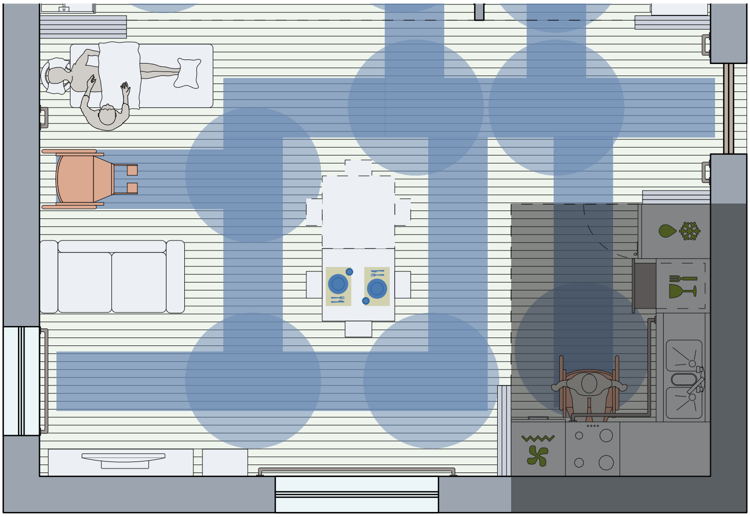
2D plans

Sheet 5.03

Living room

Dimension
approx. 37.00 mq.

SEVERE level of symptomatology



NOTE:
The living room can be used as a dining area, a relaxation area and an area for teleworking/physical activity/rehabilitation.
MILD symptom level:
This space is designed to be able to carry out 2 activities at the same time, such as teleworking and physical activity.
MODERATE symptom level:
This space was designed to be able to carry out 2 activities at the same time, such as teleworking and rehabilitation.
SEVERE symptom level:
This space is designed for rehabilitation.
Whatever the level of PD symptomatology, it will still be at the discretion of the PwP to choose how to organise and use the auxiliary space.

Living room

From sheet 5.01 to 5.03

The living room is the area of the home where collective and individual life activities take place, such as conversation, listening to music, TV, reading and resting.

In the case of separate spaces, the living room must enable access to the kitchen or cooking area, dining area, entrance, terrace or garden.

The previous sheets (Sheet 5.01 to Sheet 5.03 - 2D plan) show how the living room can be used. More specifically, two different uses have been assumed for the living room: in sheets 5.01 and 5.02 the living room can be used as a dining area and relaxation zone, while in sheet 5.03 the living room can be used as a dining area, relaxation zone and telework/physical activity/rehabilitation zone.

It will, however, be at the discretion of the PwP to choose how to organise and use this space.

(a) Position and sizing:

- organise the development and sizing of the living room in a rational and functional manner;
- ensure the necessary space of 150 cm between equipment and walls; the dimensions of the living room should ensure flexibility in

  terms of provision of grab bars or other assistive devices;
- access doors to the various spaces in the home, the entrance door and windows should be of a sliding type, equipped with handles that are easy to use by those with tremor, muscle rigidity and/or motor blocks. In an emergency, the door should also be opened from the outside;
- the dimensions of the doors should vary between 90 cm and 100 cm, so as to ensure passage from the PwP who uses crutches, a walker and/or wheelchair, or a lift.

(b) Equipments:

- the living room should have handrails installed at strategic points to ensure safety, usability, access and best use of the equipment;
- the minimum spaces to be ensured between equipment and walls should be 90/100 cm. In the case of the use of crutches, walkers, wheelchairs and/or lifts, at least 150 cm of usable space should be ensured;

continues on the other page >

Description: design consideration | Sheet **5**

- purchase a sofa or armchair of the electrically motorised type (or similar systems) to facilitate sitting and standing up for the PwP;
- as far as sports equipment is concerned, standard measurements are given below:
  - exercise bike 50x120 (folding type is recommended);
  - treadmill 70x155 (folding type is recommended);
  - elliptical 70x130 (folding type is recommended);
  - yoga mat 65x190 (folding type is recommended).

It will, however, be at PwP's discretion to purchase the best equipment to carry out the physical activity. Space must therefore be left for both the PwP and the caregiver to enter the auxiliary space.

- with regard to rehabilitation, the standard dimensions of the couch are 75x180. Space must therefore be left for both the PwP and the physiotherapist (or other similar health professionals) to enter the auxiliary space;
- with regard to teleworking, the standard size of a desk is 80x160 (many models varying in size and finish can be found on the market). Space for access under the work surface with a wheelchair and space for wheelchair rotation must be ensured;
- furniture (TV cabinet, cupboards, bookcases, etc.) should allow objects to be easily picked up even by a wheelchair user. The zone of maximum accessibility for a wheelchair user is between 40 cm and 140 cm high. Therefore, it is recommended that furniture be suspended from the ground to reduce possible falls/accidents caused by forward bending of the torso;
- in view of the symptoms of PwP and in order to limit falls caused by opening hinged doors, it is advisable to purchase furniture without doors or alternatively fitted with sliding or hinged doors including handles that can be easily used by those suffering from tremor, muscular rigidity and/or motor blockages. Avoid retractable solutions that may increase the risk of the PwP falling;
- to counteract freezing and reduce possible falls in the home, it is recommended to remove carpets and rugs in favour of a non-slip tiled floor.

VARIABLE level of symptomatology

VARIABLE level of symptomatology

Living room

From sheet 5.01 to 5.03

VARIABLE level of symptomatology

VARIABLE level of symptomatology

Virtual environments

Sheet **5**

Living room

From sheet 5.01 to 5.03

VARIABLE level of symptomatology

VARIABLE level of symptomatology

Virtual environments

Sheet **5**

Living room

From sheet 5.01 to 5.03

VARIABLE level of symptomatology

VARIABLE level of symptomatology

Virtual environments

Sheet **5**

SLIDING PANELS

SLIDING PANELS

Living room

From sheet 5.01 to 5.03

SLIDING PANELS

SLIDING PANELS

Virtual environments

Sheet **5**

Living room

From sheet 5.01 to 5.03

Armonic manoeuvrable wall (Anaunia) (top), https://www.anaunia.it/soluzioni/freespace_collection_armonic.
S 30 sliding wall (Estfeller) (bottom), https://www.estfeller-pareti.it/it/pareti-manovrabili/scorrevole-s30/?posLat=43&posLng=12.4&zoom=6.

References: Accessories

Sheet **5**

Living room

From sheet 5.01 to 5.03

July R elevating armchair (Chinesport spa) (top), https://www.chinesport.it/catalogo/poltrone-relax-per-anziani-e-disabili/poltrone-elevabili-2-motori/02089-july-r-con-ruote.
Vulcano upholstered sofa (Diotti) (bottom), www.diotti.com/it/divano-relax-alzapersona-vulcano.html.

References: Accessories

Sheet **5**

Living room

From sheet 5.01 to 5.03

Lift easy up 200 (Chinesport spa) (top), https://www.chinesport.it/catalogo/stabilizzatori-in-postura-eretta/easy-up/AV3121B3452G-standing-av3-sup-mob-fx-s-l-f-.
Shine handle (Ever Life Design by Thermomat Saniline s.r.l.) (bottom left), https://www.everlifedesign.it/shine-barra-luminosa./.
Nylon handle (Thermomat Saniline s.r.l.) (bottom right), https://thermomat.com/prodotto/saniline-accessori-bagni-disabili/maniglioni-e-corrimano/serie-nylon/maniglione-lineare-mm-300-2/.

References: Accessories

Sheet **5**

Living room

From sheet 5.01 to 5.03

Welly-M pedalboard (Chinesport spa) (top left), https://www.chinesport.it/catalogo/riabilitazione/pedalatori/XGA012-pedaliera-welly-m.
Welly-Combi pedalboard (Chinesport spa) (top right), https://www.chinesport.it/catalogo/riabilitazione/pedalatori/XGA015-pedaliera-welly-e-combi.
Nirvana immersive neuromotor rehabilitation system (BTS spa) (bottom), www.btsbioengineering.com/nirvana/it/.

References: Accessories

Sheet **5**

Living room

From sheet 5.01 to 5.03

Digital high-tech fitness rehab mirror D-Wall (Tecnobody) (top), https://www.tecnobody.com/it/prodotti/dettaglio/d-wall-elite&source=gmail-imap&ust=1644489344000000&usg=AOvVaw1rVDQVw85HgstA2esdGi2m.
Exercise mat (Chinesport spa) (bottom), https://www.chinesport.it/catalogo/ginnastica-medica/materassini-gommapiuma-colorati.

References: Accessories

Sheet **5**

Living room

From sheet 5.01 to 5.03

Tapis roulant (Chinesport spa) (top), https://www.chinesport.it/catalogo/camminatori/camminatori-reharunner-02/XRU049-camminatore-reharunner-02-51-pc/.
Cyclette (Chinesport spa) (bottom), https://www.chinesport.it/DB_files/repository/F/9/X-GA0021_1.jpg.

References: Accessories

Sheet **5**

Living room

From sheet 5.01 to 5.03

Multifunctional table (Ropox) (top), www.ropox.com/products/4single-complete/.
Manual or electric reclining table (Ropox) (bottom), www.ropox.com/product-category/vision-table-series/.

References: Accessories

Sheet **5**

Writing aids (Officina Ortopedica Ferrero s.r.l) (top), www.ferreromed.it/products/cat/ausili-per-lautonomia/ausiliper-leggere-scrivere-e-disegnare/ausili-per-scrivere-e-disegnare.
Tac Tee aids (Functionable s.r.l) (bottom), www.tactee.it.

Living room

From sheet 5.01 to 5.03

Teletyping aids, trackballs, joysticks and keyboards (Helpicare), www.helpicare.com/ausili-e-soluzioni/.

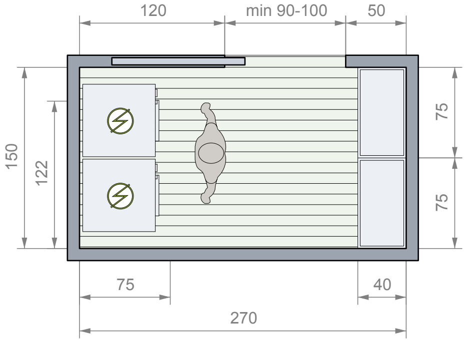
References: Accessories

Sheet **5**

Utility room and laundry room

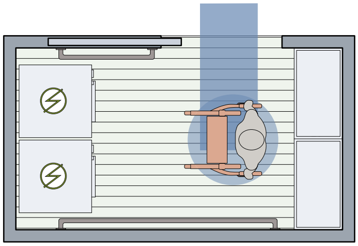
Dimension
2.70m X 1.50m = 4.05mq

MILD level of symptomatology



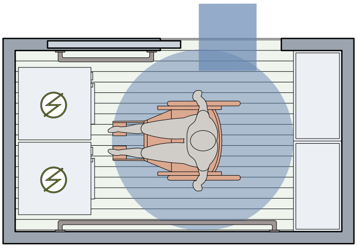
Washing machine/Tumble dryer

MODERATE level of symptomatology



NOTE:
In the “MODERATE symptom level” solution, access to the utility room/laundry room is granted to the PwP using the walker.

SEVERE level of symptomatology

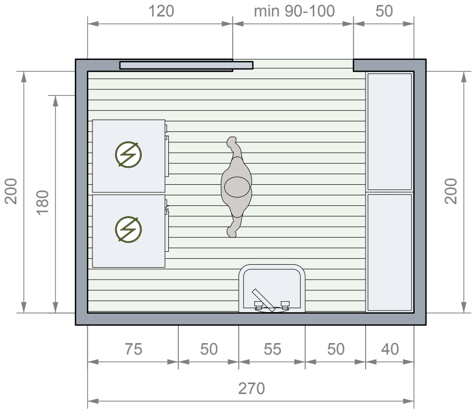


NOTE:
In the “SEVERE symptom level” solution, access to the utility room/laundry room is granted to the PwP who uses a wheelchair.

Utility room and laundry room

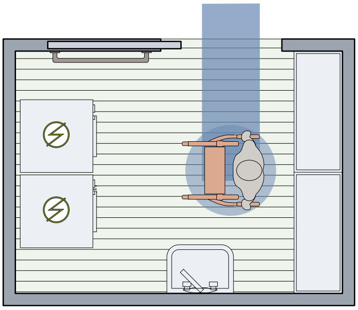
Dimension
2.70m X 2.10m = 5.67mq

MILD level of symptomatology



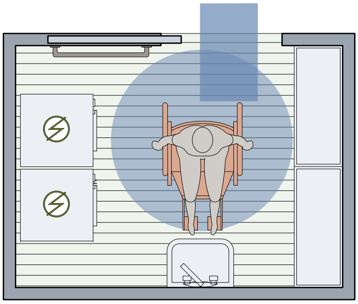
⚡ Washing machine/Tumble dryer

MODERATE level of symptomatology



NOTE:
In the “MODERATE symptom level” solution, access to the utility room/laundry room is granted to the PwP using the walker.

SEVERE level of symptomatology

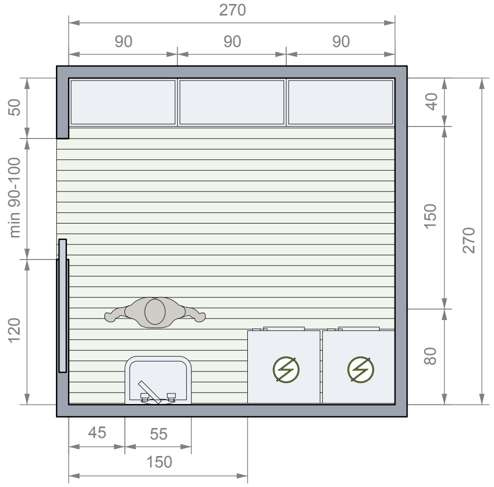


NOTE:
In the “SEVERE symptom level” solution, access to the utility room/laundry room is granted to the PwP who uses a wheelchair.

Utility room and laundry room

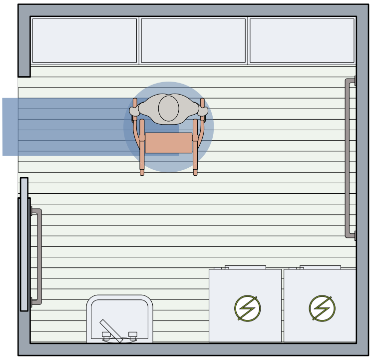
Dimension
2.70m X 2.70m = 7.29mq

MILD level of symptomatology



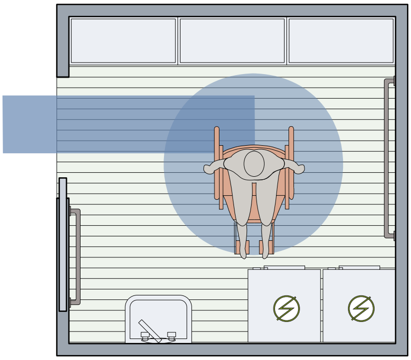
⚡ Washing machine/Tumble dryer

MODERATE level of symptomatology



NOTE:
In the “MODERATE symptom level” solution, access to the utility room/laundry room is granted to the PwP using the walker.

SEVERE level of symptomatology



NOTE:
In the “SEVERE symptom level” solution, access to the utility room/laundry room is granted to the PwP who uses a wheelchair.

Utility room and laundry room

From sheet 6.01 to 6.03

(a) Position and sizing:

- organise the development and sizing of the utility room/laundry room in a rational and functional manner;

- the ideal solution for an accessible utility room/laundry room is to have everything within reach, while providing the necessary space for wheelchair accessibility;

- appliances, household linen, foodstuffs and miscellaneous items should be within easy reach. It is, therefore, a good idea to place everything that is generally used more frequently in a prominent position. Arranging work surfaces in a coordinated manner also helps PwP to minimise movement while carrying out household tasks;

- the access door and window (if any) should be of a sliding type, equipped with handles that are easy to use for those with tremor, muscle rigidity and/or motor blockages;

- the dimensions of the door should be between 90 and 100 cm, so as to ensure passage by the PwP using crutches, a walker and/or wheelchair, or a lift.

(b) Equipments:

- purchase appliances with control buttons and door opening/closing systems at a height between 40 cm and 140 cm (maximum reachable area for a wheelchair user). If this height is not guaranteed, place the appliances on a raised floor;

- any wall cabinets should be equipped with up-and-down shelves to enable the wheelchair user to reach higher levels as well. Avoid removable solutions that may increase the risk of PwP falling;

- in view of the symptoms of PwP and to limit falls caused by opening hinged doors, it is advisable to purchase wall cabinets with sliding or hinged doors equipped with handles that are easy to use for those suffering from tremor, muscle rigidity and/or motor blocks;

- in order to limit falls, the utility room/laundry room should have handrails arranged along the walls;

- (possibly) consider home automation solutions capable of managing and controlling electronic equipment via a dedicated digital interface.

Description: design consideration

Sheet **6**

Utility room and laundry room

From sheet 6.01 to 6.03

VARIABLE level of symptomatology

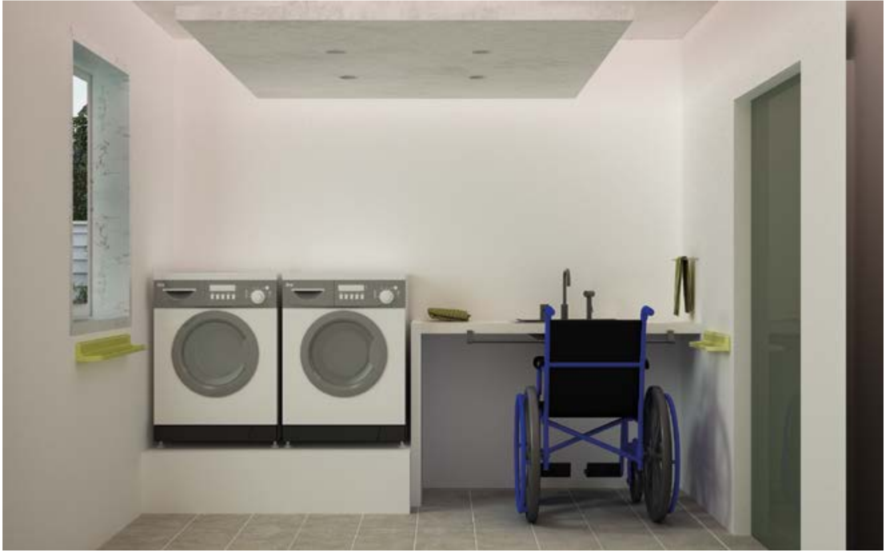
VARIABLE level of symptomatology

Virtual environments

Sheet **6**

VARIABLE level of symptomatology

VARIABLE level of symptomatology



Utility room and laundry room

From sheet 6.01 to 6.03

VARIABLE level of symptomatology

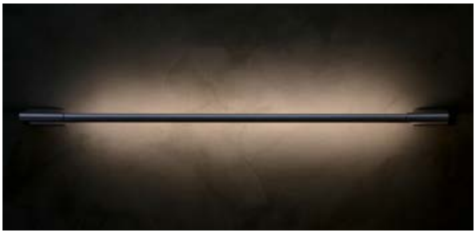
VARIABLE level of symptomatology

Virtual environments

Sheet **6**

Utility room and laundry room

From sheet 6.01 to 6.03



Laundry cabinet Birex (BIREX) (top), www.birex.it/lavanderie/.
Shine handle (Ever Life Design by Thermomat Saniline s.r.l.) (bottom left), https://www.everlifedesign.it/shine-barra-lumino- sa/.
Nylon handle (Thermomat Saniline s.r.l.) (bottom right), https://thermomat.com/prodotto/saniline-accessori-bagni-disabili/maniglioni-e-corrimano/serie-nylon/maniglione-lineare-mm-300-2/.

References: Accessories

Sheet **6**

Utility room and laundry room

From sheet 6.01 to 6.03

Cosmopolitan electronic tap (Grohe) (top left), www.grohe.it/it_it/servizi/cataloghi-brochure.html.
Electronic tap One (Idral spa) (top right), www.idral.it/categorie-prodotto/rubinetteria/rubinetti-elettronici/.
Elbow control tap (Idral spa) (bottom), www.idral.it/cat/rubinetteria/rubinetti-leva-clinica/.

References: Accessories

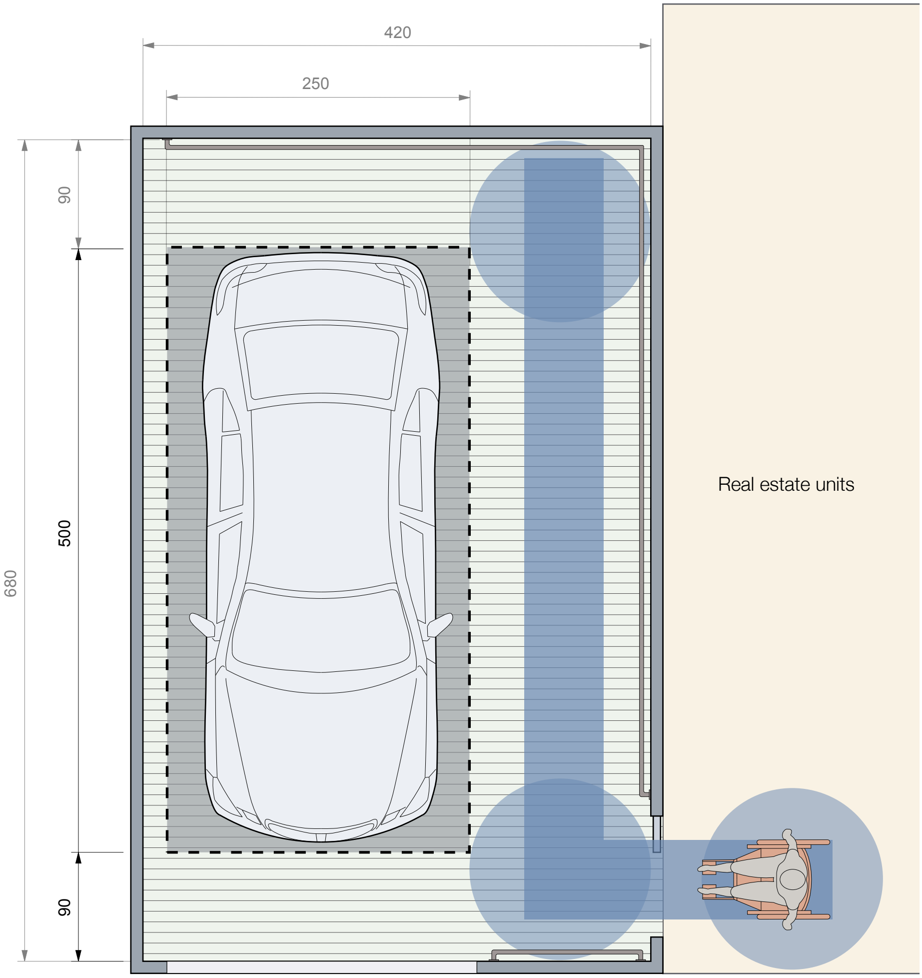
Sheet **6**

Garage

Dimension

6.80m X 4.20m = 28.56mq

VARIABLE level of symptomatology



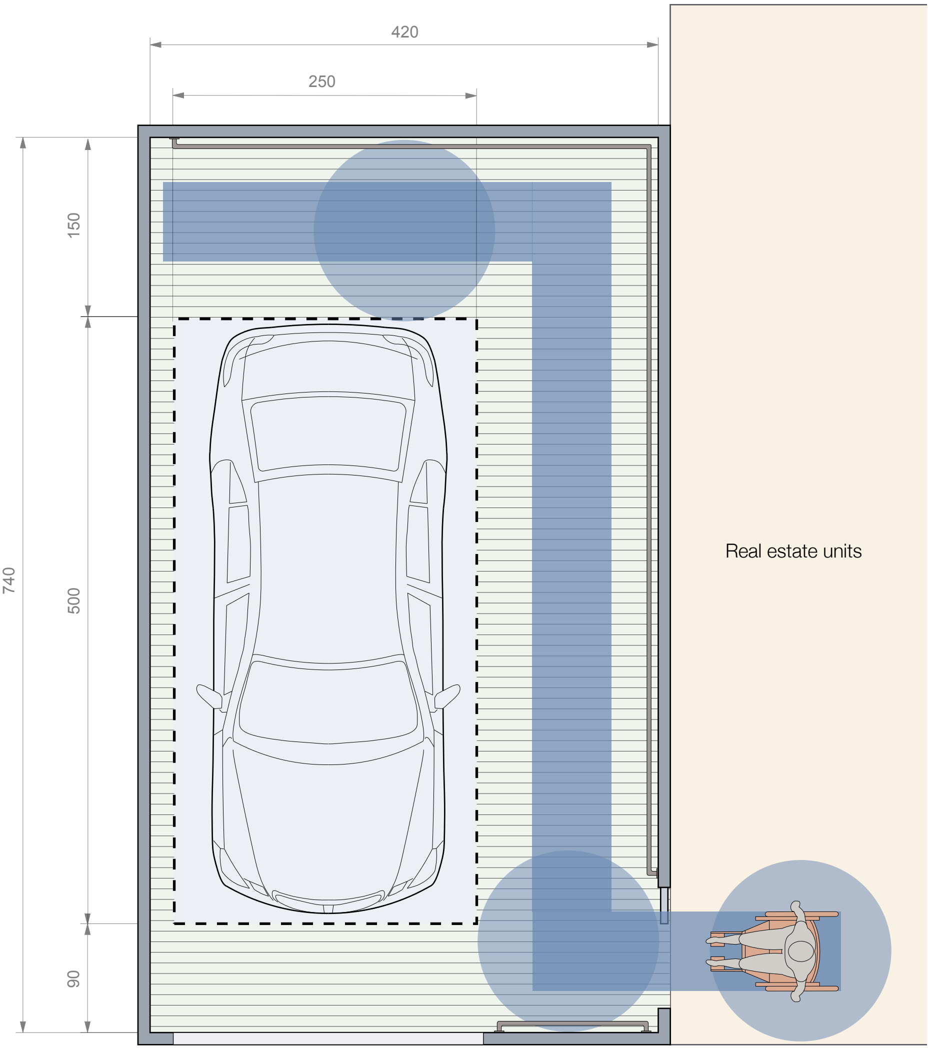
2D plans

Sheet **7.01**

Garage

Dimension
7.40m X 4.20m = 31.08mq

VARIABLE level of symptomatology



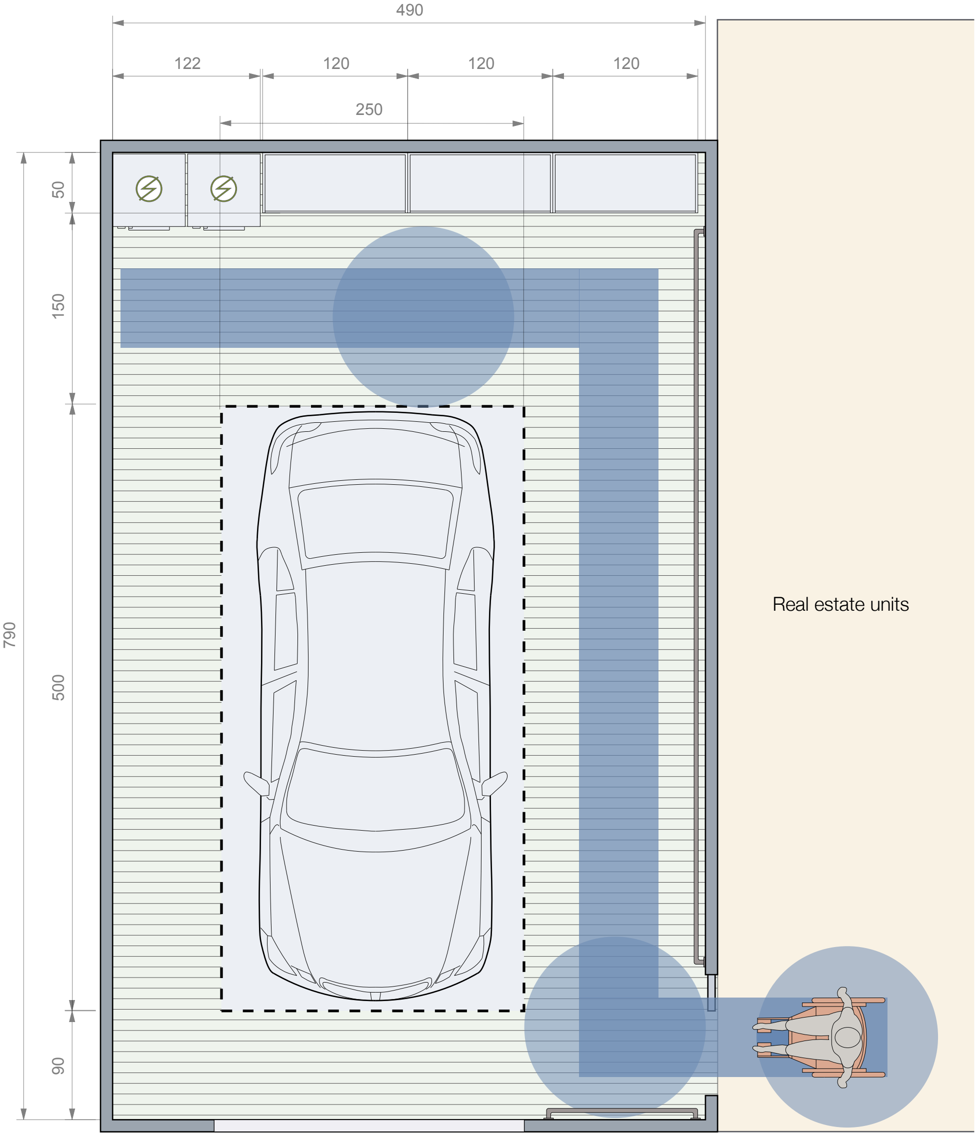
2D plans

Sheet **7.02**

Garage

Dimension
7.90m X 4.90m = 38.71mq

VARIABLE level of symptomatology



2D plans

Sheet **7.03**

Garage

From sheet 7.01 to 7.03

The regulations in force do not specify any particular technical and dimensional requirements for garages for residential use, except for fire regulations. To ensure accessibility by persons with impaired or reduced mobility or wheelchair users, who are still able to drive, the minimum dimensions of a car park must be 2.30 m x 4.50 m, but good practice usually requires a standard area of 5.00 m x 2.50 m.

(a) Position and sizing:

- organise the development and sizing of the garage in a rational and functional manner;
- the ideal solution for an accessible garage, even including accessible storage/laundry room, is to have everything within reach, while providing the necessary space for wheelchair accessibility;
- (in the case of a utility room/laundry room) it is good that electrical appliances, household linen, foodstuffs and miscellaneous items are within easy reach or are easily accessible. It is, therefore, a good idea to place everything that is generally used more frequently in a prominent position. Arranging the work surfaces in a coordinated way also helps PwP to minimise movement during the domestic activities;
- the access door and window (if any) should be of the sliding type, equipped with handles that are easy to use for those with tremor, muscle rigidity and/or motor blockages;
- ensure a minimum space of 150 cm between the car and the garage wall to allow entry/exit from the car as well as ensuring the rotation of a wheelchair;
- the dimensions of the door should be between 90 cm and 100 cm, so as to ensure passage by the PwP using crutches, a walker and/or wheelchair, or a lift.

(b) Equipments:

- the minimum spaces to be ensured between equipment and walls should be 90/100 cm. In the case of the use of crutches, walkers, and/or wheelchairs, at least 150 cm of usable space should be ensured (see sheets);

continues on the other page >

Description: design consideration

Sheet **7**

- (in the case of the presence of a utility room/laundry room) purchase appliances with control buttons and door opening/closing systems at a height of between 40 cm and 140 cm (maximum reachable area for a wheelchair user). If this height is not guaranteed, place the appliances on a raised floor;
- any wall cabinets should be equipped with up-and-down shelves to enable the wheelchair user to reach higher levels as well. Avoid removable solutions that may increase the risk of PwP falling;
- in view of the symptoms of PwP and to limit falls caused by opening hinged doors, it is advisable to purchase wall cabinets with sliding or hinged doors equipped with handles that are easy to use for those suffering from tremor, muscle rigidity and/or motor blocks;
- in order to limit falls, the kitchen should have grab bars arranged along the worktop;
- (possibly) consider home automation solutions capable of managing and controlling electronic equipment via a dedicated digital interface.

Garage

From sheet 7.01 to 7.03

VARIABLE level of symptomatology

VARIABLE level of symptomatology

Virtual environments

Sheet **7**

Garage

From sheet 7.01 to 7.03

VARIABLE level of symptomatology

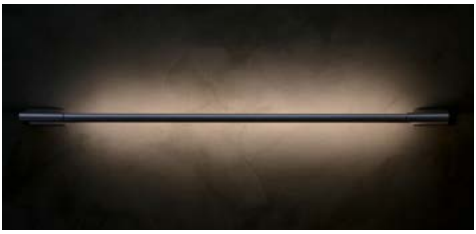
VARIABLE level of symptomatology

Virtual environments

Sheet **7**

Garage

From sheet 7.01 to 7.03



Laundry cabinet Birex (BIREX) (top), www.birex.it/lavanderie/.
Shine handle (Ever Life Design by Thermomat Saniline s.r.l.) (bottom left), https://www.everlifedesign.it/shine-barra-lumino- sa/.
Nylon handle (Thermomat Saniline s.r.l.) (bottom right), https://thermomat.com/prodotto/saniline-accessori-bagni-disabili/maniglioni-e-corrimano/serie-nylon/maniglione-lineare-mm-300-2/.

References: Accessories

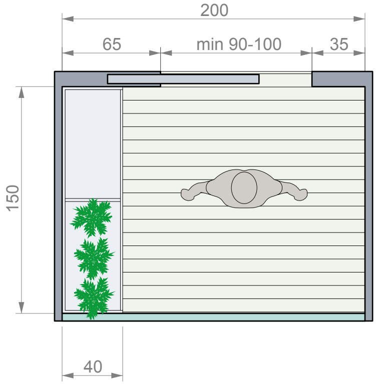
Sheet **7**

Cosmopolitan electronic tap (Grohe) (top left), www.grohe.it/it_it/servizi/cataloghi-brochure.html.
Electronic tap One (Idral spa) (top right), www.idral.it/categorie-prodotto/rubinetteria/rubinetti-elettronici/.
Elbow control tap (Idral spa) (bottom), www.idral.it/cat/rubinetteria/rubinetti-leva-clinica/.

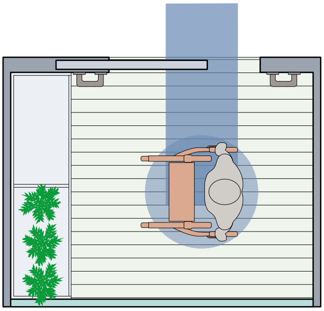
Private outdoor space

Dimension
2.00m X 1.50m = 3.00mq

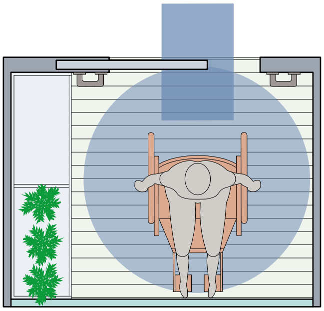
MILD level of symptomatology



MODERATE level of symptomatology



SEVERE level of symptomatology



2D plans

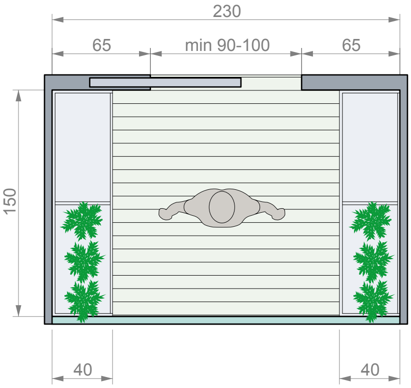
Sheet **8.01**

Private outdoor space

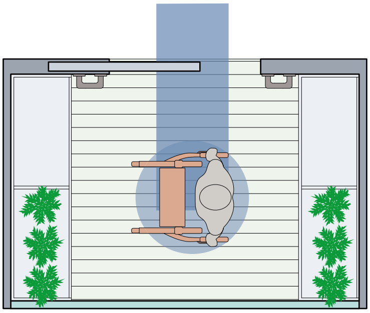
Dimension

2.30m X 1.50m = 3.45mq

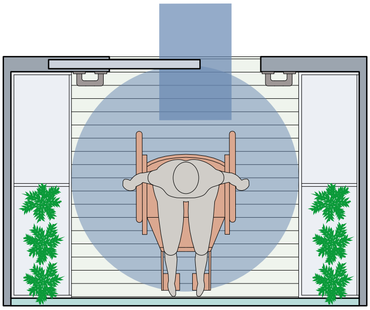
MILD level of symptomatology



MODERATE level of symptomatology



SEVERE level of symptomatology

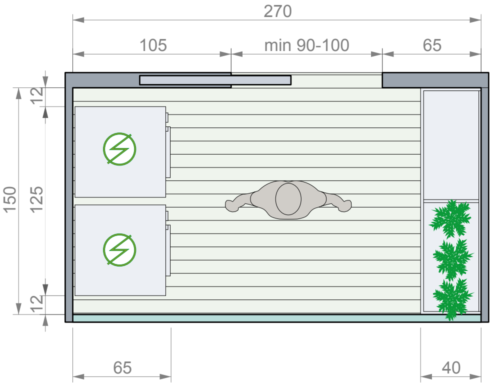


Sheet **8.02**

Private outdoor space

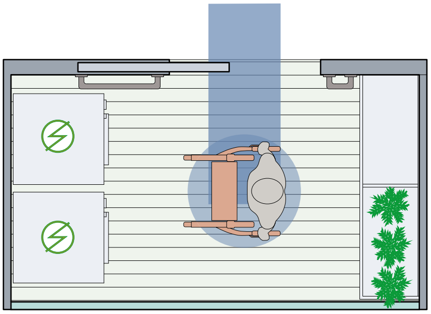
Dimension
2.70m X 1.50m = 4.05mq

MILD level of symptomatology

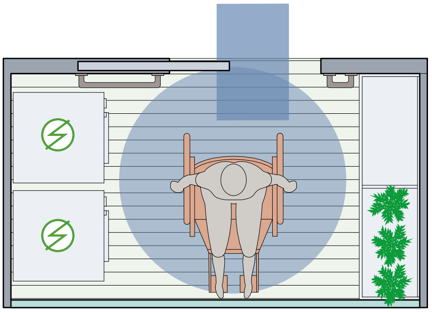


⚡ Washing machine/Tumble dryer

MODERATE level of symptomatology



SEVERE level of symptomatology



Sheet **8.03**

Private outdoor space

Outdoor space is defined as the adjacent space serving the dwelling. The outdoor space can be a terrace, a loggia or a garden.

Below are the indications that should be considered for the outdoor space.

(a) Position and sizing:

- organise the development and sizing of outdoor space in a rational and functional manner;
- the ideal solution for accessibility, even for wheelchair users, is to ensure the necessary space of 150 cm between the equipment and the walls/parapet;
- the terrace floor must be made of non-slip material, free of obstacles or unevenness;
- (in the case of an outdoor garden) minimise the presence of height differences or obstacles that may make it difficult for the PwP to walk. Outdoor paths must be made of non-slip material;
- connecting doors between house/terrace and house/garden should be of a sliding type, equipped with handles that are easy to use by those with tremor, muscle rigidity and/or motor blocks;
- the dimensions of the door should vary between 90 cm and 100 cm, so as to ensure passage by the PwP using crutches, a walker and/or wheelchair;
- between the access door and the outdoor space (terrace/garden) there must be no differences in height (even minimal) that could create obstacles or dangers for the PwP.

(b) Equipments:

- the minimum spaces to be ensured between equipment and walls should be 90/100 cm. In the case of the use of crutches, walkers, and/or wheelchairs, at least 150 cm of usable space should be guaranteed (see sheets 8.01 to 8.03);
- in the case of external laundry, purchase appliances with control buttons and door opening/closing systems at a height of between 40 cm and 140 cm (maximum reachable area for a wheelchair user). If this height is not guaranteed, place the appliances on a raised floor;

continues on the other page >

Private outdoor space

From sheet 8.01 to 8.03

- any wall cabinets should be equipped with up-and-down shelves to enable the wheelchair user to reach higher levels as well. Avoid removable solutions that may increase the risk of PwP falling;
- in view of the symptoms of PwP and to limit falls caused by opening hinged doors, it is advisable to purchase wall cabinets with sliding or hinged doors equipped with handles that are easy to use for those suffering from tremor, muscle rigidity and/or motor blocks;
- home automation solutions capable of managing and controlling electronic equipment via a dedicated digital interface should be considered;
- in order to limit falls, the terrace should have handrails arranged along the walls at strategic points (see sheets 8.01 to 8.03).

Description: design consideration

Sheet **8**

Private outdoor space

From sheet 8.01 to 8.03

VARIABLE level of symptomatology

VARIABLE level of symptomatology

Virtual environments

Sheet **8**

Doors and windows

(a) Position and sizing:

- as far as accesses are concerned, Article 4.1.1. of Ministerial Decree 236/1989 states that the minimum clear width of the access door of each building and each building unit must be at least 80 cm, while that of other doors must be at least 75 cm. A width of between 90 cm and 100 cm is recommended in order to ensure easy passage of the PwP when using assistive devices (crutches, walker, wheelchair, lift, etc.);
- the handle height must be between 85 and 96 cm (90 cm recommended);
- heavy doors and locks that require complex movements to be opened can be unmanageable by PwP, so access doors to the various rooms of the house, the entrance door and windows should be of the sliding type, or products with motorised doors and locks, controlled via push-buttons or digital systems, are recommended;
- doors and windows should be equipped with handles or handholds that are easy to use by those suffering from tremor, muscle rigidity and/or motor blocks;
- in an emergency, the door should also be opened from the outside;
- ensure that windows are well sized (equal to or greater than the aero-illuminance ratio; the opening window area should not be less than 1/8 of the floor area) to allow high levels of natural lighting and ventilation.

Description: design consideration

Sheet **9**

Doors and windows

Comfort Xterna sliding door (Scrigno spa) (top), www.scrigno.it/prodotto/porta-scorrevole-comfort-externa-p17552.
Comfort Prima sliding door (Scrigno spa) (bottom), www.scrigno.it/prodotto/porta-comfort-scorrevole-p2362.

References: Doors and windows | Sheet **9**

Doors and windows

Armoured sliding entrance door Vela (OIKOS) (top left), www.oikos.it/it/prodotti/porte-scorrevoli/vela/.
External sliding door Iride (Ermetika) (top right), www.ermetika.com/it/prodotti/sistemi-esterni/iride/.
Recessed sliding window (Eclisse) (bottom), www.eclisse.it/it/prodotti/.

References: Doors and windows

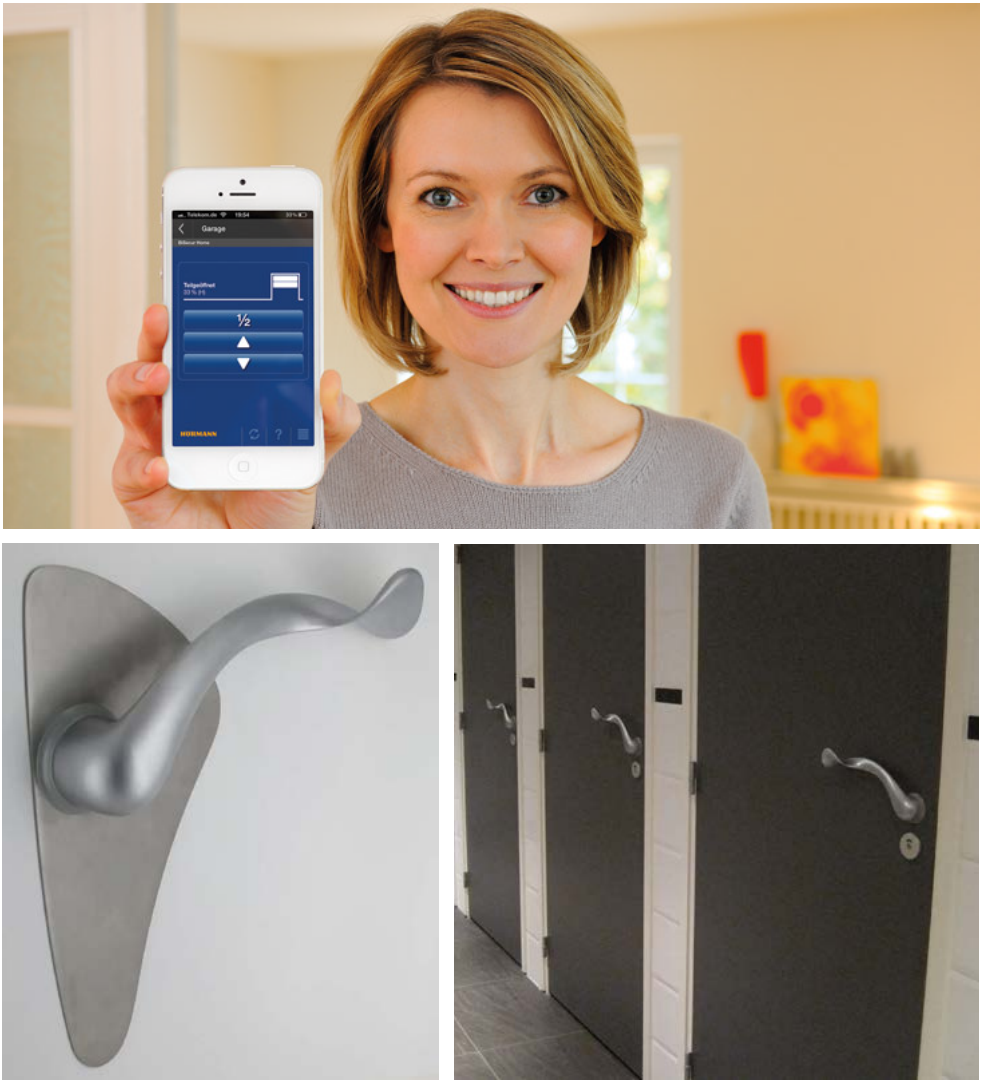
Sheet **9**

Doors and windows

Leonardo handle (Ghidini Pietro Bosco spa) (top), www.ghidini.com/it/?s=leonardo&post_type=product.
NoHand handle (Manital) (bottom), http://www.manital.com/manital-presenta-nohand-un-gesto-un-modo-concepire-la-maniglia/.

References: Accessories — Sheet **9**

Doors and windows

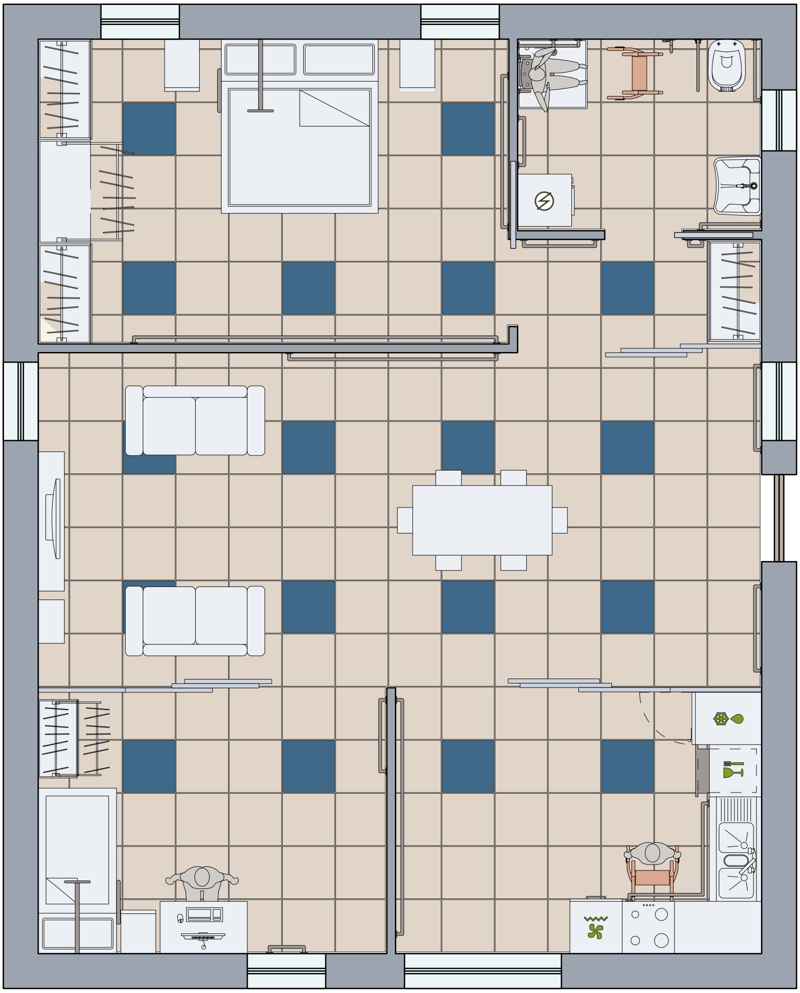


App Bisecur digital key ring (Hörmann KG) (top), www.bisecur-home.com.
Silver handle (ULNA) (bottom), www.ulna.fr/prod/ulna-silver/7-poignee-ulna-silver-mecanisme-3660182059028.html.

References: Accessories

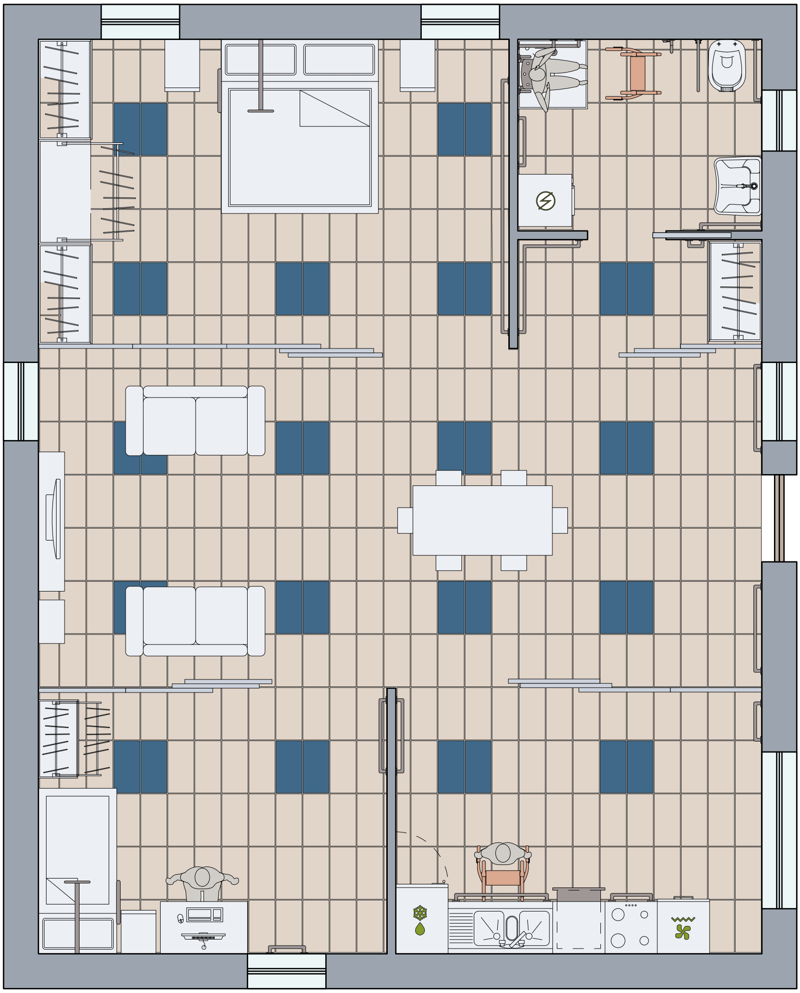
Sheet **9**

VARIABLE level of symptomatology



Internal floors

VARIABLE level of symptomatology



2D plans

Sheet **10.02**

Internal floors

From sheet 10.01 to 10.02

(a) Position and sizing:

With the aim of reducing falls and limiting damage/injuries caused by falls, the following is recommended:

- installation of flooring in non-slip material, such as porcelain stoneware tiles, or polypropylene (PP) flooring or EVA (Ethyl Vinyl Acetate) foam/rubber interlocking tiles;
- alternatively, we also recommend the installation of anti-trauma tiles or mats (usually rubber products) to be placed over the entire surface of the house or in areas where PwP is expected to stay and pass through;
- installation of low solar reflectivity tiles or mats removing carpets and rugs in favour of a non-slip tiled floor or an anti-trauma mat;
- with the aim of reducing freezing, the floor should have visual elements on the ground. Alternatively, visual feedbacks such as a laser beam attached to a stick or on a shoe help overcome freezing episodes.

Description: design consideration

Sheet **10**

Internal floors

From sheet 10.01 to 10.02

Interior non-trauma floor covering (Nanni Giancarlo & C.) (top), www.nannigiancarlo.it/index.php/blog-e-informazioni-rivestimento-pavimenti-pareti/51-blog-pavimenti/54-pavimenti-antitrauma.
Interior non-trauma floor covering (Smalls Tile & Flooring) (bottom), www.smallsflooring.ca/blog/post/46/2018-s-Flooring-Trends/.

References: Interior floors

Sheet **10**

Internal floors

From sheet 10.01 to 10.02

SensFloor sensorised flooring for health monitoring in neurology, geriatrics and rehabilitation (Future-Shape) (top), https://future-shape.com/en/gait-recording/.
Anti-shock resin flooring (Resina Italia srl) (bottom), www.resinaitalia.net/lavorazioni-in-resina/.

References: Interior floors

Sheet **10**

Internal floors

From sheet 10.01 to 10.02

Walk with path (shoe laser to alleviate freezing), www.walkwithpath.com/products/path-finder-2-0.

References: Accessories

Sheet **10**

Vertical routes

(a) Position and sizing:

- stairs must have a regular course and maintain a constant slope;
- stairs must be equipped with a continuous safety railing at least 100 cm high and a handrail on both sides;
- steps should preferably have a riser of 16 cm and a tread of 30 cm with a rounded profile, and non-slip flooring;
- the minimum useful width for each step is 80 cm. A minimum width of 100 cm is recommended in order to possibly install a stair lift for the disabled or similar systems in the future (width varying between 85 cm and 95 cm);
- (where applicable) ramps must allow for the easy bridging of differences in level and be provided as an alternative to steps or stairs. The regulations indicate a slope of 8% as the recommended slope for handicapped ramps. In facilities for the elderly, for example, it is preferable to use ramps with a 5% gradient, at least 150 cm wide;
- (where applicable) a lift must be provided in buildings with more than one floor and must conform in size to enable easy access for a wheelchair. The cabin doors must be of the automatic sliding type. Operating buttons, located indoors and outdoors at a height suitable for a wheelchair user (height between 40 cm and 140 cm), must be easy to use and provide clearly visible numbering and lettering;
- (if applicable) lifting platforms and stair lifts for the disabled may be used as an alternative to lifts. Both platforms and stair lifts must be equipped with protective systems and have, in the case of platforms, the two accesses fitted with protective gates.

Description: design consideration

Sheet **11**

Vertical routes

Stairlift (TK Home Solution) (top), www.homesolutions.tkelevator.com/it-it/montascale/montascale-a-poltrona.html.
Platform stairlift (TK Home Solution) (bottom), www.homesolutions.tkelevator.com/it-it/montascale/montascale-a-piattaforma.html.

References: Accessories | Sheet **11**

Vertical routes

HE31 GULLIVER mini-elevator (TK Home Solution), www.homesolutions.tkelevator.com/it-it/miniascensori/gulliver/.

References: Accessories

Sheet **11**

Managment and control systems

On the market there are technological remote controls (capable of combining many functions in a single object), mobile phone apps or assistive technologies that make it easier to manage certain household tasks.

Technology can be the element that can increase home accessibility for those with reduced or impeded motor and cognitive abilities.

(a) Position and sizing:

In view of the symptoms caused by PD, it is advisable to:

- install environmental sensors, based on wireless technology, in a specific area or the entire house, which offer the possibility of monitoring environmental parameters such as indoor temperature, light, humidity, water and gas leakage and smoke leakage;
- install motion sensors, based on wireless technology, in an area or the whole house, which offer the possibility of monitoring possible falls in the home and which allow lights to be switched on and off;
- install environmental sensors, based on wireless technology, in a specific area or the entire house, which offer the possibility of controlling and managing the opening of doors, windows and gates;
- ensure the proper functioning and effectiveness of sensors and cameras, making sure they are placed at strategic points in the house;
- ensure that switches, background and mounting surfaces are visually contrasting with the surrounding surfaces;
- use a consistent arrangement, position, style and sequence of accessories throughout the home;
- ensure that all sockets, switches and couplings are easily identifiable and manoeuvrable, placed at a height of between 40 and 140 cm. In addition, these must be arranged in such a way that they can also be used easily by persons with impaired or reduced mobility and wheelchair users, at least 50 cm from any inner corner of the room;
- (possibly) place light switches at the bottom and top of the stairs.

Description: design consideration

Sheet **12**

Managment and control systems

(b) Devices:

The control of domestic activities can be ensured through a series of commands that, depending on the level of PD's symptomatology, can help the PwP to complete certain tasks, such as:

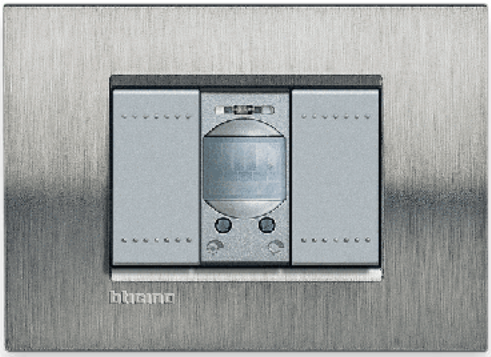
- sensors/pressure controls (a minimum of force and precision is required to operate them);
- touch sensors (no force is required to operate them);
- strain/shock sensors (a minimum of force and precision is required to operate them);
- blow sensors (a minimum of force is required to operate them)
- myoelectric potential sensors (can be operated by contracting a muscle);
- sensors/voice commands (voice-activated);
- optical sensors/controls (operable by eye movement);
- key-operated transponder (operated by touching the reader) or card-operated /operated by touching or inserting in the reader.

It will, however, be at the discretion of the PwP to choose management and control systems to be used for one or more spaces or for the whole house.

Description: design consideration

Sheet **12**

Managment and control systems



BTicino infrared controls (Bticino spa) (top), www.bticino.it/privati.

Other examples of accessories for private interiors:
Amazon Alexa (Amazon), smart speaker capable of managing indoor/outdoor lighting, IP surveillance cameras, WiFi switches, thermostats, robot vacuums and scrubbers, and smart TVs, https://www.amazon.it/Echo-e-Alexa/b?ie=UTF8&node=15619933031.
WiFi smart switch MSS710 (Meross), www.meross.com/home.
ZigBee motion sensors for switching lights on and off and controlling the home environment (ZigBee), www.zigbeealliance.org/it/soluzione/zigbee/.
Helios Touch Modular Lighting System Touch-controlled wall lamp (Helios Touch), www.heliostouch.com.

References: Accessories | Sheet **12**

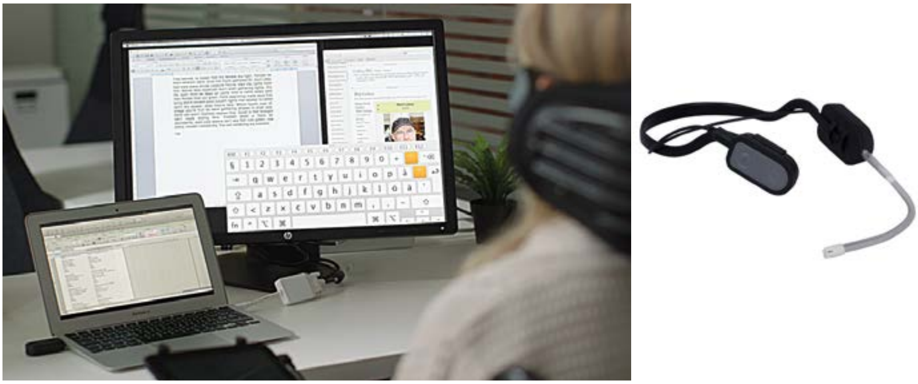
Managment and control systems

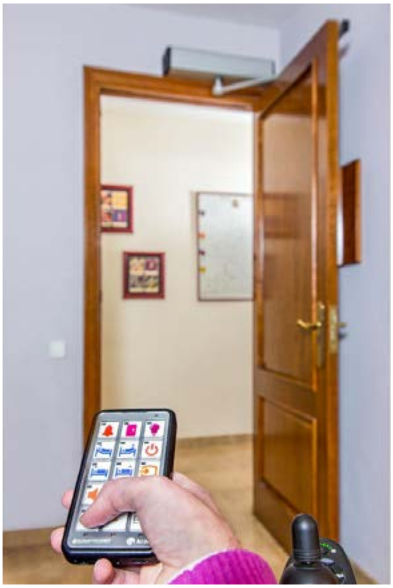
Domo Connexa (Cisa spa) (top), https://www.cisa.com/it/prodotti/serrature/smart-lock/domo-connexa-smart-door-porte-blindate.html.
Emotiv Insight Brainware, a device capable of managing certain electronic devices in the home through brain, voice and eye commands (Royal Philips e Accenture) (bottom), www.emotiv.com/insight/.

References: Accessories

Sheet **12**

Managment and control systems





Quha Pufo sensor (Quha) (top), www.quha.com/products-2/quha-pufo/.
BJ Control Pro (Helpicare), universal home automation remote control capable of accommodating up to 81 functions, including managing and controlling doors and windows, and TV (bottom left), https://www.helpicare.com/prodotto/bj-control-pro/.
BJ Control Pro universal home automation remote control (Leonardo Ausili) (bottom right),www.leonardoausili.com/controllo-ambiente/220-bj-control-pro-controllo-ambientale-personalizzato-con-scansione.html.

References: Accessories Sheet **12**

Managment and control systems

Belt including airbag with automatic Hip'Safe deployment (Helite Italia) (top), www.italia.helite.com/anziani/.
STAT-ON HOLTER wearable fall detection device (Sense4Care) (bottom), www.sense4care.com/parkinson-disease-2/.

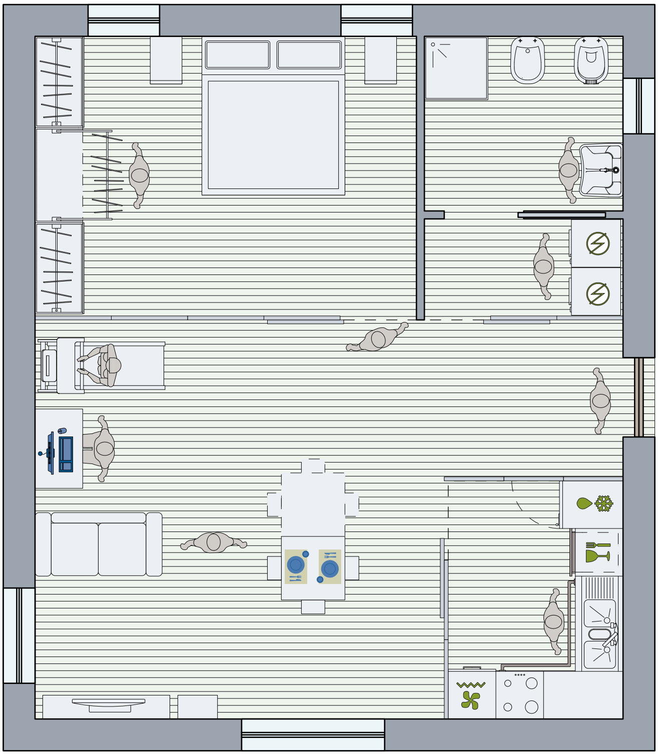
References: Accessories

Sheet **12**

Design hypotheses: household of 2 people

Dimension
7.40m X 8.60m = **63.64mq**

MILD level of symptomatology



2D plans

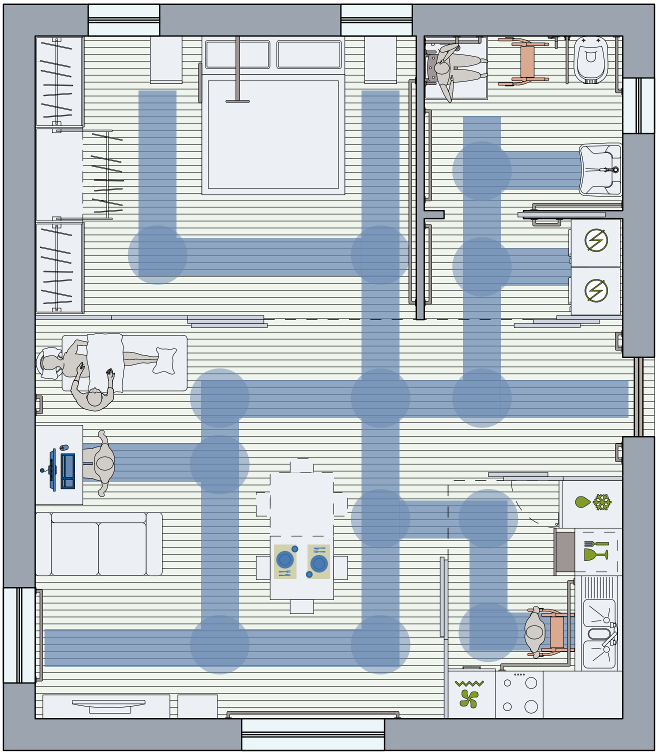
Sheet **13.01**

Design hypotheses: household of 2 people

Dimension

7.40m X 8.60m = **63.64mq**

MODERATE level of symptomatology



2D plans

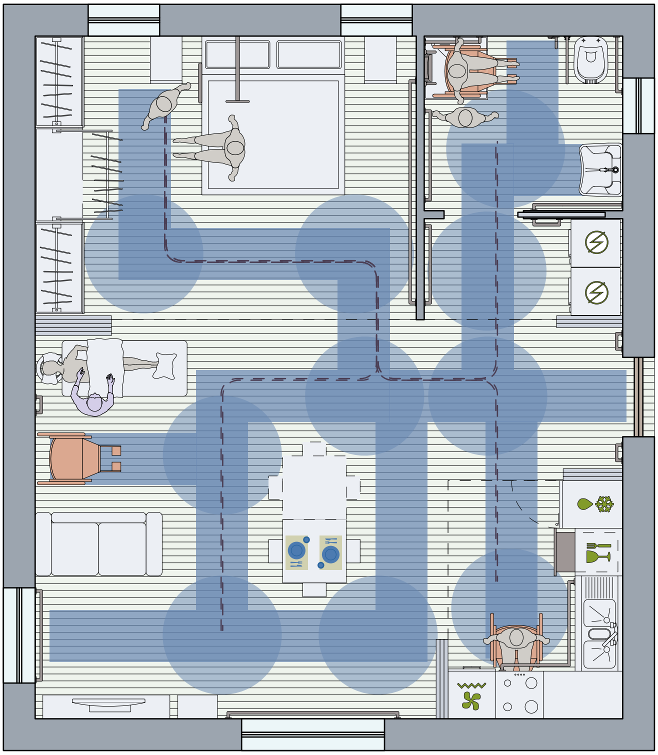
Sheet **13.01**

Design hypotheses: household of 2 people

Dimension

7.40m X 8.60m = **63.64mq**

SEVERE level of symptomatology



2D plans

Sheet **13.01**

Design hypotheses: household of 2 people

Dimension
7.40m X 8.60m = **63.64mq**

MILD level of symptomatology

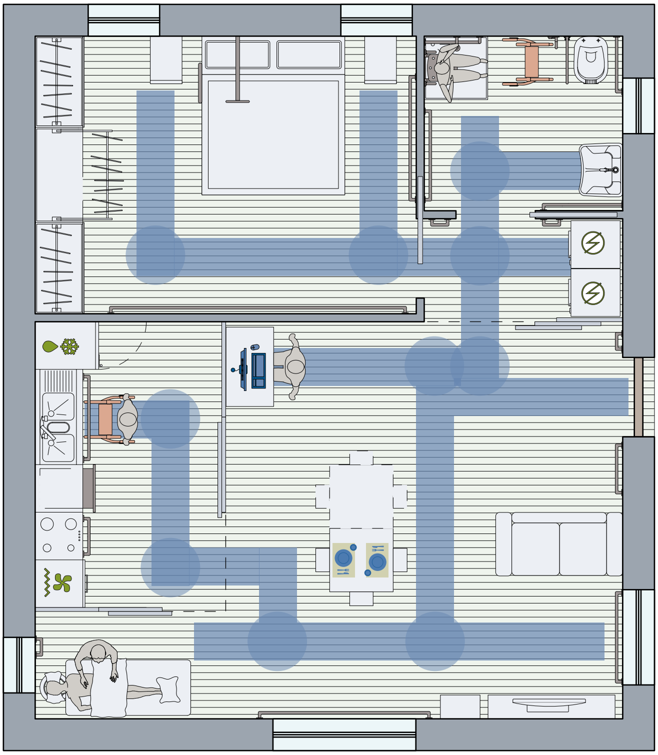
2D plans

Sheet **13.02**

Design hypotheses: household of 2 people

Dimension
7.40m X 8.60m = **63.64mq**

MODERATE level of symptomatology



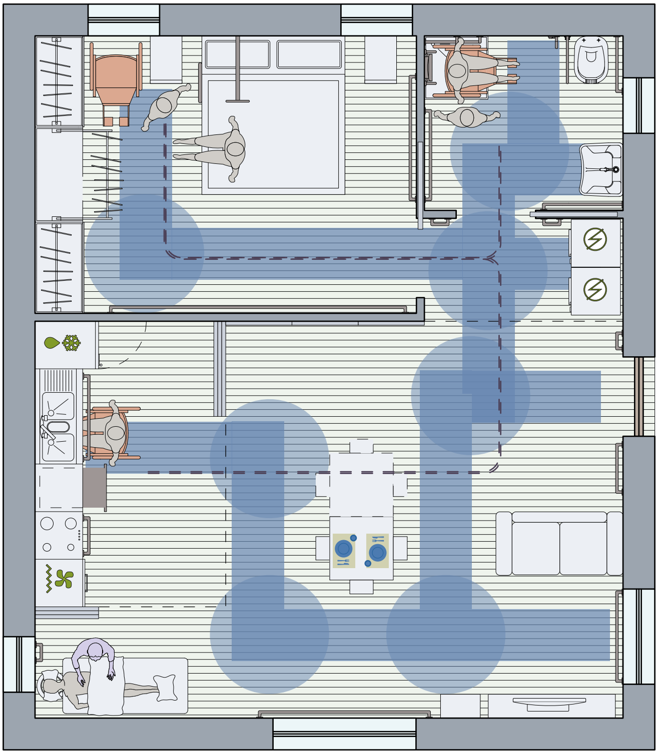
2D plans

Sheet **13.02**

Design hypotheses: household of 2 people

Dimension
7.40m X 8.60m = **63.64mq**

SEVERE level of symptomatology



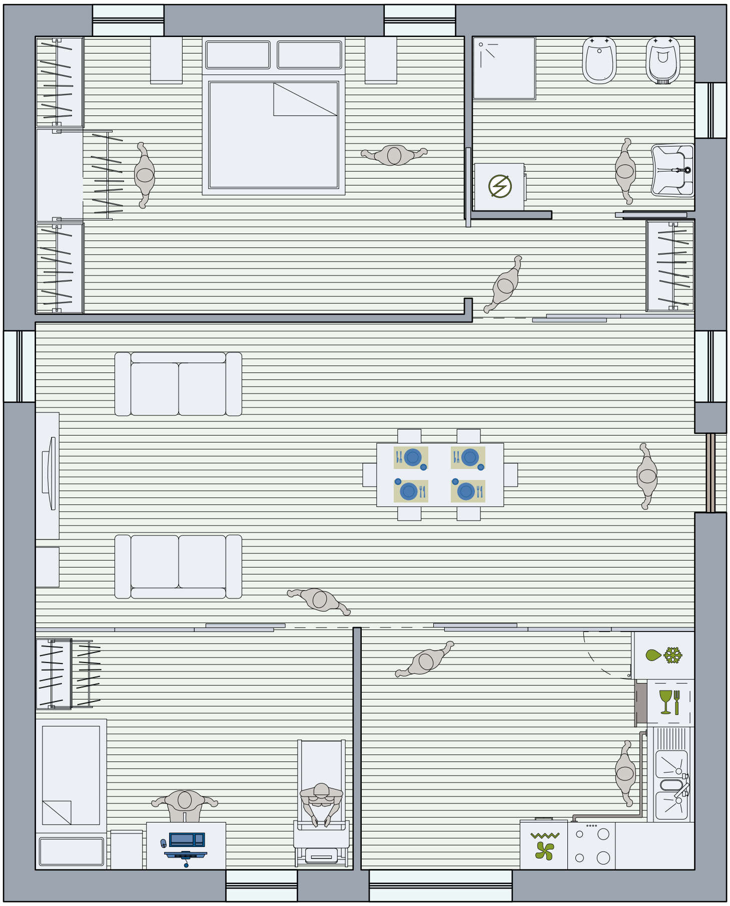
2D plans

Sheet **13.02**

Design hypotheses: household of 3 people

Dimension
8.30m X 10.50m = **87.15mq**

MILD level of symptomatology



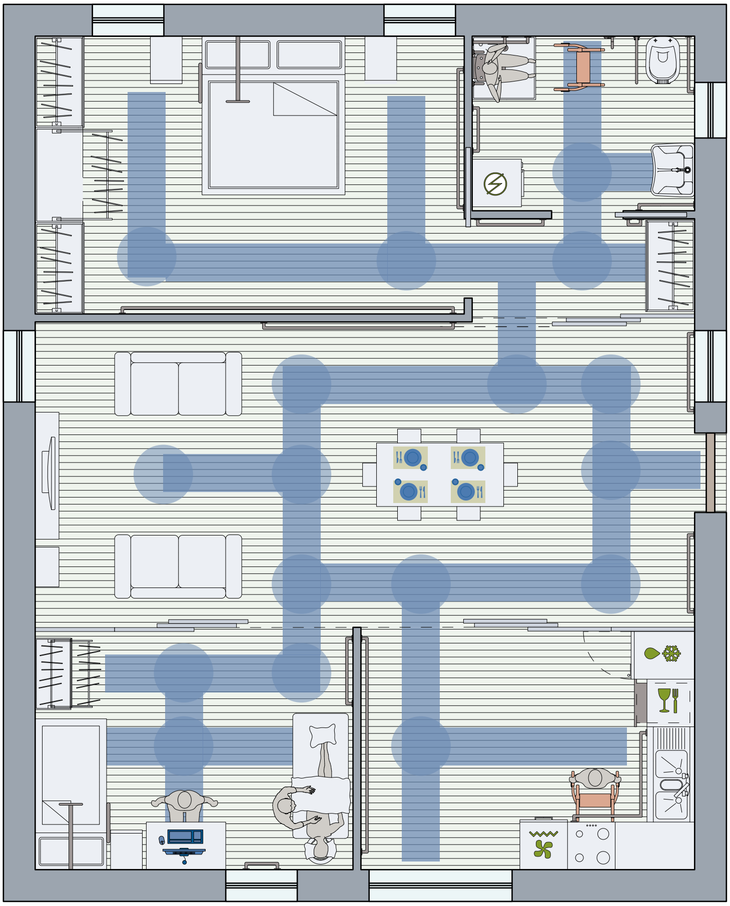
2D plans

Sheet **13.03**

Design hypotheses: household of 3 people

Dimension
8.30m X 10.50m = **87.15mq**

MODERATE level of symptomatology



2D plans

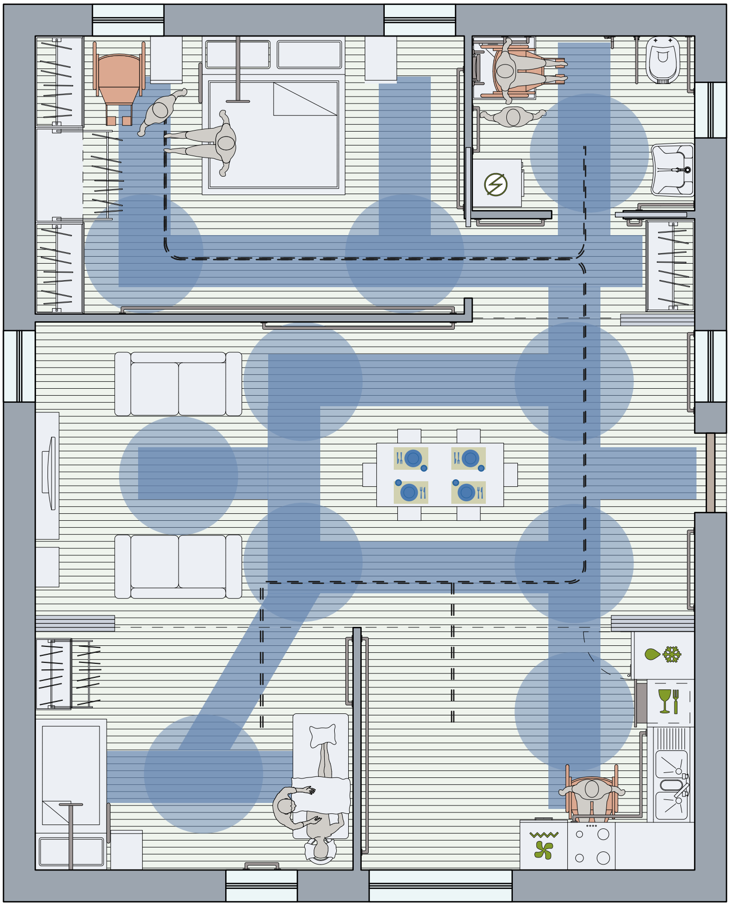
Sheet **13.03**

Design hypotheses: household of 3 people

Dimension

8.30m X 10.50m = **87.15mq**

SEVERE level of symptomatology



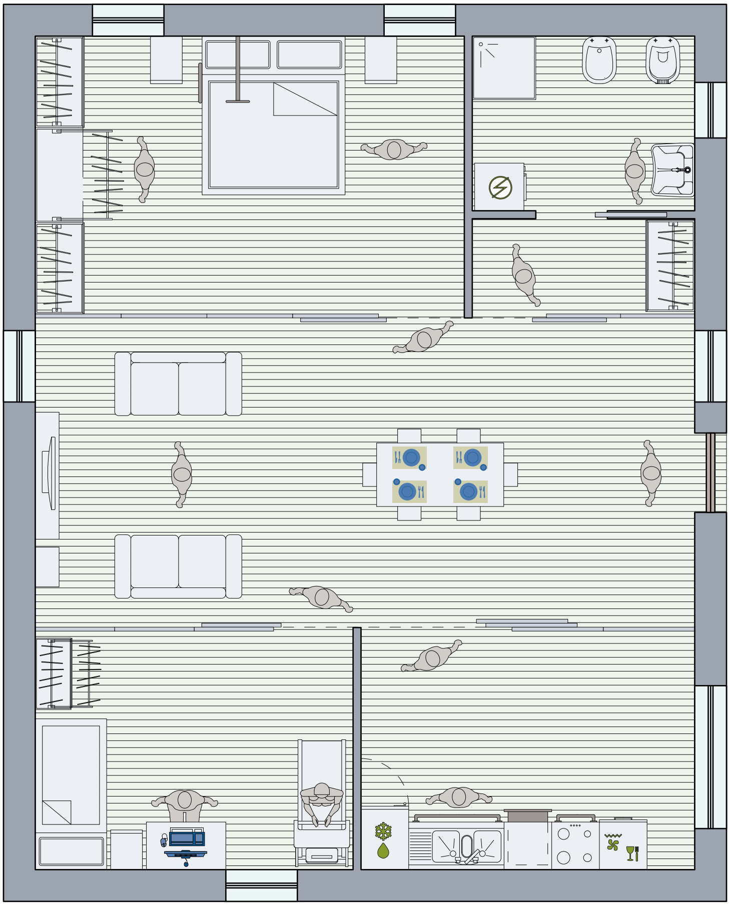
2D plans

Sheet **13.03**

Design hypotheses: household of 3 people

Dimension
8.30m X 10.50m = **87.15mq**

MILD level of symptomatology



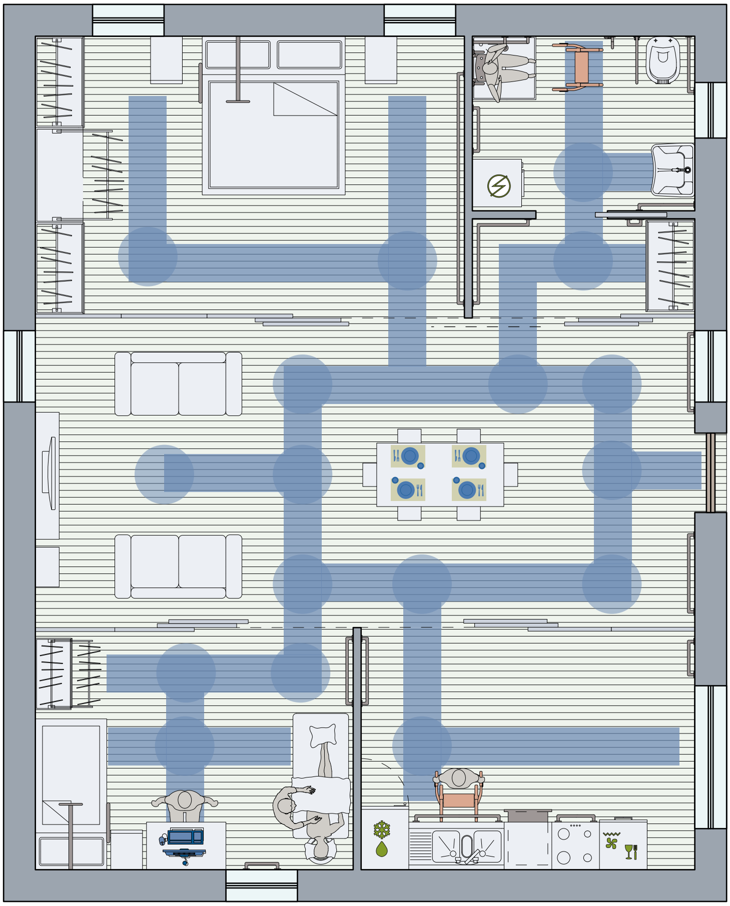
2D plans

Sheet **13.04**

Design hypotheses:
household of 3 people

Dimension
8.30m X 10.50m = **87.15mq**

MODERATE level of symptomatology



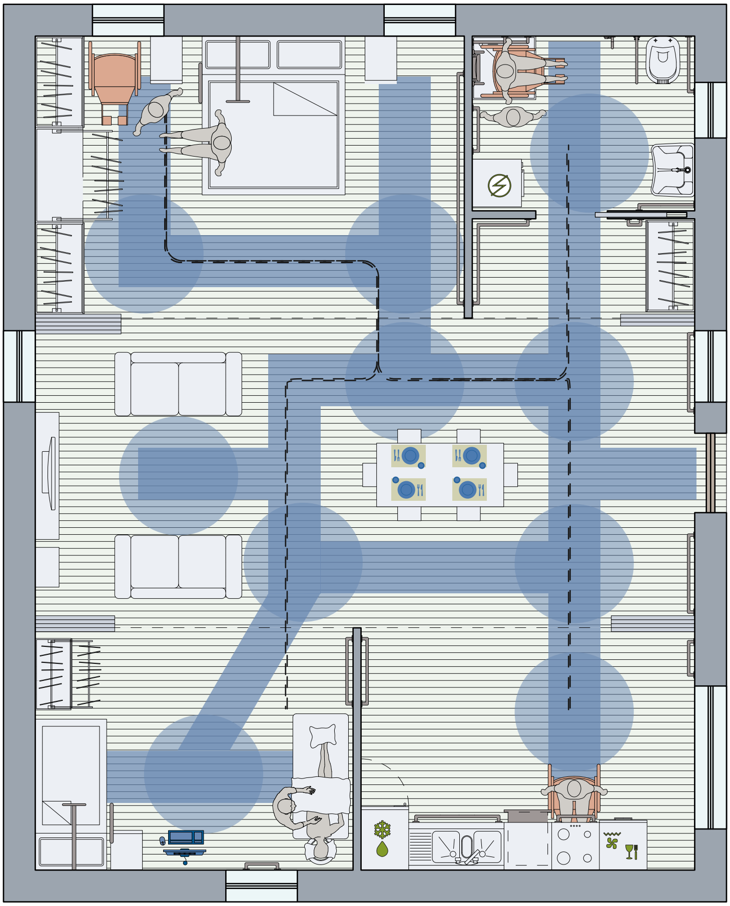
2D plans

Sheet **13.04**

Design hypotheses: household of 3 people

Dimension
8.30m X 10.50m = **87.15mq**

SEVERE level of symptomatology



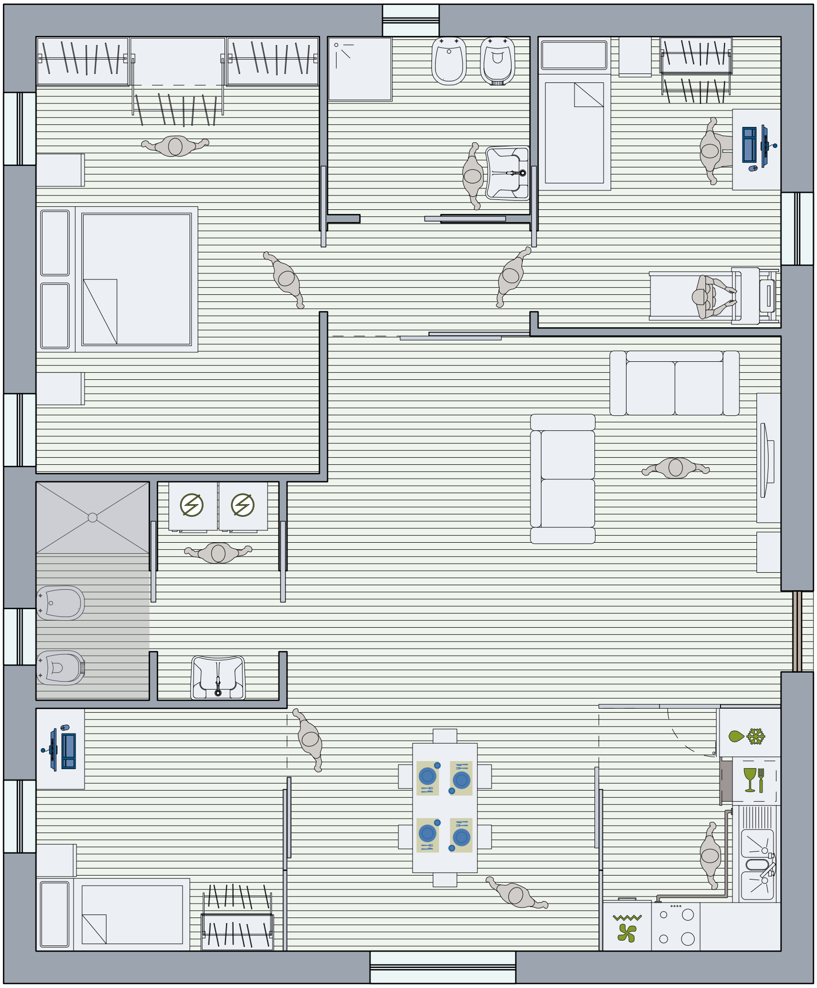
2D plans

Sheet **13.04**

Design hypotheses: household of 4 people

Dimension
9.20m X 11.30m = **103.96mq**

MILD level of symptomatology



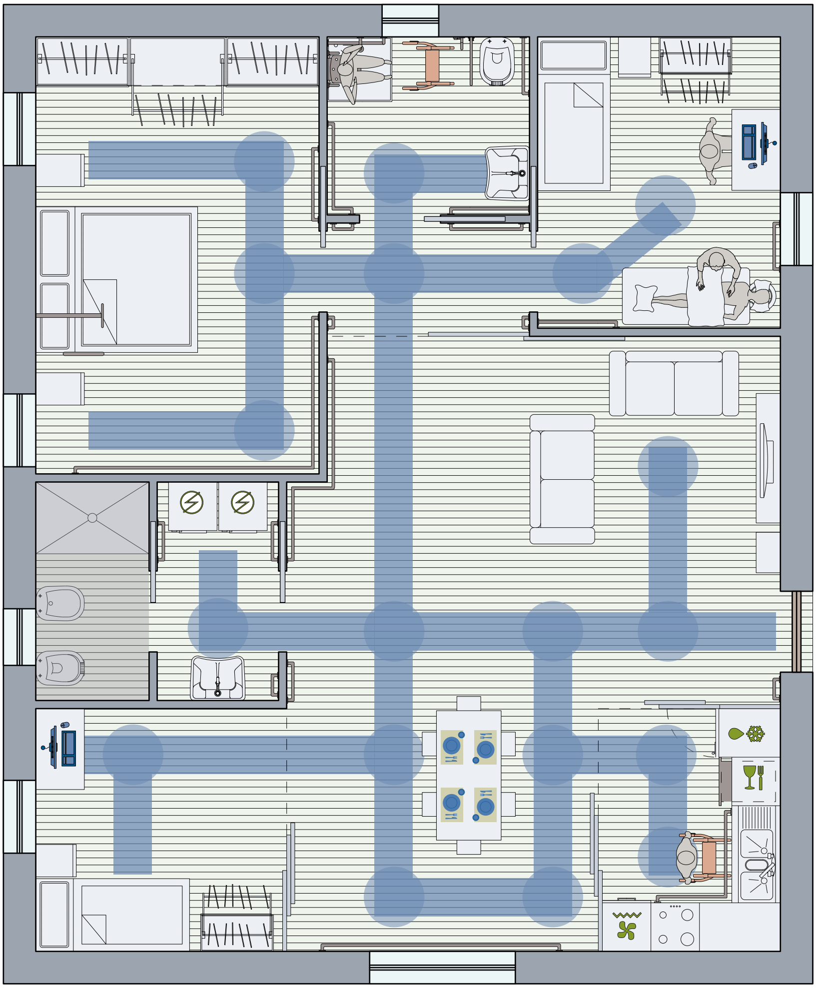
2D plans

Sheet **13.05**

Design hypotheses: household of 4 people

Dimension
9.20m X 11.30m = **103.96mq**

MODERATE level of symptomatology



2D plans

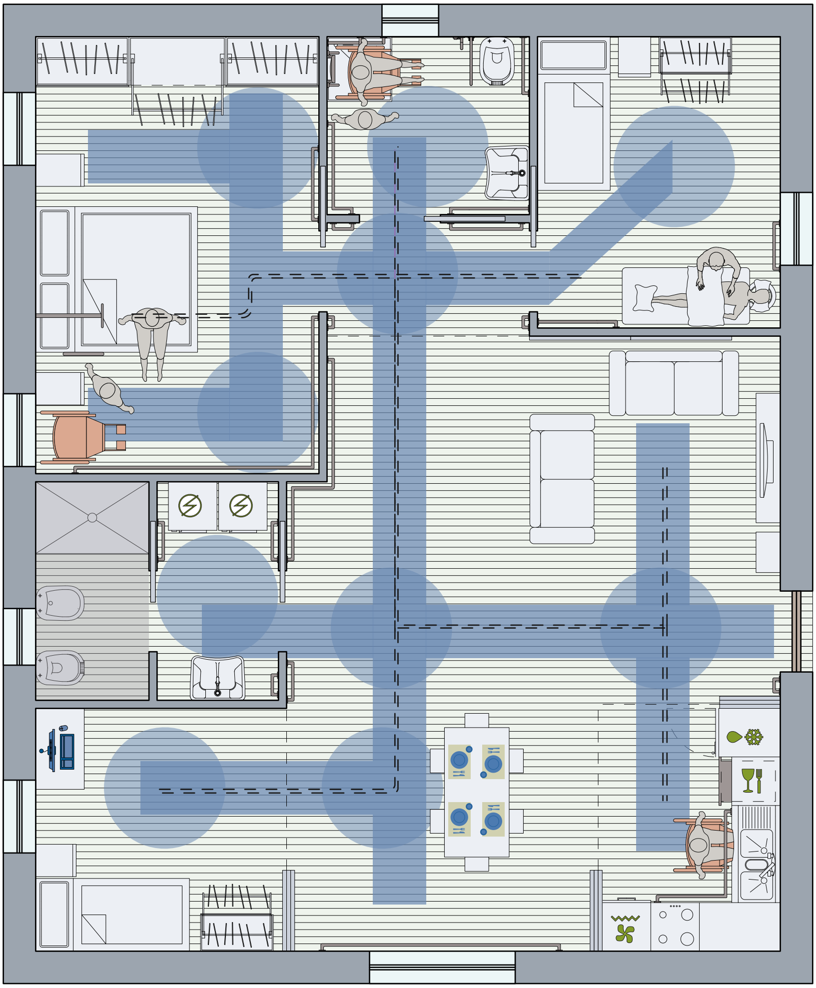
Sheet **13.05**

Design hypotheses: household of 4 people

Dimension

9.20m X 11.30m = **103.96mq**

SEVERE level of symptomatology



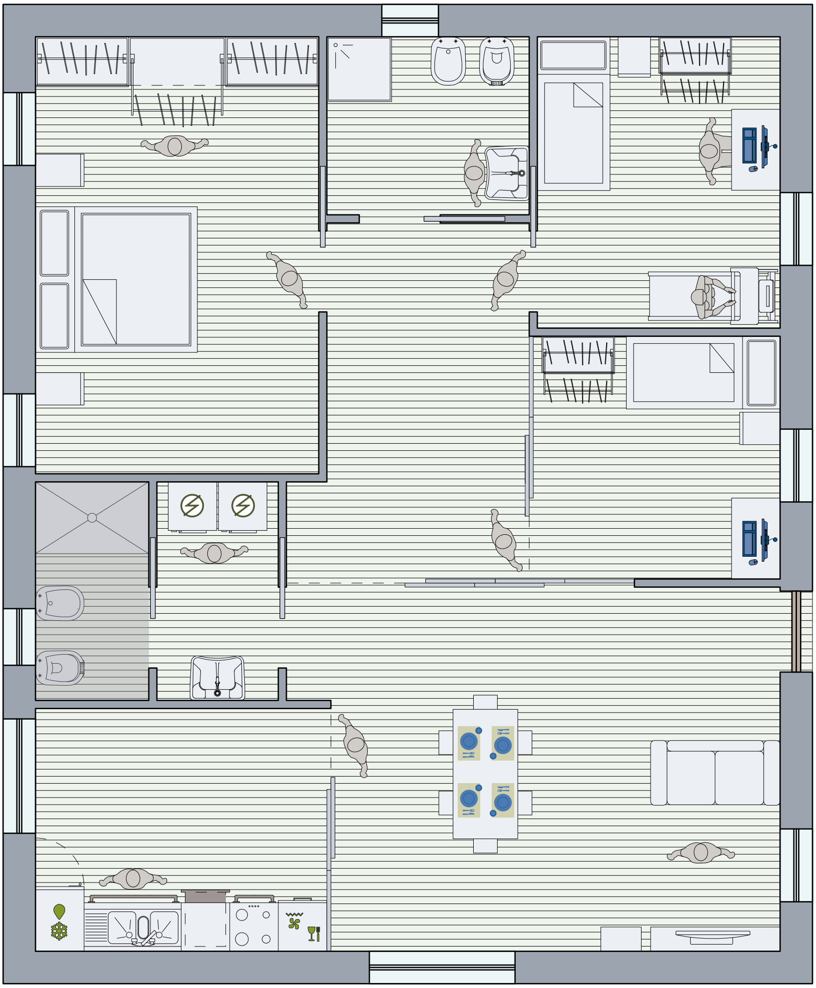
2D plans

Sheet **13.05**

Design hypotheses: household of 4 people

Dimension
9.20m X 11.30m = **103.96mq**

MILD level of symptomatology



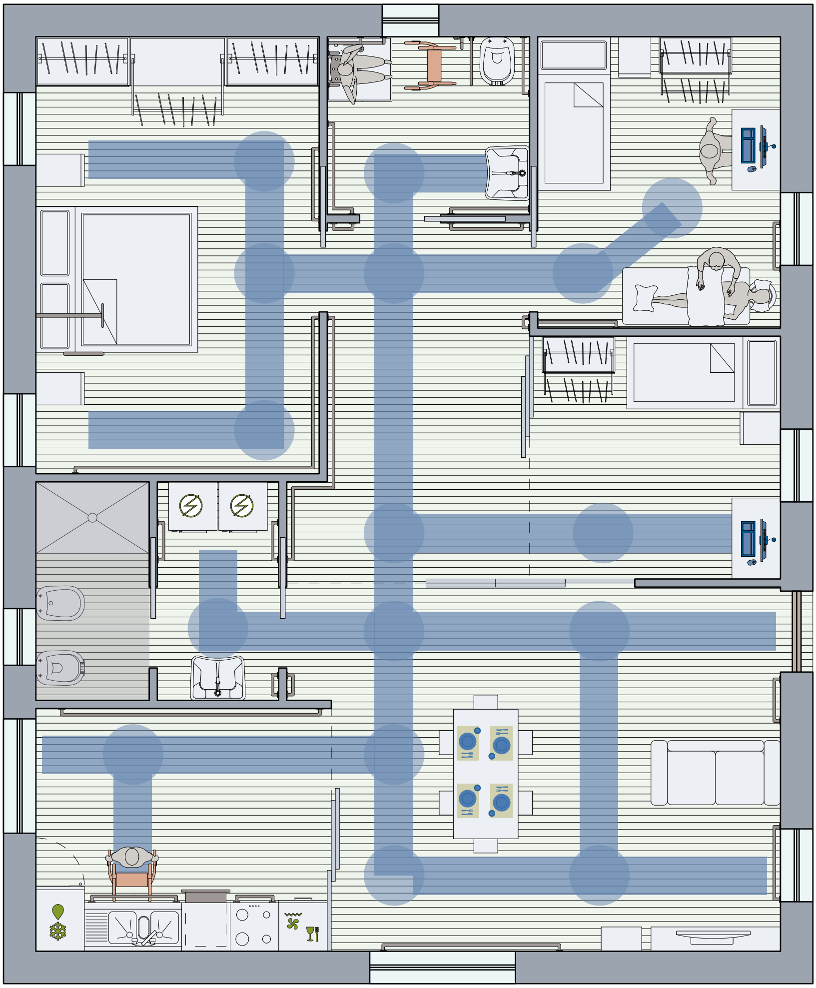
2D plans

Sheet **13.06**

Design hypotheses: household of 4 people

Dimension
9.20m X 11.30m = **103.96mq**

MODERATE level of symptomatology



2D plans

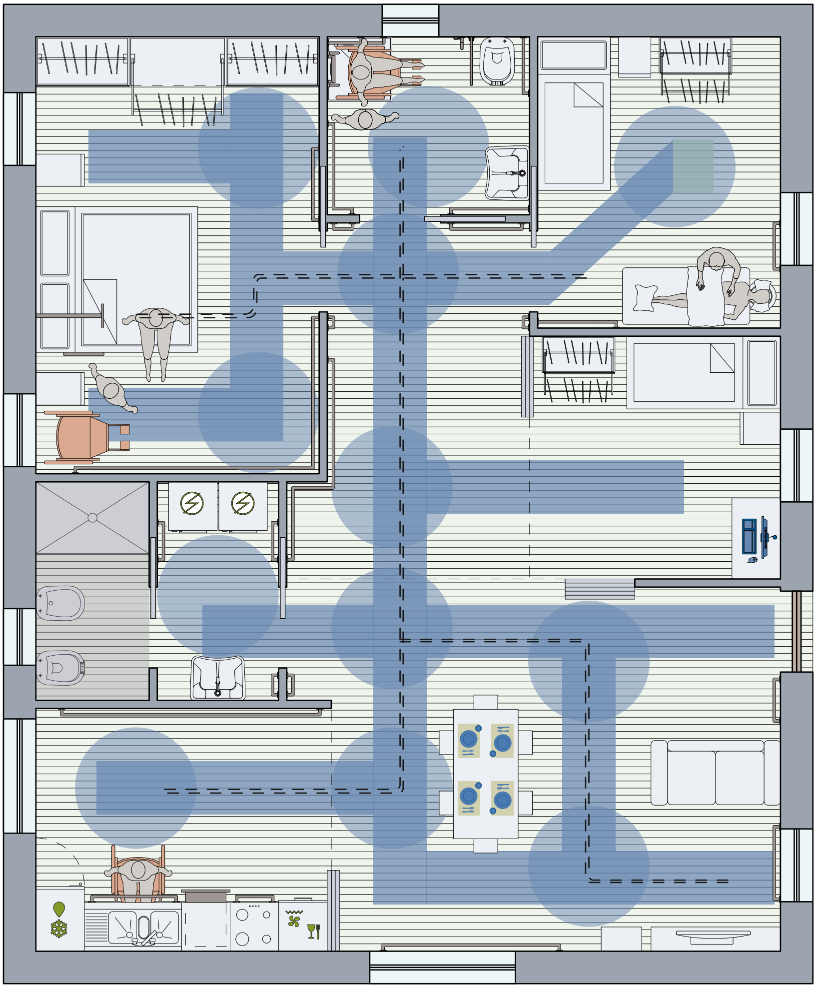
Sheet **13.06**

Design hypotheses: household of 4 people

Dimension

9.20m X 11.30m = **103.96mq**

SEVERE level of symptomatology



2D plans

Sheet **13.06**

Acknowledgements

As we come to the end of this volume and of this important and beautiful research experience, we would like to write these last words to thank first of all the people with Parkinson's disease and their families who have been actively involved in this project. Their willingness to talk about their everyday life experiences, going into detail about the difficulties they experience daily when using spaces and objects, has given us a better understanding of the reality and the specificity of the problems that these people have to struggle with and face every day.

As a working group, we owe them a great deal, not only for their essential contribution to our research, but also for having placed in our work the hope that in the near future we will be able to lead as normal a life as possible in our own homes, where the possibility of living serenely in a cosy environment adapted to everyone's needs should be normal, but unfortunately for many it is not.

We would like to thank the Zoé Foundation, represented by Elena Zambon, Mariapaola Biasi and Rita Larocca, for having believed in this project with great enthusiasm and passion.

We would also like to thank the entire working group, made up of Prof. Leonardo Lopiano, Prof. Linda Lombi, Dr. Carlo Alberto Artusi, Prof. Adson Resende, Giangi Milesi, Giorgia Surano and Giulia Quaglini, for their scientific support and constant commitment throughout this experience.

We would like to conclude by quoting a sentence written by the British designer Viktor Papanek around 1970, which is still very relevant today and, above all, should be a mantra for design professionals: “Designers should design for the needs of society. They should consider the needs of developed and developing countries. They should consider the needs of users without any complications or criticality, the special, the elderly, the poor, the disabled and finally the sick” (Papanek V., 1972, Design for the real world).

As researchers and designers, we are convinced that the innovativeness of Design is determined by its ability to identify and understand the needs and expectations of each individual or group of individuals and, through research and experimentation, to design and implement new solutions capable of improving people's quality of life.