Francesca Tosi, Mattia Pistolesi

Home Care Design for Parkinson's Disease

Designing the Home Environment for People with Parkinson's Disease





Serie di architettura e design Ergonomia & Design / Ergonomics in Design

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Designing the Home Environment for People with Parkinson's Disease

> Serie di architettura e design FrancoAngelia

Ergonomics&Design

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6. Design and disability: emotional impact

by Ester lacono¹

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 Engage³ 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).

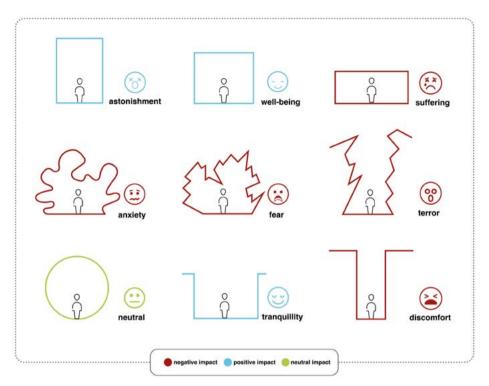


Fig. 6.1 Emotional states relating to the built environment. Graphic elaboration of the author, source: Ferrari (2018, p.3).



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 Soneii 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 Talk⁶ 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 *Empa*thic Design, there is still no definition of empathy widely accepted and consistently used in Design.

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):

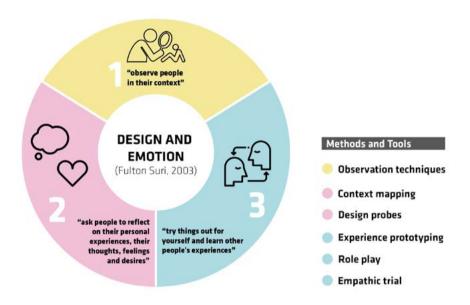
1. observe what people do in their own context through observation techniques (Stanton et al., 2014).

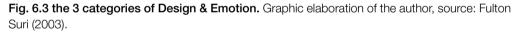
2. ask people to participate by reflecting on their personal experiences and expressing their thoughts, feelings and desires through methods and techniques such as context mapping (Sleeswijk Visser et al., 2005), Design probe⁸ (Mattelmäki, 2005). In particular,

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).





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.

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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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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