



# YOUNGCARE

RELIEF FOR YOUNGER PEOPLE IN NEED OF  
CARE AND THEIR INFORMAL CARERS

National report:

## **An Overview of the Situation of Informal Caregivers and Younger Adults in Need of Care in Portugal**



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the European Union

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## ABOUT THIS PUBLICATION

This report summarizes the national overview of informal care services and caregivers of individuals aged 18 to 65, outlines the needs and challenges encountered by the YoungCare target group, and provides practical support along with examples of good practices. Erasmus+ project **YoungCare: Relief for Younger People in Need of Care and their Informal Carers** (Grant agreement: 2022-1-DE02-KA220-ADU-000086558). **PROJECT WEBSITE:** <https://youngcare.eu/>

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## SYMBOLS, ABBREVIATIONS AND ACRONYMS

ANCI	Associação Nacional de Cuidadores Informais - National Association of Informal Carers
APELA	Associação Portuguesa de Esclerose Lateral Amiotrófica - Portuguese Amyotrophic Lateral Sclerosis Association
APPACDM	Associação Portuguesa de Pais e Amigos do Cidadão Deficiente Mental - Portuguese Association of Parents and Friends of the Mentally Handicapped Citizen
CAVI	Centros de Apoio à Vida Independente - Support Centres for Independent Living
CVI	Centro de Vida Independente - Centre for Independent Living
EU	European Union
ECI	Estatuto do Cuidador Informal - Statute of the Informal Caregiver
ENIPD	Estratégia Nacional para a Inclusão das Pessoas com Deficiência - National Strategy for People with Disabilities
ICF	International Classification of Functioning, Disability and Health
INE	Instituto Nacional de Estatística – National Institute of Statistics
INR	Instituto Nacional de Reabilitação - National Institute for Rehabilitation
IPSS	Instituição Particular de Solidariedade Social - Private nonprofit social welfare institution
MCCI	Movimento Cuidar dos Cuidadores Informais - Movement Caring for Informal Carers
MAVI	Modelo de Apoio à Vida Independente - Support Model for Independent Living
ODDH	Observatório da Deficiência e dos Direitos Humanos - Observatory on Disability and Human Rights
RACCI	Rede de Autarquias que Cuidam dos Cuidadores Informais - Network of Local Authorities Caring for Informal Carers
RNCCI	Rede Nacional de Cuidados Continuados Integrados - National Network for Integrated Continued Health Care
RNCP	Rede Nacional de Cuidados Paliativos - National Palliative Care Network
UN	United Nations
UNECE	United Nations Economic Commission
UNCRPD	UN Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation
WP	Work Package

## 1. AIMS OF THE NATIONAL REPORT

The project “YoungCare - Relief for younger people in need of care and their informal carers” aims at improving the situation of younger people in need of care. This is a group of younger adults up to the age of 65 who have become dependent on care as a result of a drastic event, such as an accident or serious illness and can no longer manage their everyday lives without help. In most cases, these people are neglected in care services and have problems receiving care tailored to their needs. In most cases, therefore, they are cared for at home. The partner organizations from Germany, Italy, Lithuania, the Netherlands and Portugal want to draw attention to the sometimes precarious situation of young adults in need of care and the people who care for them.

The national report is supposed to be an important part of assembling an European compendium. The compendium is meant to provide a scientifically based but practice-oriented and easily accessible overview of the situation of younger people in need of care and their informal carers. It is aimed primarily at these informal carers and people in need of care who are confronted with disease and care for the first time or who feel the need to improve their situation. It is part of Work Package 2 of the YoungCare project, which is intending to collect evidence on the perspectives of the target group, creating an extended knowledge base and developing solution strategies. The results of this work package are also meant to contribute to the development of the digital learning opportunities and the development of the publicity strategy in the following work packages. In order to accomplish the task of the European compendium being the main output of this Work Package the national reports from all the partner countries (Germany, Portugal, Italy, Lithuania and the Netherlands) are an important piece of input and information.

Although the main aim is to be a fundamental piece towards completing the European compendium the publication of the national reports also gives an overview of the situation of YoungCare in each of the countries represented by a partner organisation. It is important because it sheds a light on the daily struggles and hurdles young people in need of care and their informal carers have to face locally. Also, the political, public, and scientific discussion will be elaborated. Particularly because of the scarcity of data and information, it is important to use the national reports to provide an insight into the everyday lives of young people in need of care and their informal caregivers.

## 2. METHODOLOGY

Before describing the methods applied to achieve the above-mentioned aims, it is important to specify the target groups summarized as “younger adults in need of care”. The main criterion for the differentiation is the question if the need for care existed since



birth or was acquired during life (between 18 and 65 years of age). We intentionally use the term “younger adults” for the project to describe the age group that can neither be described as children and young people, nor as senior citizens. This is done with the knowledge that this age group encompasses a large age variation.

The distinction between the need of care since birth and a later acquisition seems to make sense in the context of the YoungCare project's objective to develop a practical educational tool. The thesis is that the first group (from birth) is already introduced into the social and care system through the offers in the child and youth sector. Even if problems arise with the transition to adulthood and care services (presumably) deteriorate, this group has experience with the issues of care and the social system. In the second group, there is a need to acquire this knowledge in an extreme situation.

People in need of care are defined as those persons who are dependent on help in managing their daily lives. All people who informally help other people to cope with their everyday life are defined as informal carers.

The following methods were applied during the finalisation of this National Report.

### 2.1 Desk Research

The partners conducted the desk research in their countries with a special focus on the national situation and focussed on the following topics:

- Facts and figures on care services, care needs, types of illnesses and types of care provided
- Scientific work on the topic
- Political and practical debates on the topic
- Obstacles and difficulties for the YoungCare target group in the provision of care and services
- Suitable offers and good practice offers for the YoungCare target group
- Suitable practical support for those affected and their carers (first aid)

### 2.2 Interviews

In each country, interviews with an open structure were conducted. They were conducted primarily with informal carers but, if possible, depending on the individual situation of the persons concerned, persons in need of care were also interviewed. A short amount of the interviews was conducted with experts to improve the understanding of the overall situation.

In Portugal the following interviews were conducted:

- **Experts:**
  - The President of National Association of Informal Carers (*Associação Nacional de Cuidadores Informais - ANCI*).





- A physiotherapist from Portuguese Amyotrophic Lateral Sclerosis Association (*Associação Portuguesa de Esclerose Lateral Amiotrófica - APELA*), specializing in amyotrophic lateral sclerosis.
- **Individuals in need of care:**
  - Person A: Required care from the age of 32.
  - Person B: Required care from the age of 33.
  - Person C: Became paraplegic due to an accident at the age of 40.

Two of the individuals (Persons A and B) were diagnosed with amyotrophic lateral sclerosis.

- **Informal carers of people that are in need of care in the age of 18-64 years old:**
  - Informal Carer A: A partner who takes care of his spouse with Parkinson's disease and dementia.
  - Informal Carer B: A caregiver for her son who is paraplegic.
  - Informal Carer C: Provides care for her mother, who is currently over 60 years old, and was previously a caregiver for two brothers, one of whom passed away from cancer and the other struggled with drug addiction.
- **Other informal carers:**
  - Informal Carer D: Takes care of her sister with Down Syndrome and her mother, who has dementia.
  - Informal Carer E: Provides care for her sister with Down Syndrome.

These interviews captured a range of experiences and perspectives within the realm of informal caregiving, shedding light on the challenges and responsibilities faced by both caregivers and those in need of care. Based on one of these interviews, there will be a short portrait of one person in need of care, which can be found in chapter 3.5



## 3. RESULTS

### 3.1. OVERVIEW OF THE NATIONAL SITUATION

There is no universally accepted definition of *disability*. The World Health Organisation (WHO) in its International Classification of Functioning, Disability and Health (ICF) considers the social aspects of disability, going beyond the understanding of disability as a sole *medical* or *biological* dysfunction.

Two key concepts are distinguished by the WHO:

- *Impairment*: Any loss or abnormality of psychological, physiological, or body structure or function, for example, paralysis or blindness.
- *Disability*: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (European Parliament, 2017).

There is also no European Union (EU) definition of *disability*, and concepts vary from one Member State to another. Nevertheless, since the *UN Convention on the Rights of Persons with Disabilities* (UNCRPD) in 2006 was signed by both the EU and its Member States, the definition provided by the United Nations (UN) has become a common reference. This states that “*disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others*”.

According to Article 1, “*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments...*”. The extent to which these impairments disable someone depends on the level of barriers encountered in society (Council of Europe, n.d.; European Commission, n.d.).

Due to the absence of a standardized definition of *disability* across the EU and considering the diverse range of statistical surveys that vary in terms of the questions asked and the population studied, it is currently unfeasible to obtain a comprehensive statistical assessment of the disabilities landscape in Europe and to make meaningful comparisons between countries. Nevertheless, the European Survey on Health and Social Integration conducted in 2012-2013 sheds light on the differences that exist within Europe. The survey indicates that disability is more prevalent among women, older individuals, and those with lower levels of education, as reported by the European Parliament (2017).

In Portugal, in the more recent Census (2021), data was collected regarding the existence of difficulties in performing six types of activities/functions defined in the model recommended by the *United Nations Economic Commission* (UNECE), which uses a concept of disability based on functionality, i.e., as a result of the interaction between the person and contextual factors, and not the result of an assessment based on medical diagnoses of disability.



According to this data (INE, 2022), 10.9% of the Portuguese population aged 5 and over have at least one disability. This means that approximately 1.127.394 people have disabilities in Portugal, with a strong prevalence in women (62% female and 38% male). Data from people that started to need care between 18 and 65 years of age was not found.

### **Some discrepancies in the data**

It is worth noting that the methodology used to collect data for the 2021 Census was different from the 2011 Census, resulting in approximately 700.000 fewer individuals being reported with disabilities in the latest edition.

The disability question was not mandatory, and more options were introduced to answer the question. According to Fortuna (2023), published data on this topic is unclear and requires more investment in studies to characterize this population. A comprehensive study is needed to identify various aspects, such as where these individuals are in the country, the degree of their disability, their occupation, travel habits, entertainment preferences, and the obstacles they face in their daily lives.

According to Diário de Notícias (2019), it is estimated that in Portugal, there are between 230.000 and 240.000 individuals who require care due to dependency. This suggests that a corresponding number of informal caregivers should exist, as reported by Expresso (2019). However, in 2017 Eurocarers states that approximately 8% of the Portuguese population provides informal care, which would amount to around 800.000 people in absolute terms. Out of this figure, 25% are classified as "full-time" caregivers, which corresponds to approximately 200.000 individuals (Araújo & Soeiro, 2021).

In contrast, the European Commission's projections indicate that the percentage of people providing informal care is 13% of the total population and 3.6% among employed workers, as reported in their 2018 publication (European Commission, 2018). A recent study conducted by the Movement Caring for Informal Carers (*Movimento Cuidar dos Cuidadores Informais* - MCCI) in 2021 suggests an even larger population of nearly 1.5 million people (approximately 15% of the total population) in this caregiving role. This increase is attributed to the closure of social services during the COVID-19 pandemic (Araújo & Soeiro, 2021).

It is estimated that 80% of caregiving in Portugal is carried out by non-professional caregivers, with a majority being women (Teixeira et al., 2017). If these caregiving responsibilities were to be taken over by formal public services, it is estimated that the cost to the State would exceed €4 billion annually, as mentioned by Eurocarers in 2017 (Araújo & Soeiro, 2021).



No further information on people with disabilities in need of care was encountered. Therefore, the following results are based on the most recent and accessible data for people with disabilities in Portugal, based on Census 2021.

The disability in walking or climbing steps is the most predominant and affects 6.1% of the population. Other impairments are related to eyesight (3.5%), cognition/memory (3.4%), hearing (2.8%), difficulty bathing or dressing without support (3.0%), and understanding others or making themselves understood (1.5%). The prevalence of disability increases progressively with advancing age, especially from 70-74 years onwards (see Figure 1).

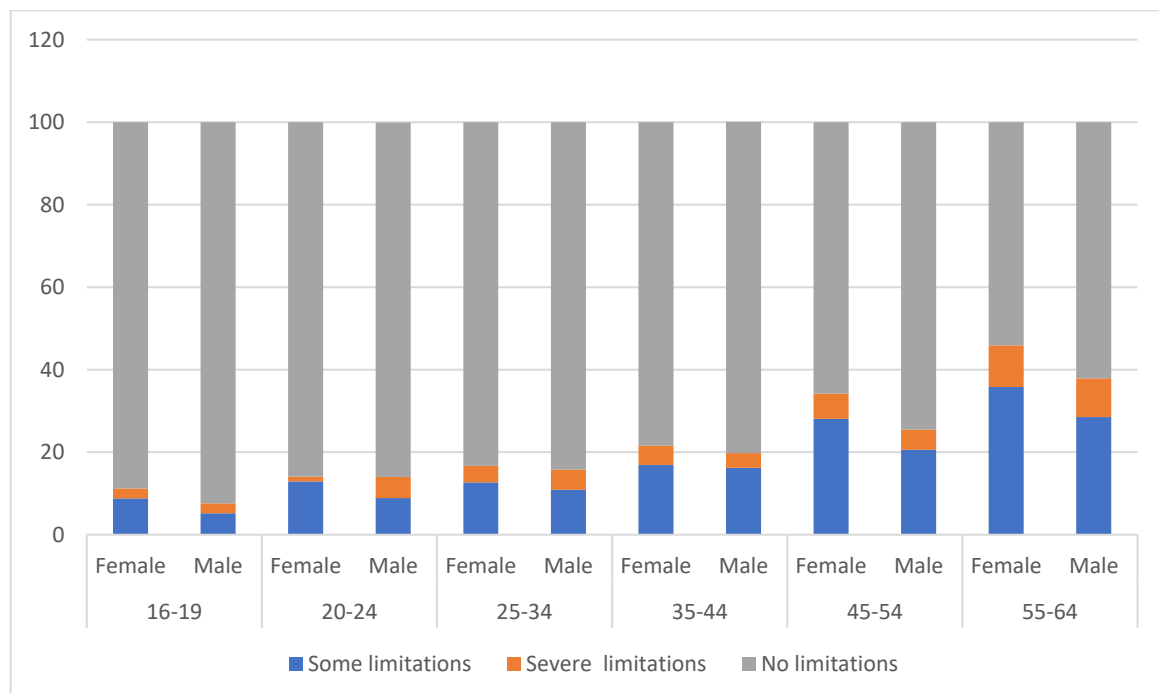


Figure 1 – Share of Portuguese individuals with self-reported long-standing limitations in usual activities, by age sex and different limitations. Source: Eurostat (2023).

According to the Observatory on Disability and Human Rights (*Observatório da Deficiência e Direitos Humanos - ODDH*) (2020), people with disabilities have a poverty risk of 31.2% (compared to 18.8% for the general population).

### 3.1.1. Education

According to the National Institute of Statistics (*Instituto Nacional de Estatística - INE*) (2022), 64.7% of the Portuguese population with disabilities aged 15 or over have completed only basic education. Although the Census reports show that 21.5% of the population with disabilities have not completed their schooling, the 2021/2022 academic year witnessed the highest number of young individuals with disabilities attending higher education institutions, with a total of 2779 students - representing an 8% increase from



the previous year. This increase has been consistent in recent years, as reported by Fortuna (2023) and the ODDH (2020).

### 3.1.2. Employment

In Portugal, there has been a small increase in the percentage of workers with disabilities in the private sector over the last five years, from 0.51% to 0.59% (ODDH, 2020).

Despite a law created in 2001, which retains 5% of external public competition vacancies for people with disabilities, only 2.8% of civil servants with disabilities were hired in 2022 (Expresso, 2023).

Women with disabilities face double discrimination in accessing employment, with greater difficulty than men with disabilities and anyone without disabilities. The employment rate gap between the disabled and non-disabled population was close to 16% in 2021, with a larger decrease for men than women (Lusa, 2022).

The inability to move is the most challenging disability for employment, with only 7.1% of people with mobility impairment being active in the workforce. Meanwhile, the inability to see is the impairment that relatively least affects the employment of people with disabilities (20.0% were active and 17.5% were employed at the time of the 2021 Census) (INE, 2022).

According to INE (2011), 16.2% of the population with at least one long-term health problem or difficulty performing basic activities require special work arrangements, such as sedentary work, teleworking, flexible hours, and less strenuous tasks. Women reported a relatively higher need for special work arrangements at 18.3%, compared to 13.6% for men. 13.4% of people with health problems and/or difficulties require personal assistance to work, while 8.1% require special equipment or workplace adaptations.



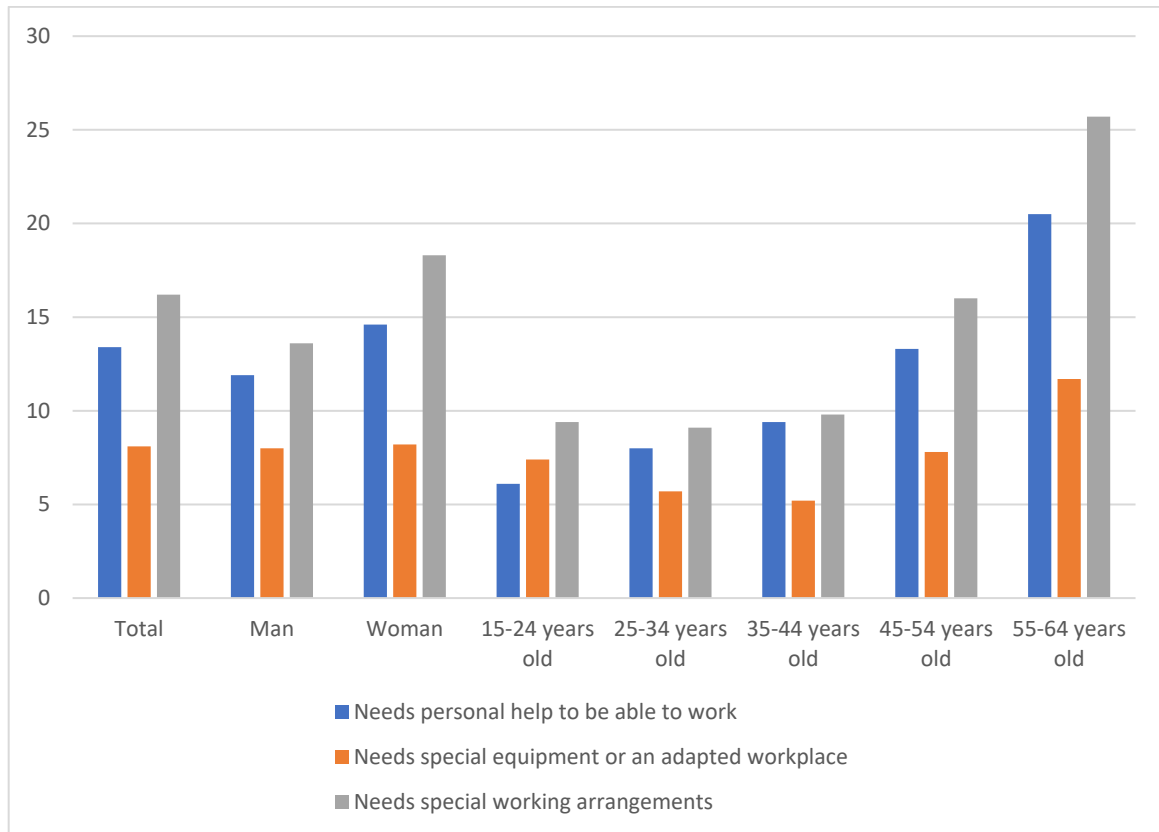


Figure 2 – Population with special needs for work due to health problems or difficulties by type of need, gender and age group. Source: INE (2011).

### 3.1.3. Housing

8.0% of the population aged 5 or more with a disability reside in collective housing, a significantly higher proportion than the general population aged 5 or more (1.5%). Additionally, 68.1% of the population living in conventional dwellings with mobility impairment and aged 5 or more live in dwellings that lack accessibility for wheelchair users without assistance. Only 3.2% of the population aged 15 or over with a disability travel to work or study, which represents a mere 13.3% of the total population aged 15 or over with a disability (INE, 2022).

### 3.1.4. Further limitations that may require care

According to Ribeiro and Pinto (2013), along with ageing and chronic illnesses, the significant number of road traffic and work accidents has also contributed to the increase in the number of people dependent on self-care.

Since numerous diseases have varying severity and care requirements, it is challenging to provide a comprehensive list. However, a compiled list of prevalent diseases that typically require care within this age range, based on the literature review, is presented in Table 1. It also includes the names of several associations that offer significant support in the field



of care, as examples. It is essential to acknowledge that this is not an exhaustive list of diseases, nor is it an exhaustive list of associations (a list of social associations recognized by the National Health Service can be found [online](#)<sup>1</sup>).

Table 1 – List of common diseases and accidents that may affect adults between 18-65 years old and require care, along with the respective Portuguese associations that offer support for each condition.

Disease / accident	Portuguese associations
Stroke <sup>2</sup>	Portugal AVC: <a href="https://www.portugalavc.pt/">https://www.portugalavc.pt/</a>
Motor disability (whether or not caused by road accidents)	Associação Salvador: <a href="https://associacaosalvador.com/">https://associacaosalvador.com/</a>
Alzheimer and (early) dementia	Alzheimer Portugal: <a href="https://alzheimerportugal.org/">https://alzheimerportugal.org/</a>
(Early) Parkinson	YoungParkies: <a href="https://www.youngparkiesportugal.org/quem-somos/">https://www.youngparkiesportugal.org/quem-somos/</a> APDPK: <a href="https://parkinson.pt/?lop=conteudo&amp;op=02e74f10e0327ad868d138f2b4fdd6f0">https://parkinson.pt/?lop=conteudo&amp;op=02e74f10e0327ad868d138f2b4fdd6f0</a>
Amyotrophic Lateral Sclerosis	APELA <a href="https://www.apela.pt/">https://www.apela.pt/</a>
Multiple Sclerosis	SPEM <a href="https://spem.pt/">https://spem.pt/</a>
Paramilodoise	Associação Portuguesa de Paramilodoise <a href="http://www.paramiloidose.com/">http://www.paramiloidose.com/</a>
Machado-Joseph	Associação Atlântica de Apoio aos Doentes de Machado-Joseph <a href="https://www.aaadmj.com/a-doenca/">https://www.aaadmj.com/a-doenca/</a>
Accidents in the workplace	Associação Nacional Deficientes Sinistrados do Trabalho <a href="https://cnod.pt/associacoes/andst-associacao-nacional-deficientes-sinistrados-do-trabalho/">https://cnod.pt/associacoes/andst-associacao-nacional-deficientes-sinistrados-do-trabalho/</a>
Depression and bipolar disease	Associação de Apoio aos Doentes Depressivos e Bipolares <a href="https://www.adeb.pt/">https://www.adeb.pt/</a>
Partnership of care associations in Portugal: <a href="https://plataformasaudeemdialogo.org/associados-main/">https://plataformasaudeemdialogo.org/associados-main/</a>	

<sup>1</sup> <https://www.dgs.pt/ficheiros-de-upload-2013/adus-lista-de-associacoes-reconhecidas-pdf.aspx>

<sup>2</sup> Stroke is a severe medical condition that requires immediate attention as it is presently the primary cause of death and permanent disability in Portugal. Every hour, three Portuguese individuals experience a stroke, with one of them ultimately succumbing to the condition. Furthermore, nearly half of the survivors are left with disabling after-effects. Annually, around 25.000 stroke patients require hospitalization in Portugal (Diário de Notícias, 2022a; SPMI, 2021).

### 3.1.5. Informal caregivers

In 2016, an organized movement of informal caregivers emerged in Portugal. Subsequently, a public petition was delivered to the Portuguese Parliament in support of their cause (Petição Pública, 2016). Finally, in July 2019, the Parliament approved the Statute of the Informal Caregiver (*Estatuto do Cuidador Informal* – ECI, 2019). The government proposed pilot projects to analyze the needs of the sample and provide more comprehensive coverage. As a result, the ECI pilot projects began in March 2020, lasting for 12 months and were carried out in 30 municipalities across the country. However, the arrival of COVID-19 in Portugal during that time led to social, economic, and political instability, which also affected the ECI program's implementation and caused delays and changes (Araújo & Soeiro, 2021; Canha, 2020; Diário de Notícias, 2022b; Soeiro & Araújo, 2020). Nonetheless, in early 2022, the Statute of the Informal Caregiver was extended to the entire country (eportugal.gov.pt, 2022).

Currently, the ECI guarantees a set of fundamental rights for informal caregivers (Segurança Social, 2022a), which are as follows:

- Recognition of their fundamental role in providing and maintaining the well-being of the person under their care.
- Accompaniment and training to develop their skills and acquire the necessary competencies to provide adequate health care to the person under their care.
- Access to information from healthcare and social care professionals.
- Access to information that, in conjunction with healthcare services, can provide insight into the progress of the illness and all available support.
- Access to information on best practices for training, monitoring, and advice for informal caregivers.
- Psychological support from healthcare services, as necessary, even after the death of the person under their care.
- Rest periods (“descanso do/a cuidador/a” meaning caregiver’s rest) are aimed at promoting their well-being and emotional balance.
- The ability to balance caregiving with their professional life, for non-primary informal caregivers.
- Eligibility for the student worker scheme when attending an educational establishment.
- The right to have a voice in the definition of public policies aimed at informal caregivers.





In addition, the informal main caregiver<sup>3</sup> is eligible for entitlements, including the informal main caregiver support allowance, which provides financial assistance from Social Security in the amount of €480.43 to those who meet the eligibility criteria (note that the minimum monthly wage in Portugal is €760 (*Decreto-Lei n.º 85-A/2022, de 22 de dezembro*)). The caregiver can also apply for Social Security benefits under the Voluntary Social Security Scheme. Furthermore, the caregiver can seek opportunities for reintegration into the labour market once their responsibilities as a caregiver come to an end (*Segurança Social, 2022a; Segurança Social, 2022b*).

The Labour Code Law has recently been updated to provide new rights to informal caregivers. Starting from May 1st, 2023, informal caregivers have the option to choose to telework, flexible working hours or part-time work. Non-main informal caregivers now have access to five days of leave and 15 days of justified absence. Additionally, they are protected from dismissal and discrimination in the workplace (*Lei n.º 13/2023, de 3 de abril*).

According to *Diário de Notícias* (2022b), Portugal has around 11.000 officially recognized informal caregivers, out of which only 2.689 receive an allowance. Most caregivers are women (83%) with an average age of 55 years and 30% of the informal caregivers show intense overload. From 22.078 applications submitted for subsidies, 6.672 were rejected for not fulfilling the eligibility criteria. Additionally, out of the 12.587 subsidy requests made, only 2.689 were approved, while 7.105 were rejected. According to the coordinator of the Social Security Informal Carers Working Group, the low number of subsidies awarded is due to a lack of resources, which leaves many caregivers without support.

From the survey results provided by MCCI (2021), media highlights and the narratives of the people interviewed for this report, it is possible to determine the slow process of scheduling, formulation and implementation of the ECI, the bureaucratic burden, the number of requirements, the lack of information and the unpreparedness of officials in the corresponding services (*Canha, 2020; DECO, 2022; Diário de Notícias, 2022b; Expresso, 2022a*).

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<sup>3</sup> The **main informal caregiver** is the person who provides full-time care to the person in need, lives with them in the same home and is a spouse, unmarried partner, relative or kin up to the 4th degree in the direct or collateral line of the person being cared for (e.g., children, grandchildren, great-grandchildren, siblings, parents, uncles, great-grandparents, great-uncles or cousins). They cannot be employed or paid for their caregiving, nor can they receive unemployment benefits.

The **non-main informal caregiver** provides care to the person in need on a regular basis, but not full-time. They may be employed and paid for their services, and need not be a family member of the person being cared for (*Segurança Social, 2022*).

### 3.1.6. Health and social care system

The health and social care systems in Portugal are governed by two Ministries, the Ministry of Health and the Ministry of Labour and Social Solidarity, and they include a vast network of public services, institutions and joint initiatives that aim to provide medical and social assistance to citizens. Among these initiatives are the National Network for Integrated Continued Health Care (*Rede Nacional de Cuidados Continuados Integrados - RNCCI*) and the National Palliative Care Network (*Rede Nacional de Cuidados Paliativos - RNCP*), which offer services for people with disabilities. The availability and quality of disability care services in Portugal largely depend on private non-profit social welfare institutions (*Instituições Particulares de Solidariedade Social - IPSSs*) that are co-funded by the government but have varied coverage in different regions of the country (Pinto, 2020).

The **National Network for Integrated Continued Health Care (RNCCI)** is an organisational model created by the Ministries of Labour and Social Solidarity and of Health, formed by a set of public and private institutions that provide continued health care and social support. Users can be referred to RNCCI services in two ways: if they are hospitalised in a National Health Service hospital; or if they are in the community (at home, in a private hospital or other institutions or establishments).

Moreover, with the specific aim of ensuring the rest of the informal caregiver, the latter can benefit from the following measures:

- Referral of the cared-for person, under the National Network for Integrated Continued Care (RNCCI), to an inpatient unit, with the RNCCI and RNCCI mental health institutions ensuring the appropriate response.
- Home support services are appropriate to the situation of the person being cared for, in situations where it is more advisable to provide care at home, or when this is the wish of the informal caregiver and the person being cared for (Fausto et al., 2019; National Health Service, 2021; Silva, 2021).

The **National Palliative Care Network (RNCP)** is a network based on an integrated and articulated intervention model, which envisages different types of units and teams for the provision of palliative care, cooperating with other hospitals, community, and home health resources (Fausto et al., 2019; National Health Service, 2021; Silva, 2021).

In Carta Social (n.d.) it is possible to search for **social institutions** by area of location that may help with health and social support. For the adult population in this context, three options are available:

- Adult people with disabilities: care, monitoring and rehabilitation centre; activities and empowerment centre for inclusion, residential home, autonomy and inclusion residence, home support service, transport for people with disabilities.
- People in a situation of dependency: integrated home support, integrated continuous care team, home support service, integrated support unit,



convalescence unit, palliative care unit, long-duration and maintenance unit, medium-duration and rehabilitation unit.

- People with mental/psychiatric illness: mental health home support team, socio-occupational forum, autonomous mental health residence, moderate support residence, maximum support residence, autonomy training residence, autonomy training residence, socio-occupational unit, supported living unit, independent living unit, protected living unit.

There are also **support measures for people with disabilities and/or incapacity**, such as the **Inclusion Desk**. It aims to provide information and specialized and accessible mediation to people with disabilities, their families, organizations and others who directly or indirectly intervene in the disability area. The main themes are accessibility; priority service; medical certificate of multi-use disability; tax benefits; culture, sports and leisure; education; employment and vocational training; parking; housing; early intervention; model of support to independent living; non-discrimination; parenting; social benefit for inclusion; support products/technical aid; social protection; health (Fausto et al., 2019; Simplex+, 2019).

### 3.2. OVERVIEW OF THE POLITICAL, PUBLIC AND SCIENTIFIC DISCUSSION

In recent years, there have been several **political discussions** about the status of informal caregivers in Portugal (Araújo & Soeiro, 2021; Soeiro & Araújo, 2020). Since this statute has been formally implemented at national level in 2022, informal caregivers have reported several difficulties with the long duration for approval of the statute, services it should provide that do not function properly, among other aspects (referred to in more detail in the section "Informal carers"). According to the Director of National Association of Informal Carers (*Associação Nacional de Cuidadores Informais – ANCI*), informal caregivers face challenges such as social isolation, psychological stress, and economic dependence, which are often overlooked by society and policymakers. Also, according to the director, one of the main challenges is the insufficient availability of human resources. It is crucial to have professionals from the health and social sectors who can form support teams for informal caregivers, by assessing the caregiver's burden and providing appropriate referrals. Additionally, there is a lack of resources for psychological support, which is currently not being provided and is foreseen in the ECI.

The President of ANCI also mentioned that the MCCI developed a comprehensive manual<sup>4</sup> to guide municipalities in providing care for informal caregivers. They have also introduced a Merit Label, which recognizes municipalities with exemplary practices and

<sup>4</sup> <file:///Users/utilizador/Downloads/Manual-RACCI.pdf>



support measures for the benefit of informal carers. Currently, 42 municipalities are part of the Network of Municipalities Caring for Informal Carers (*Rede de Autarquias que Cuidam dos Cuidadores Informais* - RACCI).

In 2021, Portugal became the first European country to approve a National Strategy for People with Disabilities – *Estratégia Nacional para a Inclusão das Pessoas com Deficiência* ENIPD (2021-2025), following the approval of the European strategy. The strategy is divided into eight axes, which include the revision of the national table of disabilities, the creation of inclusion plans by ministries to adapt to the needs of people with disabilities in their contact with public services, and the creation of resource centers to support students with disabilities in higher education institutions. The Secretary of State has also mentioned the creation of a support line to improve accessibility to culture and enable people with disabilities to participate in cultural production (INR, 2021; Observador, 2021; Recuperar Portugal, n.d.). In September 2022, the Annual Report had still not been delivered, even though it was already six months overdue. Out of a total of 175 planned measures to be implemented between 2021 and 2025, INR only listed approximately 20 measures for 2021, falling significantly short of the target of 75 for that period. Some examples of these measures include launching programs to eliminate architectural barriers under the Recovery and Resilience Plan, establishing a Portuguese sign language interpretation service in the SNS24 (digital platform of the National Health System), implementing nationwide measures to support informal care, and creating the Sport + Accessible award (Expresso, 2022b).

Associations and movements of people with disabilities have a significant impact on **public discussions** in Portugal. The development of the statute for informal carers, for example, was due to pressure from such a movement (Soeiro & Araújo, 2020). These associations regularly discuss their concerns and organize events to raise awareness on disability-related issues. For instance, on the *European Day of Independent Living* in 2023 (5<sup>th</sup> May), associations held demonstrations in four different locations, including Vila Real, Porto, Lisbon, and Guimarães. During one of these events, Jorge Falcato, the leader of Centre for Independent Living (*Centro de Vida Independente* - CVI), criticized the State's delegation of the policy related to personal assistance to IPSS. He argued that "*The vision that some IPSS have of what independent living is will not be the most correct. Dependent people who have very few hours [of assistance] just so [the IPSS] can have 50 recipients of personal assistance does not seem right to us*" (RTP, 2023).

Portuguese Association of Parents and Friends of the Mentally Handicapped Citizen (*Associação Portuguesa de Pais e Amigos do Cidadão Deficiente Mental* - APPACDM), another association, has launched a public campaign called *Open to Work* to promote the integration and empowerment of people with intellectual disabilities in the labour market. The campaign will use *mupis* placed in public spaces to raise awareness of the new quotas for hiring people with disabilities in companies (Sapo, 2023).

Despite the existence of a considerable number of **scientific** papers on the care of older people and children, there is a noticeable lack of literature concerning people in need of care between 18 and 65 years of age and their informal caregivers. Although some studies exist that focus on the inclusion of people with disabilities in the University and labour market, they appear to address those who require less care. Unfortunately, there is a scarcity of statistical data regarding this age group in Portugal. Fortuna (2023) highlights this deficiency and points out that the census data available is insufficient to answer essential questions such as: *“who these people are: where are they in the country? What degree of disability do they have? What do they work in? Do they travel? Do they invest in entertainment? What obstacles do they encounter in their daily lives? Do they suffer discrimination? The censuses ask some of these questions, but they are insufficient.”* (Fortuna, 2023).

It is however promising the work developed by the ODDH, which aims to improve the status and development of human rights for people with disabilities by monitoring disability policies in Portugal and Portuguese-speaking countries. Since 2017, the ODDH has produced annual reports on people with disabilities in Portugal to measure progress towards greater disability rights.

### 3.3. NEEDS, CHALLENGES AND SOLUTIONS

In order to delve further into the report, a series of interviews were conducted, as discussed in section 2.2. The details of these interviews can be found in that section and in



Table 2.

Case no.	1	2	3	4	5	6	7
Status in research	Person in need of care P1	Person in need of care P2	Person in need of care P3 Informal Caregiver (IC3)	Informal Caregiver (IC4)	Informal Caregiver (IC5)	Informal Caregiver (IC6)	Informal Caregiver (IC7)
Reason(s) to be in need of care	Amyotrophic lateral sclerosis	Amyotrophic lateral sclerosis	Paraplegic	Parkinson /dementia	Down syndrome	Sister: Down syndrome Mother: Dementia	1 brother : drug abuse; 1 brother : cancer; mother : ageing
Age	36	45	43	45	54	Sister: 59 Mother: 91	--
Age, when need of care was diagnosed	32	40	33	Before 40	Born	Sister: born Mother: 86	--
Caregiver	Mother, partner, formal caregiver	Mother, 2 informal carers	Mother	Husband	Sister	Sister / mother	Sister / mother

Table 2 – Overview based on interviews with informal caregivers and their caregivers.

### 3.3.1. Role of associations and the Statute of the Informal Caregiver

Individuals with higher literacy levels and favorable socioeconomic backgrounds often conducted online research when they began caring for the adult in need. Through their research, they discovered the potential support available from associations and the importance of requesting the ECI.

According to one caregiver, associations not only offer practical tips and training but also provide psychological support, which is a legal requirement but currently not implemented. They create a sense of understanding and connection, as expressed by the following quote from caregiver of case 4: “And when I called there [Parkinson's Association], I felt for the first time that the person on the phone finished my sentences,

knew exactly what stage I was in, I explained a little bit the diagnosis, how long ago and I felt understood for the first time.”.

Regarding the ECI, the interviewees pointed out the difficulties in the application process. As stated by caregiver of case 4: “To apply for the ECI, you need to have a degree, if not a post-graduate degree, to be able to fill in all those forms. It's not simple at all”. The renewal process was also mentioned as a challenge. The interviewees expressed the need for a reference person at Social Security, but the process was slow, as highlighted by caregiver of case 4: "I've already renewed the card, I'm already on my fourth time, they haven't called me once".

The interviewees emphasized the need for significant changes to the system. They called for the extension of the ECI measure to friends and neighbors beyond relatives, the elimination of the need for frequent status renewals, simplifying bureaucratic processes, ensuring inclusive criteria for caregiver support allowances, recognizing caregiving as a legitimate profession with appropriate remuneration, and reevaluating the concept of caregiver's rest. As expressed by one caregiver (IC6): "The way it is, I think that even if it was already in the field, people would hardly accept it. Which is the carer that goes on holiday and leaves the cared one to go to an institution? I would prefer not to go on holiday, because my mother is at home at the moment and often, she doesn't know whose house it is anymore. And we go to the bathroom, and she asks where I am going, if it is here or there. So, if she went to an institution, no matter how well looked after she was and how good the conditions were, she would certainly come back worse.”

Additionally, one interviewee, who is an amputee and an informal carer, mentioned the lack of monetary support. While being autonomous, she is considered ineligible for caregiving benefits, which puts her in a financially tight situation as she lives in social housing.

These interviews shed light on the crucial role of associations, the challenges in the ECI application process, and the need for significant improvements in the support measures for informal carers.

### 3.3.2. The importance of support networks

In general, the interviews revealed a significant burden and caregiver syndrome, characterized by exhaustion and overload. The caregivers emphasized the importance of services that facilitate their rest and provide support. Some of the services include:

- Nursing homes: One caregiver mentioned enrolling their loved ones in nursing homes due to their own inability to provide adequate care as they age. One caregiver expressed: “I went looking for and enrolled in the nursing homes there were because with age, as age advances, I didn't know how to take care of myself anymore, so it was necessary to take care of her.” (IC5).





- Day centres: Other caregiver highlighted the value of day centers, even though they are often associated with older people. One caregiver stated: “It is good that we have that day center. [although] it is often [associated with] older adults, when they should be talking about the user.” (IC4).
- Associations with volunteers: Caregivers mentioned associations that provide volunteers to look after the person in need of care for a week. This allows the caregiver to have a break. As one caregiver shared: “I heard about one center that receives people once a year [...]. I started going to that annual center for a week year by year. My sister could stay at this center where there were volunteers to accompany her.” (IC5).
- Family support: Caregivers acknowledged the importance of family members who can offer assistance. For instance, one caregiver mentioned asking her mother-in-law to care for her daughter one week a month.
- Hiring assistance for hygiene services and night accompaniment: caregivers who had the financial means mentioned hiring individuals who can assist with hygiene services and accompany the person in need of care during the day and/or nights. This arrangement allows caregivers to have some rest. As one caregiver explained: “And then the two ladies come, and in the meantime, I have also asked them to do alternating Saturdays. So that on Saturday, I could organize my house, go to lunch with my husband, and relax a little bit.” (IC6).

It is worth noting that two interviewees with vulnerable socioeconomic backgrounds relied heavily on family support. For one caregiver (IC7), being with her daughter, who lives in another country, provides her with “another energy, more positive”, and she feels she can rest more in that environment. Another caregiver (IC3) emphasized the significance of living close to her sister, even though it restricts the son she cares for from leaving home due to the inaccessibility of their current accommodation.

### 3.3.3. Voices of those in need of care

For two individuals diagnosed with Amyotrophic lateral sclerosis, who require significant care, certain services fall short, placing a tremendous burden on their informal caregiver. One of them, with a 97% disability, only receives 18 hours of caregiver support per week, leaving her mother and husband responsible for most of her care. The other person also faces issues with some services. Despite being eligible for a personal assistant from the Support Centers for Independent Living (CAVI), they describe the following situation: “...multiple times, the assigned assistant was absent in the morning without any notice. As a result, I had to contact everyone I knew to see if someone could come to the house before they went to work, as using the bathroom in the morning is a basic right. Moreover, the assistant exhibited depressive behavior and said things to me that I believe no





terminally ill person should have to hear. Eventually, the situation escalated, and CAVI accused me of being rude, leading to my exclusion from the project.”.

These individuals emphasize the importance of a reliable informal caregiver who is capable of performing transfers, effective communication, shared interests, mutual respect, empathy, and a positive attitude. Possessing a driver’s license is also essential for facilitating transportation to appointments and other necessary outings.

One of the individuals being cared for, who is paraplegic, expressed a sense of relative autonomy. However, his living environment is not wheelchair-accessible, preventing him from leaving his home unless he has an appointment and can rely on the fire brigade for transportation. Currently unemployed and facing economic challenges, he managed to take some online courses during the pandemic, but he currently feels isolated.

### 3.4. GOOD PRACTICE EXAMPLES

#### CAVI – Centro de Apoio à Vida Independente [Centre for Independent Living]

The Support Model for Independent Living (*Modelo de Apoio à Vida Independente - MAVI*) programme is a pilot project in Portugal that started in 2019. The goal of this project is to support people with disabilities to live independently, breaking the cycle of institutionalization and dependence on family members, which also benefits informal caregivers. The MAVI programme provides **personal assistance** to people with disabilities through Support Centres for Independent Living (*Centros de Apoio à Vida Independente - CAVI*) (INR, 2022). The personal assistance provided through the MAVI programme covers several areas, such as:

- Support activities in the fields of hygiene, food, health maintenance and personal care;
- Support activities in domestic assistance;
- Support activities in travel;
- Communication mediation activities;
- Support activities in the work context;
- Support activities to attend vocational training;
- Support activities to attend higher education and research;
- Culture, leisure and sport support activities;
- Support activities in the active search for employment;
- Activities to support the creation and development of social support networks;
- Activities to support participation and citizenship;



- Activities to support decision-making, including the collection and interpretation of information necessary for it (*Decreto Lei nº129/2017, de 9 de Outubro 2017*).

The MAVI programme is based on the philosophy of Independent Living, which is a way of life for people with disabilities that covers all aspects of life, including access to goods and services, starting a family, accessibility, and mobility. This philosophy assumes that people with disabilities have the right to self-determination and can decide about their own lives (CVI, n.d.; ENIL, 2023).

The MAVI programme is co-funded by the European Structural and Investment Funds - Portugal 2020 Operational Programmes and is managed by the National Institute for Rehabilitation (*Instituto Nacional de Reabilitação - INR*). Currently, there are 35 approved CAVIs in Portugal, serving the North, Centre, Lisbon, Alentejo, and Algarve regions (INR, 2022), and in 2023, there are 1058 recipients and 783 personal assistants enrolled in the project.

This project ends in June 2023. The current Secretary of State hopes to make the MAVI model a permanent fixture in Portuguese law, but there is no certainty about this happening yet (*Diário do Minho, 2023*).

The Portuguese government has pledged to introduce legislation by the end of this year to regulate the definitive version of personal assistance for people with disabilities. The project is set to expire in June 2023, and the current Secretary of State hopes to establish the MAVI model as a permanent fixture in Portuguese law. However, it is uncertain whether this will come to fruition. Members of the CVI (2023) have expressed concerns over the lack of information regarding access and conditions of the provision of Personal Assistance in 2024. They are particularly worried about how many people will be entitled to assistance, how many hours of assistance they will receive, and who will manage personal assistance.

### **C<sup>2</sup> ID - Capacitar os Cuidadores Informais na Área da Deficiência [Empowering Informal Carers on Disability]**

This project aims to provide support for informal caregivers of people with disabilities in the northern Portuguese municipalities of Porto and Vila Nova de Gaia. The goal is to recognize and address the significant physical, emotional, and social burdens placed on caregivers, which can greatly impact their quality of life.

The project provides a **personalized intervention** for the caregiver, carried out at home by a multidisciplinary technical team consisting of a Social Worker, Psychologist, Occupational Therapist, and Physical Trainer. The team works with the caregiver on strategies for the act of caring, tailored to the individual characteristics of the caregiver and the person they are caring for.



The initiative also offers participation in **sharing groups**, where caregivers can exchange experiences and knowledge about caregiving and develop new relationships of support and mutual help. This helps strengthen the link between the caregiver and the local community and enables them to make active use of existing resources in their area.

In addition, the project offers an **app** that caregivers can use to access activities, videos, exercises, and useful information. This app is initially aimed at users of the Portuguese Association of Disabled People - District Delegation of Porto.

This project is supported by the Portugal Social Innovation Programme and has partners including the Porto City Hall, the Vila Nova de Gaia City Hall, and the Parish Councils of Bonfim, Paranhos, and Campanhã. However, the project is, unfortunately, ending this year, and the team is actively seeking new funding to continue providing this much-needed support for informal caregivers in the region (APD, n.d.).

### Access Lab

Access Lab is a company that works on the **access of people with disabilities, as for example deaf people, to culture and entertainment** as a fundamental human right, as these are spaces for maintaining freedom. It was co-founded by Tiago Fortuna in 2021 and they work to promote accessibility on websites, physical routes and in programming; inclusive ticketing systems; and audience mediation through the collaboration from artists, professionals, politicians, institutions and people with disabilities and deafness (Access Lab, 2023).

### Resource 1 - Guia Prático: Os Direitos das Pessoas com Deficiência em Portugal [Practical Guide: The Rights of People with Disabilities in Portugal]

*Guia Prático: Os Direitos das Pessoas com Deficiência em Portugal* is a practical guide on the rights of people with disabilities in Portugal. It was published in 2019 by the INR.

The guide provides information on the legal framework and the rights of people with disabilities in Portugal. It covers a wide range of topics, including accessibility, education, employment, health, social security, and transportation. It also provides practical advice on how to access these rights and where to seek assistance.

The guide is organized in a user-friendly manner, with clear and concise information, and is available in both print and digital formats. It is intended for people with disabilities, their families, caregivers, and professionals who work with them (Simplex+, 2019).

### Resource 2 – Portal eportugal.gov.pt



Portal [eportugal.gov.pt](https://eportugal.gov.pt) is a comprehensive online platform that provides a wide range of public services to users. One of its offerings is a practical guide tailored specifically for informal caregivers, which provides relevant information regarding the healthcare system and other related topics. The guide can be accessed via a browser search for "Área do Cuidador Informal" or through this direct link: <https://eportugal.gov.pt/pt/guias/cuidador-informal>. It should also be noticed that some links are not available. However, the website contains some relevant information.

This practical guide offers a range of information and resources to support informal caregivers. Here are the main topics covered:

- **Capacitation and Training:** This section provides information on training programs, videos, manuals, reports, and mobile applications that may facilitate and assist caregivers and the individuals they care for.
- **Social Protection and Benefits:** Informal caregivers may provide care for individuals with disabilities, dependency, or incapacity. This section explains how to access social security benefits and support products for those who qualify.
- **Helplines and Other Support:** This section provides a list of contact numbers for various helplines, including emotional support, suicide prevention, public health, medicines, and dementia support. The guide also lists informal caregiver associations, associations recognized by the Directorate-General for Health, and related public and private entities.
- **Frequently Asked Questions:** This section answers common questions about informal caregiving.
- **Legislation:** This section outlines health, social, labour, and other legislations that may be useful to informal caregivers.
- **Recognition and Allowance:** This section provides information on how to request recognition of the informal caregiver status and how to claim the informal main caregiver's allowance.
- **Health and social support services and measures:** This section presents a list of existing social and health bodies, a search for the public, social and private healthcare providers and also health support measures.

### 3.5. PORTRAIT

All the individuals we interviewed, including informal caregivers and those in need of care, shared deeply challenging stories at various levels. They spoke of struggles such as insufficient state support, financial hardships, and the overwhelming physical and psychological toll of their circumstances. However, their stories also revealed tremendous



resilience, deserving further analysis. We will focus on one particular story that addresses multiple points raised by other interviewees.

This is a husband caring for his wife, who was diagnosed with Parkinson's disease before the age of 40 and has since also been diagnosed with dementia. At 45 years old, she is now retired. This husband, referred to as IC4, shared his experience of gradually assuming the role of an informal caregiver of case 4. Reflecting on this transition, he mentioned:

*"I can tell you exactly when I got married, when I dated, when I became a father. I can give all those dates. Now, when I became an informal caregiver, I don't know. It was a role that I took on, without knowing that this had a name."*

Although his wife received good communication and explanation of the diagnosis from the neurologist, IC4 admitted that they didn't immediately grasp all the implications the diagnosis would have on their lives. In their search for assistance, he discovered various associations. However, IC4 expressed the challenges he faced during this process, stating:

*"Little by little this is a bit of a treasure hunt, we go from one to the other and we pick and choose. But it would be so much easier if neurologists or doctors or specialists could recommend an association. Because there you are, I have the capacity to go online, to go on the Internet. Now, if the same diagnosis happened to my parents, none of this would have been done."*

These associations have played a vital role in improving the quality of life for both IC4's wife and himself. His wife has access to online classes such as yoga, singing, and physiotherapy. Additionally, IC4 has received training on caregiving techniques and participates in group sessions with other informal caregivers. He emphasized the importance of these associations in feeling understood by others in similar situations and being part of a supportive community. Recounting an event organized by one association, he described the profound impact of witnessing a community come together, stating, "It is wonderful to see people suffering from the same illness, the same disease, some in more advanced stages than others, but sometimes accompanied... This community is fundamental".

Moreover, the association has provided IC4 with crucial information, including his eligibility for a specific subsidy that he believes he wouldn't have been informed about if he had solely relied on Social Services. He expressed a sense of distrust towards public services, mentioning that when visiting such organizations, "We already have to go there with some information. That's why there are a lot of people who are in this informal caregiver world that don't receive allowances and don't have access to information."

Daily, IC4 faces several challenges. Although he has some flexibility in his work schedule and can accompany his wife to appointments, they have had to adapt their lives. For instance, their travel plans had to be put on hold due to the complications caused by his



wife's dementia. Furthermore, the dynamics of their relationship have changed, and IC4 has had to handle his two daughters' activities more independently. Seeking support, both daughters receive psychological counseling to learn how to manage their mother's illnesses. He emphasized the potential impact of the diagnosis on his daughters' lives, saying:

*"Although nobody realized at the time what it [diagnosis] would entail later on, but as they grow up, they will see it and they will cope. And this family could have been destroyed by the disease. This diagnosis is very strong. It affects the body, but it affects the whole household."*

IC4 acknowledged the importance of self-care, recognizing that he must take care of himself in order to effectively care for his wife. After his wife's dementia diagnosis, he realized the need for more rest, as her presence at home often disrupts his own activities. To address this, he requested help from his in-laws to care for his wife for a week, allowing him to rest and recharge. He described this respite as "my way of getting rest."

In addition to these challenges, IC4 encountered a lack of understanding from certain healthcare professionals and a lack of state support. He recounted an incident when his wife went missing. He was contacted by the health centre and as soon as he got there a nurse argued with him in front of everyone, saying that in the state his wife was in he had to lock her in the house. Reflecting on this experience, IC4 expressed the impact of such judgments from healthcare professionals, stating, "when you have a health professional who disrespects you like that, that is very harsh. The judgment is hard." Furthermore, as an informal caregiver who continues to work, IC4 is unable to access certain allowances despite his caregiver status, which he considers unfair. The increasing expenses related to his wife's care, including medications and necessary examinations that sometimes require travel, further compound these challenges.

IC4 endeavors to maintain a social life with his wife, understanding the importance of their quality of life. He mentioned making adaptations to their social activities, avoiding restaurants where his wife may feel uncomfortable and instead hosting gatherings at home, such as barbecues. He emphasized that "we have to have some quality of life. And this part also has to be understood, that the caregivers don't have to be punished".

As a man occupying a role predominantly filled by women, IC4 noticed a gender disparity during a public session on informal caregivers. There were more women talking than men and he felt a stronger sense of strength and resilience from the women. He mentioned:

*"I want to be more like women than like men. I felt much more strength in women than in men. There is that resilience, but there were also some lives that were sacrificed, where there is no quality of life, where there is great wear and tear, where the person does not take care of themselves. And that's something I don't do."*





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