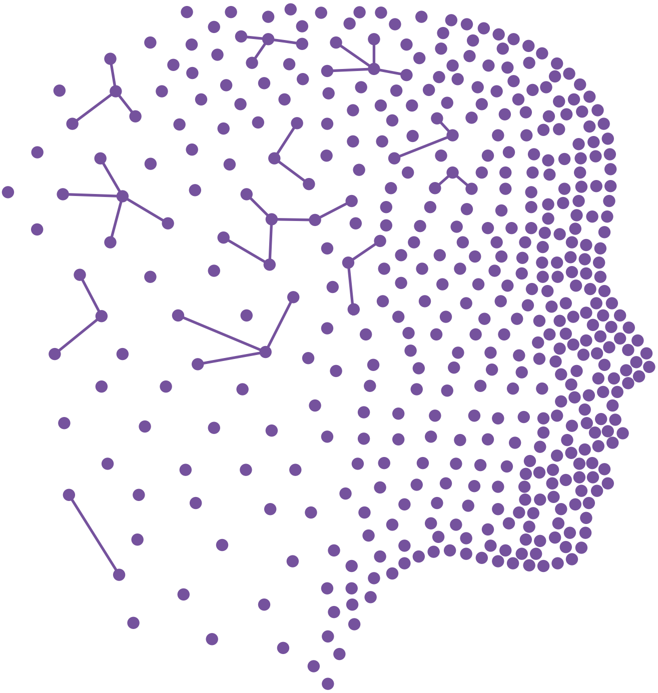
Henrique Lopes,
NOVA Center for Global Health,
NOVA IMS, June 2024

Preface
Rosário Zincke

LIVING WITH DEMENTIA



An insight into the lives of informal caregivers of people living with dementia in Portugal

NOVA Center for Global Health,
NOVA IMS, Universidade NOVA de Lisboa
Campus de Campolide
1070-312 Lisbon, Portugal
Tel. 351 213 828 610
globalhealth@novaims.unl.pt

Title
Living with Dementia: An Insight into the Lives of Informal Caregivers of People with Dementia in Portugal

Author
Henrique Lopes

Pagination and cover design
Laura Mariana Silva (linkedin.com/in/laura-mariana/)

e-ISBN 978-972-8093-30-3
DOI 10.34619/dtnk-g4cr

Translated from the portuguese edition originally published as *Viver com Demência: Um Olhar sobre a Vida dos Cuidadores Informais de Pessoas com Demência em Portugal*, 2024

All proceeds generated from the sale of this book are fully donated to Alzheimer Portugal Association.

How to cite
Lopes, H. (2026). *Living with Dementia: An Insight into the Lives of Informal Caregivers of People with Dementia in Portugal*. (NOVA Center for Global Health). Lisboa: Instituto Superior de Estatística e Gestão de Informação da Universidade Nova de Lisboa. NOVA Information Management School (NOVA IMS). ISBN: 978-972-8093-30-3. DOI: https://doi.org/10.34619/dtnk-g4cr

TECHNICAL INFORMATION

Writer and Scientific Lead:
Prof. Henrique Lopes, PhD

Scientific & Technical Collaboration and Review:
Prof. Ana Valverde, PhD
Filipa A. Gomes

Project Scientific Secretariat:
Catarina Hermenegildo

Ethics Statement

The Living with Dementia project received sponsorship from the pharmaceutical company Roche, including the publication of this e-book.
The sponsor had no involvement at any stage of the scientific research—from its conception to the production of this book.

ACKNOWLEDGEMENTS

On my own behalf, as scientific coordinator of the Living with Dementia project, and on behalf of the NOVA Center for Global Health, as its Director, I would like to express my gratitude to Alzheimer Portugal for their ongoing support and professionalism, for the many contributions they provided, for their constant availability and, above all, for the emotional commitment that went far beyond any professional duty, making each step of this work a moment dedicated to the Person living with Dementia.

I am also grateful to the individuals who had the patience to listen to us and to speak with us over countless hours of in-depth interviews - moments in which they voluntarily shared very difficult memories and deeply personal aspects of their lives, something only possible out of love for the person they care for.

My thanks also go to the hundreds of people who agreed to answer a lengthy survey, in the hope that their participation could be one more step on a journey that we wish to walk together towards the future.

Henrique Lopes
June 2024

PREFACE

Living with Dementia – An Insight into the Lives of Informal Caregivers of People Living with Dementia in Portugal is, without a doubt, an invaluable tool for convincing our political decision-makers of the urgent need not only to develop but, above all, to implement policies that truly make a difference in the lives of People with Alzheimer's Disease or other forms of Dementia, as well as in the lives of their Caregivers.

As the study rightly notes, there is some bias, since the questionnaire was applied mostly to members of Alzheimer Portugal - that is, to people who have already sought information, who know and have used our services, and who may even have participated in our initiatives.

Despite the large number of Alzheimer Portugal members and the fact that this nationwide organisation, now 36 years old, is known to many, the reality is that there are still many Caregivers who are unfamiliar both with our association and with any form of support or services available to them.

The study highlights precisely the geographic and social inequalities that manifest in discrepancies in health literacy levels and, consequently, in reduced access to care and poorer quality of life when information, economic resources, and social support fail to reach people.

The **"Insight into the Lives of Informal Caregivers of People Living with Dementia in Portugal"** offered in this book clearly illustrates the relevance of the National Health Strategy for Dementia (Order No. 5988/2018 of 06.06), which recognises as "fundamental the support provided to informal caregivers." The strategy underscores the importance of assessing their needs and explicitly refers to supporting and empowering them in their role, integrating them into the planning of care for the Person with Dementia, and acknowledging that those who provide informal care also require health interventions that promote their own well-being and quality of life.

However, both the national plan and the corresponding regional plans - designed to put this Strategy into practice - are still in the implementation phase. These plans include: operationalising care pathways through the creation of Functional Coordinating Units (teams of professionals who coordinate across levels of care, following a proximity-based logic with a strong emphasis on Primary Health Care); developing specific therapeutic interventions; strengthening the training of professionals; increasing citizens' health literacy; and reducing stigma through information and awareness campaigns, as well as providing a dedicated microsite offering information to the public about Dementia and updates from the National Dementia Plan Commission.

The questionnaire responses make very clear the urgent need to implement a national, integrated response for the approximately 205,000 People living with Alzheimer's Disease and other forms of Dementia in our country - and for their caregivers. Such a response must be capable of reducing inequities and guaranteeing access to specialised, high-quality care from diagnosis through end-of-life.

As we stated in the **Manifesto for a Future Memory**, launched in 2022, we must **Prioritise** - recognising Dementia as a national social and public health priority; **Implement** - putting into practice the policies already developed; **Raise Awareness** - through a national campaign to combat stigma; and **Strengthen Coordination** - ensuring effective articulation between different sectors, particularly Health and Social Security.

We believe that this publication will help reinforce the work we have been doing - thus far without the desired level of success - among political decision-makers.

From the **"Insight into the Lives of Informal Caregivers of People Living with Dementia"**, it becomes unequivocally clear that the Informal Caregiver Statute, created in 2019 and its corresponding regulations, falls far short of what should be the effective recognition of the social and economic role that Caregivers play in our society. This is evident from the outset, as it excludes the vast majority of Caregivers from its measures, particularly financial ones. Even the amendments to the Labour Code introduced under the Decent Work Agenda, which recognise the figure of the Worker-Caregiver, only very timidly enable the reconciliation of professional life with caregiving responsibilities for the Non-Primary

Informal Caregiver. As the survey responses show, this is one of the major challenges faced by Caregivers of working age.

We congratulate the entire team for the quality and relevance of the work carried out and express our appreciation for the opportunity given to Alzheimer Portugal to participate.

Rosário Zincke
President of Alzheimer Portugall

LIST OF ACRONYMS

AP: Alzheimer Portugal Association
ERPI: Residential Long-Term Care Facilities for Older People
INE: National Statistics Institute (Portugal)
WHO: World Health Organization
PwD: Person(s) with Dementia
EU: European Union

EXECUTIVE SUMMARY

We have grouped the main conclusions into seven key areas:

1. **About the sample participating in the study**
    a. The study is declarative in nature, based on the personal experience of informal caregivers of People with Dementia (PwD). The respondents were primarily members of Alzheimer Portugal (AP) and individuals active on the social media platforms where AP communicates.
    b. It is based on a sample of more than 300 informal caregivers from across the country, with strong representation along the coast and in major urban centres.
    c. The individuals who chose to participate represent the best-case scenario in Portugal, as they come from groups that differ significantly from national averages in terms of literacy and digital integration.
    d. Their association with dementia-related organisations also demonstrates a level of proactivity far above national averages.
    e. The gender distribution in the study aligns with European patterns among caregivers of PwD.
    f. The average age of respondents (57 years) highlights two age groups in need of targeted solutions: those who are of working age and must balance employment with caregiving responsibilities, and those of advanced age who nonetheless remain active as informal caregivers.
    g. Seventy-six percent of validated responses indicated that the PwD for whom they care is still alive, while the remaining 24% reported that the PwD had passed away.

2. **Dementia diagnosis**
    a. According to informal caregivers, 53% of PwD in the study were unaware of their diagnosis, which represents a negative scenario with regard to patient rights. However, there has been positive progress: compared with 10 years ago, the likelihood that a PwD knows their diagnosis—should they wish to—has doubled.
    b. Underestimation of dementia symptoms, attributing them instead to normal ageing, resulted in delayed diagnosis and appropriate treatment for 37% of respondents. This highlights the need for increased

dementia training in areas outside neurology and psychiatry, to allow quicker identification of suspected cases and referral to specialist care.

c. Only one quarter of PwD represented in the sample received information about disease progression at the time of diagnosis, demonstrating the need for improved communication at this difficult stage.

d. The dementia diagnosis affected the employment situation of all PwD in the sample who were still active in the workforce.

3. **After the diagnosis, much changes**

   a. Eighty-six percent of informal caregivers reported that holidays and similar relaxation activities became more difficult after the dementia diagnosis, with 51% stating that taking holidays became “very difficult”. It was also observed that children were more affected than spouses in terms of loss of rest and relaxation time.

   b. Sixty-one percent of informal caregivers recognised changes in the PwD’s leisure activities after diagnosis, ranging from reduced participation to complete discontinuation.

   c. A large proportion of informal caregivers reported an almost complete disappearance of the PwD’s social activities, while the remaining respondents noted a partial or significant decline.

   d. Most informal caregivers described a strong decline in the PwD’s engagement in cultural activities.

   e. The vast majority of PwD exhibited some form of sleep or eating disturbances. Children reported greater changes compared with the pre-diagnosis period than spouses did.

   f. Eighty-three percent of PwD in the study require(d) accompaniment when leaving the house, reflecting the need for supervision, safety, and adequate preparation by the informal caregiver.

   g. Seventy-six percent of PwD became dependent on others for domestic activities. Individuals who already did not perform these tasks prior to the diagnosis were not counted.

   h. Seventy-one percent depend(ed) on others for their personal hygiene needs. Informal caregivers are not provided with training that would enable them to perform these tasks proficiently and with minimal physical strain.

i. In terms of direct costs, informal caregivers reported an average monthly expense of €1,042 due to the disease. Indirect costs averaged €574 per month.
j. Contrary to common perceptions, informal caregivers prefer to reinforce care at home rather than opt for institutionalisation in long-term care facilities such as ERPI.
k. Fifty-four percent of informal caregivers reported that dementia became the dominant aspect of the PwD's life.
l. Most respondents who were still professionally active stated that it is very difficult to reconcile work with caregiving duties, describing the effort required as "superhuman".
m. There has been a substantial increase in the proportion of male informal caregivers of PwD, in line with international trends.
n. Seventy percent of participants believe that their personal experiences as caregivers hold valuable knowledge that can help others in similar situations.

4. **Education protects against dementia**
   a. Education was shown to be a protective factor: PwD with higher levels of education experienced less isolation after diagnosis than those with lower educational levels.
   b. PwD with lower health literacy reported a greater reduction in social and family activities compared with those with higher educational levels.
   c. Engagement in individual activities and self-care also varies with educational attainment; PwD with lower levels of education show poorer performance than those with university degrees or higher.

5. **What support is available?**
   a. A significant shortage of health and social care professionals specifically trained to work with dementia was identified, especially outside major urban areas.
   b. Only 48% of PwD in the study participate(d) in activities aimed at exercising cognitive abilities. Since the sample is more advantaged than the general population, this suggests worryingly low levels at the national level.

c. Half of the informal caregivers who sought institutional support for PwD chose non-specialised providers—not generalist services with dementia training, but services lacking specialised capacity—due to limited availability, reflecting a growing gap in service provision in Portugal.
d. Caregivers' perceptions of healthcare services indicated that most felt the PwD under their care did not have access to the necessary health services. For example, 54% highlighted the lack of services that could help slow disease progression, such as cognitive stimulation, physiotherapy, and psychological support.
e. Fifty-six percent of caregivers reported that the PwD under their care did not have access to physiotherapy or similar services, or that such services were insufficient.
f. The greatest barrier to accessing these services is their limited availability within the National Health Service (SNS), often forcing families into additional expenses that many cannot afford. Although the sample is predominantly urban, the lack of territorial equity was clear, with people living in inland areas reporting greater difficulty accessing services than those in major cities.
g. Only 27% of PwD receive(d) support from a trained professional health team capable of delivering specialised care. This does not necessarily mean that the team was multidisciplinary (the ideal scenario).
h. Seventy-eight percent of informal caregivers expressed a need for home-based support; however, only 20% have access to such services.
i. No participant reported receiving help with housing rent payments.

6. **The informal caregiver of a PwD is a person at risk**
    a. Around 60% of caregivers report a very high level of physical fatigue, with women being significantly more affected than men.
    b. Reports of emotional fatigue are even more extreme than those related to physical fatigue: about 70% of caregivers report a very high or extreme level of emotional exhaustion.
    c. More than 80% of families report financial impact due to providing care to a PwD. This situation is even more concerning considering the high literacy and social advantage of the sample.
    d. Among informal caregivers, 82% feel or have felt the need for respite support, but only 4% receive(d) such support.

e. Two-thirds of caregivers report lack of access to psychological services for themselves, and 5% do not know whether such access exists.
f. When asked about the need for home-based support, 78% of informal caregivers state that they need or have needed home care services, but only 20% have or have had access to such services.
g. About half of respondents state that they need meal delivery services, but only 10% have access to them.

7. **Functioning of the dementia-care ecosystem**
   a. The high frequency of multimorbidity among PwD underscores the need for integrated care responses, in which the informal caregiver acts as a partner, managing day-to-day needs and ensuring the PwD's safety. There is a significant lack of training in Portugal aimed at empowering informal caregivers for this role.
   b. Forty-two percent report difficulty dealing with the lack of integration between health services and social services.
   c. In this sample, children who are informal caregivers are associated with a 25% likelihood of the PwD receiving social support, whereas for spouse-caregivers this likelihood drops to 13%.
   d. A clear majority of caregivers report that the PwD under their care is not linked to any social support service.
   e. Most caregivers express an extremely negative view of the coordination between health and social services, and of the level of bureaucracy involved in processes related to the PwD.
   f. Most informal caregivers—even those with high literacy and relatively easy access to care—state that they do not know whether Social Security provides support services in their area of residence.
   g. Recognition of the informal caregiver has been discussed in Portugal for years, yet significant practical challenges remain before informal caregivers of PwD can truly feel that their role is valued.
   h. When asked about the impact of dementia on intimate life, 84% of spouses/partners reported that their sexual life became impaired or ceased entirely after the onset of the disease in their partner, compared with the pre-diagnosis period.

Twenty action recommendations, based on the testimony of study participants

1. **It is necessary to make the informal caregiver a partner in the dementia-care response system, placing them at the centre of care alongside the patient.** To achieve this, the caregiver must become a full social actor within the health ecosystem, rather than a passive recipient of information—often inconsistent—coming from multiple sources. Their insight into daily reality is invaluable for tailoring care and must therefore be integrated into PwD care management.
2. **Every effort should be made to enable the PwD to remain in their home** for as long as possible, as preferred by the majority of informal caregivers and beneficial for the PwD, for social support systems, and for the healthcare system.
3. When remaining at home is no longer possible, professionalised care must be adopted. **There is an urgent need to increase the number of institutions (ERPI and equivalents) specialised in dementia and to develop specialised competencies within existing facilities.** Specialisation involves training staff and providing adapted materials and environments, even when the institution is not exclusively dedicated to dementia. Housing PwD in non-specialised facilities compromises the potential benefits of care and negatively affects well-being and disease progression.
4. Supporting the PwD at home requires appropriate resources and must not result in unsustainable burden on the family or caregivers. There is therefore a need to **develop a Training Plan for Informal Caregivers of PwD**, to be initiated simultaneously with the moment of diagnosis, addressing the training needs of all parties involved. This ensures adequate preparation for the challenges caregivers will face across the different stages of the disease.
5. **Existing labour legislation must be assessed** to determine whether it provides adequate protection to employees who care for PwD, enabling effective reconciliation of work responsibilities with caregiving duties. This challenge will grow as society ages and family sizes shrink.
6. **Opportunities for informal caregivers—particularly those with low educational attainment—to return to education and to engage in learning processes** should be promoted. This strengthens their capacity to understand and process information related to dementia and contributes to the

protection of their mental health. Lifelong learning should be available to all caregivers who wish to benefit from it.

7. **Support should be given to the increasing number of men assuming the role of informal caregivers**, acknowledging that they may require training in tasks they may never have performed before. This will enable them to provide better care with less effort.
8. **Preventive measures and support initiatives are needed to safeguard the physical and mental health of informal caregivers of PwD**, given their continuous and intensifying exposure to the challenges of the disease. These include risks of physical deterioration, emotional strain, weakened social networks, and other factors that make informal caregiving a high-risk role.
9. **Preventing emotional exhaustion among informal caregivers is essential.** A burnt-out caregiver is a caregiver who is also unwell and thus entitled to recover—something that may conflict with ongoing care obligations, making prevention the only sustainable strategy. Women tend to report higher emotional burden than men, although both groups show high levels of strain. Multiple parallel interventions should be implemented according to disease stage and family context. Psychological support must go beyond therapy aimed at preventing exhaustion; it must provide a space for reassurance, recovery, and guidance for managing challenges that exceed what caregivers can handle alone. This support must be specialised, accessible, and clearly communicated so caregivers know where and how they can obtain it.
10. **Appropriate support must be ensured for the large number of people over 75 years old who act as informal caregivers.** This group faces unique challenges and requires physical and emotional empowerment to manage the daily demands of caring. Key areas include physical and mental health maintenance, as well as technical preparation for delivering care with minimal strain—such as assisting with hygiene, dementia-adapted nutrition, and cognitive stimulation.
11. **The right of PwD to know their diagnosis must be upheld for all who wish to receive that information.** There has been a positive chronological trend in diagnostic disclosure, but continued effort is required to ensure that anyone who wants to know their diagnosis can do so—something that is still far from universal.

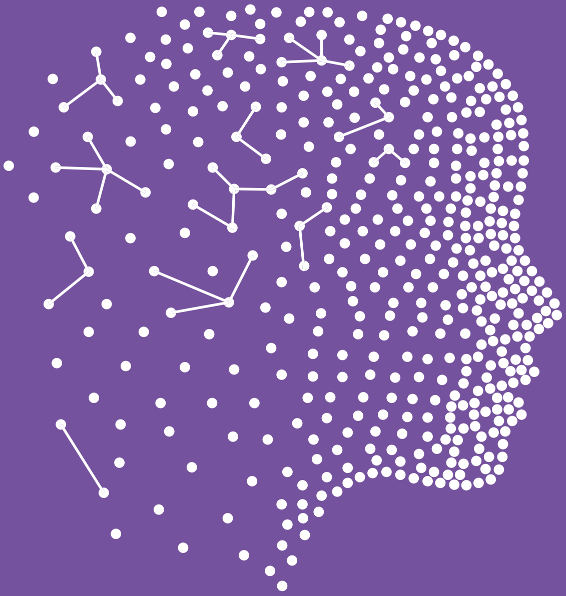
12. **Access to quality care for PwD must not depend on the family's financial capacity.** Sixty percent of respondents reported facing high or very high financial burden due to dementia within their caregiving role.
13. **Ensure access to physiotherapy and occupational therapy services in proportion to each person's actual needs,** according to the stage of their disease, rather than in the limited way that currently occurs.
14. **Improve coordination between the various health services from which the PwD receives care and the social support services,** so that responses become integrated. Ideally, there should be an integrated team that coordinates all the health services used by the person with the corresponding social assistance services. This measure responds to the perception among informal caregivers that coordination between health services themselves—and between these and social services in the context of dementia—is almost nonexistent, and it also aims to avoid duplication of efforts, something reported by nearly all participants.
15. **Reduce the bureaucratic burden associated with accessing and navigating processes involving PwD, creating a type of "Simplex for dementia".**
16. **Ensure that informal caregivers have access to rest,** including holidays, respite periods, and domestic support. This support may include assistance with meals, home maintenance, and similar tasks, depending on what the care management team identifies as necessary for each PwD.
17. **Improve communication between the dementia care and support ecosystem and informal caregivers.** Despite the high literacy levels and relatively easy access to care in this sample, the vast majority of informal caregivers reported not knowing whether they were entitled to support or where such support could be obtained. They also expressed difficulty integrating the wide range of information coming from the healthcare system. If this research were extended to the national level, this number would likely increase significantly.
18. **The sexuality of PwD** has very specific characteristics, affecting both the individual and their partner, and must therefore be **understood in the same way as any other dimension of health**—with rights that must be respected, appropriate safety considerations for the PwD, and awareness and understanding on the part of the spouse.

19. **Strengthen training for all professionals who may have to deal with dementia:** (1) doctors who are not in specialities that work primarily with dementia but who may encounter situations that could potentially be dementia and therefore need to ensure timely diagnosis; (2) health professionals who may lack specific training on this topic to carry out their work (physiotherapists, occupational therapists, nurses, etc.); (3) other professionals who are more distant from healthcare but may occasionally need to work with dementia cases (social assistance services, formal caregivers, etc.).
20. **Create an integrated care system for people living with dementia.** This would avoid duplication of caregivers' efforts and improve the quality of care provided, while at the same time reducing costs.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES



INTRODUCTION

Being an informal caregiver of a Person with Dementia (PwD) is often more than an effort — it can become a true ordeal in one's life. Physical effort and, above all, emotional strain intertwine in a mixture that sometimes leans toward exhaustion, other times toward affection. The person being cared for is someone who, little by little, is no longer "there," as if involuntarily abandoning the informal caregiver. What remains are memories, affection, and the longing to have that person back.

Caring for someone with Dementia is an act of love — an attempt to delay the outcome of a journey with no return, a journey one knows will be lost. Yet caregiving continues day after day, month after month, year after year. The absence of alternatives certainly contributes to this persistence, but it does not explain everything — in fact, it often explains very little of what truly happens.

Caring for someone with Dementia is, at times, also a moment of repairing the past. Whatever was difficult — and everyone has lived through difficult moments — is often resolved through the act of caring, because caring is a sublime form of loving.

Dementia exposes the stark reality of no longer being who one once was in one's interactions with others. It means gradually losing the ability to make decisions, to choose — those innate characteristics of one's very Being.

Watching someone forget tasks and obligations is heartbreaking because it makes the decline visible. But being forgotten by someone one loves is devastating. For the informal caregiver of a PwD who has maintained, for many years — sometimes an entire lifetime — a spousal or parental relationship with that person, the progressive loss of recognition of who they are may be one of the greatest trials they will ever face. The day a spouse, child, or grandchild becomes someone the PwD no longer recognises is a defining moment — a blow to the stomach that only love can help overcome. And yet, in the next moment, the next hour, the next day, care continues.

Caring in the context of Dementia encompasses all the physical and emotional wear inherent to caregiving in any disease, combined with the unilateral loss of relationship. In most illnesses, one can still speak to the person being cared for, hear their worries, listen to their wishes, receive a word of recognition, share memories of better times. Even if there are conflicts, one eventually returns to the familiar — the body may fail, but the relationship remains.

In Dementia, everything is slowly lost — reciprocity, shared meaning, family dynamics. Added to this are the financial burdens that arise from new care needs such as continence products, special meals, or simply travelling to appointments, examinations, physiotherapy, and everything else the disease demands.

This raises the question: does it really have to be this way? Must caring for someone with Dementia necessarily be a plunge into the abyss? Science — and decades of accumulated experience with millions of people in similar circumstances — tells us no. Much can be done for the PwD, for the informal caregiver, and for the Health and Social Support systems. It is not even fundamentally a financial issue when viewed holistically. It is a matter of managing complexity through the creation of a model of care in which Dementia is understood within an ecosystem that integrates the person with the disease and their family at the core of the health and social support systems.

If the clinical assistance provided to PwD is unquestionable, so too must be the protection of the informal caregiver's physical and mental health, the family's balance, and the objective and subjective conditions under which the family unit experiences Dementia.

On another level — yet fully connected to what has been described — lies the need to prepare Residential Homes for Older People (ERPI), Long-Term Care providers, and other structures that receive PwD to deal appropriately with both the person with the disease and their family, enabling joint and complementary work.

The key to an integrated support system for families living with Dementia is training. Training for the PwD in the early stages of the disease; training for managers and colleagues if the person is still working; training for the informal caregiver throughout the entire process, so they have the appropriate tools for each moment and so that the person can remain at home as long as possible — where many of their remaining points of reference still exist — in conditions that are dignified and sustainable for all parties; training for professionals involved in each act of healthcare or social support, so that care can be specifically oriented toward Dementia.

In Portugal, we are far from having an integrated framework of care and training at every point in the network. The family-based, home-based component is especially underdeveloped, still needing to be built and expanded.

Let us turn to the focus of this study: the informal caregiver. Who provides guidance and teaches them how to care for PwD? How is the family included in the process of training and support? There are interesting experiences in the country, but they are far from ensuring full territorial coverage or guaranteeing caregivers access to training from the outset.

The absence of a training network forces informal caregivers to make decisions based only on common sense and goodwill. Is that enough to face the reality before them? Probably not. It may be the best possible — but it is not the desirable. No one is born knowing how to manage care, and learning how to cope with someone who is losing their cognitive and relational abilities is profoundly difficult.

There is also the issue of consent: would the person allow this or that if they were fully conscious? Would they like what is being done for them now? How should one act in the absence of explicit permission? How can one respect what is presumed to be the will of the person?

One acts because there is no alternative — because it must be done. The bath must be given, meals must be provided, companionship must be offered, even when work does not wait and tasks multiply from all spheres of life.

Being an informal caregiver of someone with Dementia is an act of personal courage and a necessary response that the family places upon one person or a small group within that family.

Understanding their reality is essential to develop constructive proposals that can meet the real needs of informal caregivers and families in general. The study presented here is, in essence, a snapshot of informal caregivers of PwD in Portugal.

This report explores the perceptions, doubts, challenges, anxieties, and hopes of informal caregivers, covering 14 areas of their daily lives.

The study was developed by the Nova Center for Global Health at NOVA IMS, NOVA University Lisbon, in partnership with Alzheimer Portugal, the organisation that has led national representation of people with Dementia and their families.

METHODOLOGY

The research conducted for the development of this report sought to obtain a broad and as in-depth as possible understanding of the experience of caring for PwD from the perspective of Informal Caregivers. To achieve this purpose, a survey was created focusing on several areas of the PwD's and the informal caregiver's daily life.

The construction of the measurement tool—the survey—began with the creation of a framework of the most relevant topics from the perspective of the informal caregiver, which was validated by senior specialists from Alzheimer Portugal (AP). This was followed by a cycle of in-depth interviews where each topic was discussed, incorporating the perspectives of professionals from different fields—namely neurology, psychology, and social work—who work specifically with people living with Dementia. Naturally, informal caregivers were also interviewed, both of people who were alive and of people who had passed away.

These results were then analysed and transformed into the final survey. From the extensive set of topics collected—far too many to include—priority was given to those most relevant for AP's strategic action and to those that best characterised Portuguese informal caregivers, taking into account what is typically needed for public health policy development. The result was a tool balanced between the respondent's feasible time commitment and the most urgent topics to be captured for the study.

The survey was managed using the EU Survey platform. This online platform was chosen due to its flexibility in creating surveys, allowing for diverse question formats and providing a user-friendly interface for participants. In addition, EU Survey offers the level of security and privacy required to handle sensitive data, ensuring the confidentiality of participants' responses.

The survey included an Informed Consent statement that explained the purpose of the study and guaranteed anonymity and the right to non-response, ensuring compliance with data protection regulations. All survey questions were structured to fully respect participants' privacy and their willingness to share their experiences. To guarantee this, the option "Prefer Not to Answer (NR)" was always available.

Furthermore, the option "I Don't Know (NS)" was included to allow participants to indicate when they lacked knowledge of the topic under analysis or when they did not have a definite answer, thus ensuring the integrity of the data collected and the transparency of the research process. This type of answer was treated as valid or invalid depending on the context in which it occurred.

Whenever a response was clearly incorrect or raised significant doubts about the respondent's understanding of the question, it was removed.

All survey distribution, promotion, and participant recruitment were handled by AP. NCGH did not have access to any personal data that could identify respondents or be linked to their email addresses, identities, or similar information.

The survey was launched on 17 October 2023, with invitations sent to members of Alzheimer Portugal. Distribution took place on 17 and 18 October. In addition to invitations, dissemination on the association's social media channels enabled wider public awareness and participation.

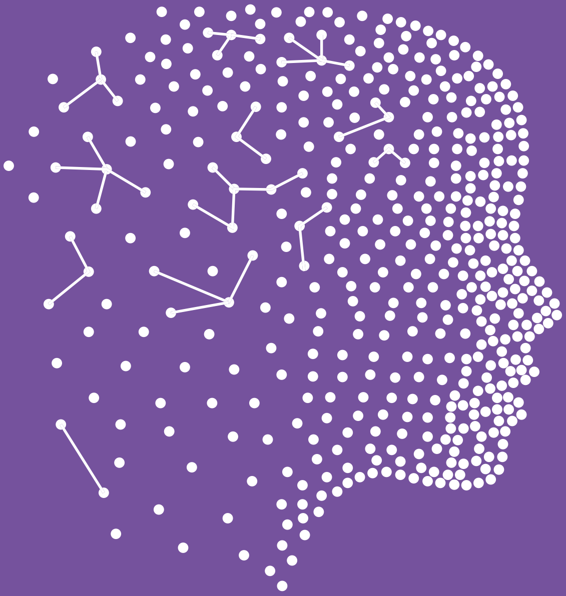
The deadline for participation was set for 30 November 2023. After the survey closed, the results were collected, processed, and analysed.

This study presents scientific and ethical limitations that must be considered. Two key limitations stand out:

Only individuals with digital proficiency could access the survey, which seriously limits participation by older or less literate populations—groups known to be under-represented in Portugal in terms of digital literacy. There is also a strong correlation between digital literacy and other forms of resources, particularly financial means, health literacy, and access to healthcare.

Individuals who seek support from a disease-focused association demonstrate a proactive behaviour in searching for solutions, indicating a capacity that many others may not have. Because the survey had to place emphasis on AP members, the scenario captured is narrower and more favourable. The Portuguese reality is also shaped by individuals facing exclusion, limited access, and knowledge constraints—groups who, by definition, are not represented in this survey.

This means that the picture captured here is the most positive scenario that can be found in Portugal—an insight with profound implications for the interpretation of results. Whatever the outcome, the reality is almost certainly worse when considering the population of Portugal as a whole.



SAMPLE

The sample consisted of members of Alzheimer Portugal and was complemented by individuals who volunteered to participate after learning about the study through the association's communication channels, social media, and other means of dissemination.

In total, 310 responses were received, of which 305 were considered valid and therefore used in the study sample.

CHARACTERISATION OF PARTICIPANTS

This section provides information to help understand the profile of the informal caregivers who participated in the study and the ways in which they are (or were) connected to the experience of Dementia.

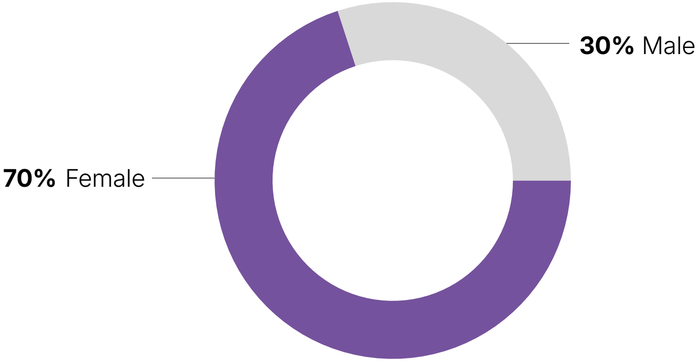
Distribution by Sex

The distribution by sex among respondents is relevant for understanding who assumes the role of informal caregiver within the family dynamic. The functions each person takes on are largely shaped by socially and culturally defined expectations. Traditionally, women assume responsibility for the family's health—physical, mental, and social (1). Men, according to international studies, tend to carry out tasks outside the home, such as shopping and other activities requiring travel. Across all diseases, informal caregivers contribute an estimated 3.6% of countries' GDP annually when measured on a global scale.

In the specific case of Dementia, scientific literature shows—based on a meta-analysis of 22 studies conducted in various Western countries—that women assume informal caregiving responsibilities 60% to 80% of the time (2). Another meta-study covering Western countries found slightly lower values (55% to 62%) or "Westernised" countries such as Japan (52%) (3), while very little is known about the situation in other types of countries. However, if Dementia follows patterns observed in other diseases, women's predominance may be even more pronounced due to the culturally assigned caregiving roles in many societies.

The distribution by sex of informal caregivers of PwD in the present study is fully consistent with what is described above. Among participants, 70% of respondents were women and 30% were men.

Figure 1. Distribution of participants by sex.



These findings highlight the importance of adapting communication strategies and the presentation of topics, focusing messages on women—the predominant group—while considering their specific needs and the overlap with other responsibilities typically assigned to them. This aligns with the logic of audience segmentation used in communication and knowledge dissemination strategies.

Focusing on women as the predominant caregiver group must not overlook the gradual increase in men's involvement. For example, a study conducted in the USA—though in a very specific population—identified men as the majority of informal caregivers for Dementia. In other diseases where men's role as informal caregivers has been studied, the responsibilities and challenges they face require different types of learning and they express different concerns compared with women.

The progressive equalisation of caregiving tasks between genders suggests that, as older male populations are replaced by men who have grown up in a more modern social-role context, men will increasingly take on informal caregiving roles.

Thus, different social segments are present, resulting in different informational needs and different levels of preparedness, which must be taken into account when designing a Training Plan for Informal Caregivers of PwD.

The educational component, in this case, should respect and complement the types of tasks typically performed by each gender. This topic is well explored in the literature regarding the main needs of male and female caregivers, making it feasible to design appropriate curricula. It may also be advisable to link this to educational attainment. Everyone should have access to the same information—but the method of delivery and the way content is structured may need to vary to ensure that all caregivers receive the support they require.

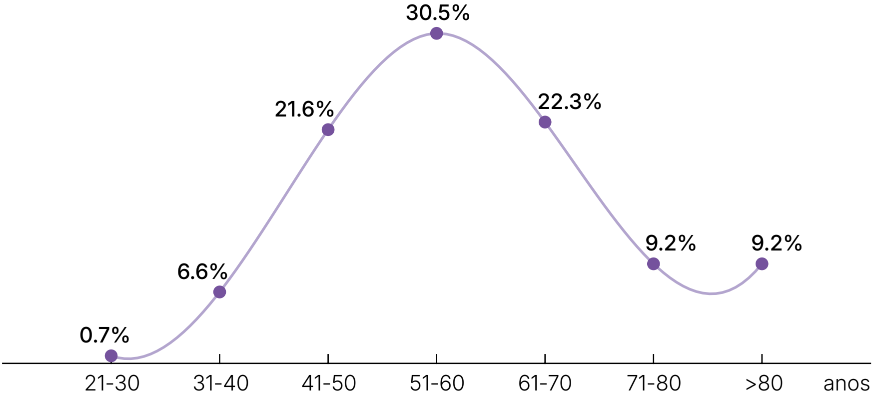
Distribution by Age

Understanding the age distribution of participants is important because it helps shape public policies and solutions adapted to the stage of the life cycle in which people find themselves. Different ages deal with health problems in different ways, and the same naturally applies to Dementia.

Age also often determines the expected health of the informal caregiver and the tools they can rely on to manage problems. Simple factors such as ease of mobility, accessing an online portal, or translating a text in a foreign language may determine the ability to access and use available resources.

According to the WHO (World Health Organization), women aged 50 to 64 are the group most likely to provide health-related care within the family (1,4). However, life inevitably intervenes, and within the study sample one finds informal caregivers beginning as early as young adulthood.

Figure 2. Age distribution of participants.



Two elements stand out in the respondents' age distribution:

- The large concentration of people between 40 and 50 years old, and
- A smaller, older group of participants aged 75+, among whom the act of caregiving is presumed to be particularly demanding.

As expected, it is individuals of the age group typically corresponding to the children of PwD who assume the central caregiving role. Most caregivers are between 45 and 65 years old, resulting in an average age of 57 (this average is influenced by the significant presence of participants aged 75+ and a standard deviation of 12 years).

This means that the majority of people caring for PwD are still in the workforce and must combine employment responsibilities with caregiving. Fourteen participants declined to answer this question.

These results raise several points for reflection:

1. Does current legislation sufficiently protect those who work and care for PwD, enabling them to balance both responsibilities? If not, what happened in the majority of cases described in the qualitative phase of the study? What is the impact on increased institutionalisation of PwD?

Institutionalisation always carries an additional burden for PwD due to the loss of familiar references, which may accelerate disease progression, particularly through loss of functional abilities. A dedicated study would be essential to determine the actual costs for families and the State when institutionalisation happens earlier than it might under a legal framework more favourable to informal caregivers.

2. The high number of people aged 75+ caring for PwD (and this is likely underestimated at the national level, given the lower digital access of this age group, which was required for participation) raises questions about their physical and emotional capacity to manage daily caregiving demands. Older informal caregivers may also exhibit mild cognitive decline. What level of strain does caregiving represent relative to their effective capacity? What specific support is available to compensate for age-related limitations? To what extent do public policies adequately address these challenges, and what consequences do these limitations have for PwD?

Distribution by Educational Literacy Level

Formal education is an important factor in designing public policies and support tools for informal caregivers because it significantly shapes health literacy, influencing caregivers' ability to understand information and find solutions to the problems they face daily. Health literacy refers to the ability to access, understand, evaluate, and apply health-related information (5).

Several studies on Dementia have examined this issue. One attempted to model the relationship between the health literacy of informal caregivers and their ability to obtain support and provide care to PwD (6). It showed that individuals with lower literacy resources obtain fewer supports and tend to provide care with greater difficulty. It is also known that caregivers of PwD with lower educational attainment often struggle to accurately or fully communicate clinical information to healthcare teams. Another factor contributing to delayed clinical assistance is that people with lower education tend to seek their first medical appointment later (7).

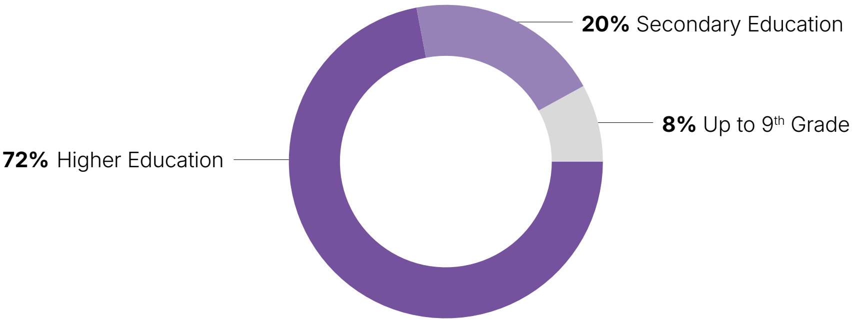
Overall, studies exploring the literacy of informal caregivers of PwD identify significant vulnerabilities, especially among older caregivers. A recent study in Italy

(8), a similarly Southern European context, found that clinical teams should gather information on the caregiver's literacy level to design more personalised care plans. The study also recommended improving caregiver training, which is often unavailable. Another Italian study found that 70% of informal caregivers of PwD were not fully prepared for their role (9).

Increasing the educational level of informal caregivers and providing adequate training in dementia-specific literacy can reduce the length of hospital stays for PwD (10) and improve therapy adherence and the adoption of healthy behaviours.

In this study, the following education categories were used: "Up to 9th grade," "12th grade," and "Higher education," based on the legal description of the last completed level of formal education.

Figure 3. Educational qualifications reported by participants.



There is a high percentage of informal caregivers who reported having higher education (72%). When compared with the national average in Portugal, there is a significant discrepancy. According to the National Statistics Institute (INE), in its December 2023 update, less than one quarter of the population aged 16 or over had completed higher education, and another quarter had completed secondary education (11). These numbers should be interpreted with the understanding that younger generations heavily influence educational attainment statistics.

Table 1. Population aged 16 or over in 2022.

Education Level	Total 8 693 million	Women 4 635 million
No formal education	4%	6%
Basic - 1st cycle	20%	20%
Basic - 2nd cycle	9%	7%
Basic - 3th cycle	19%	17%
Upper secondary and post-secondary education	26%	24%
Higher education	23%	26%

Source: INE, PORDATA

A 2023 report by the José Neves Foundation, based on INE and other data sources, shows that in 2022, 39.7% of adults aged 25 to 64 had completed, at most, basic education, compared with the EU average of 20.5% (12).

In the sample used for this study, combining those who reported having higher education with those who completed secondary education results in an average educational level higher not only than that of Portugal but than that of any EU country. This reflects the previously mentioned greater capacity for engagement among individuals with higher literacy and greater digital inclusion

The educational level of PwD caregivers who participated in this survey is not representative of the general Portuguese population. Instead, it reflects those who are involved in the field of Dementia and who actively follow AP's communication and activities.

The immediate consequence is that any problem identified in this study will be significantly more severe in the general population, as previously noted. This sample should therefore be understood as the visible tip of the iceberg.

The proportion of participants who reported completing upper secondary education (20%), although lower than the percentage of caregivers with higher education, remains relevant. It indicates that a substantial segment of caregivers has a solid educational background, though not necessarily at higher-education level.

The smaller fraction of caregivers (5%) reporting education up to the 9th grade may reflect several challenges, including reduced access to information and digital resources, or even a lower likelihood of assuming primary caregiving responsibilities due to the complexity of the disease.

This highlights that low literacy is a discriminatory factor, disproportionately affecting the most vulnerable. It is also worth noting that three participants declined to answer this question, a surprisingly low number, as refusal to answer educational-level questions often signals difficulty in disclosing lower education.

Given the known correlation between literacy and other personal resources, the results presented here describe, on average, the most capable, relatively "enabled" and prepared segment of the Portuguese population undertaking informal caregiving of PwD. This corresponds to what the scientific literature often refers to as the "Matthew Effect"[1], understood here in its socio-educational sense.

Given the scientific evidence and the assumption that Portugal faces far poorer literacy conditions than those identified in this study, it is essential that caregivers with lower educational attainment be offered the opportunity to return to learning processes, as a way of strengthening their capacity to interpret reality, apply information, and protect their mental health.

All caregivers who may benefit from reinforcing competencies in dementia-related health literacy should be provided with tailored training resources that protect their physical and mental health and support the quality of the care they provide.

A final alert: responses were self-reported and not verified against documentation, a factor that typically increases the proportion of individuals declaring higher educational attainment.

---

[1] *The concept of the "Matthew Effect" originates in the field of education sciences and draws on the biblical analogy that the more one has of a resource—such as literacy—the more likely one is to accumulate even more. The opposite is also true: the less one possesses, the harder it becomes to progress.*

Distribution by Place of Residence

The geographical location of participants is relevant as it provides insight into the level of participation across districts and autonomous regions. In Portugal, access to healthcare is often shaped by where one lives. Although the law guarantees equal access to public services for all citizens, regardless of residence, everyone is familiar with situations in which those who do not live in Porto, Coimbra, or Lisbon face greater difficulties accessing healthcare resources—whether specialist consultations or even basic diagnostic and treatment services.

Another consequence of living outside major urban centres, directly contributing to the burden experienced by PwD and their families, is the cost associated with healthcare-related travel. In large cities, most care needs can be met with short trips. However, those living in peripheral regions must not only manage the illness but also cover travel expenses that may involve journeys of hundreds of kilometres. In a country where wages are low and pensions even lower, any additional monthly expense has a significant impact, often forcing families to make difficult financial choices. As a result, PwD living in more remote areas frequently benefit less from the possibilities that modern healthcare provision can offer.

Table 2. Distribution of participants by district/Autonomous Region of residence.

Districts	Total Population in 2022 (%)	Participants (%)
Lisboa	22	49,8
Porto	17	11,7
Setúbal	8	5,5
Braga	8	2,7
Aveiro	7	3,4
Faro	5	7,2
Leiria	4	4,1
Santarém	4	1,7
Coimbra	4	5,2
Viseu	3	1,0
Madeira	2	2,1
Açores	2	0,3

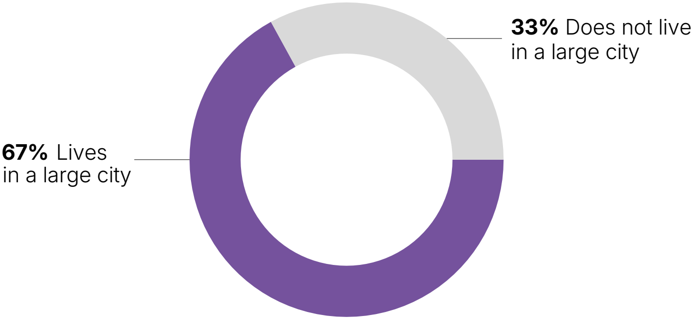
Districts	Total Population in 2022 (%)	Participants (%)
Viana do Castelo	2	1,4
Vila Real	2	0,3
Castelo Branco	2	0,7
Madeira	1	1,0
Beja	1	0,7
Guarda	1	0,7
Bragança	1	0,0
Portalegre	1	0,3

The results reveal a markedly high concentration of respondents in the district of Lisbon (49.8%). This is partially explained by Lisbon's higher population density compared to other regions of Portugal, as well as the greater presence of highly educated individuals—those who were more likely to participate in the study. The district of Setúbal completes the Lisbon Metropolitan Area. The district of Porto also shows a relatively high percentage of respondents (12%) for similar population concentration reasons.

As is common in many national studies, the coastal regions account for the majority of responses, while the interior is underrepresented, with few or no responses from several areas. This is concerning, as the interior of the country has the highest proportions of older residents and the most significant gaps in healthcare provision.

The study also sought to assess how informal caregivers are distributed according to the size of their place of residence.

Figure 4. Percentage of caregivers living in large cities vs. outside large cities.



The results show a marked geographical divide among caregivers: 67% live in large cities, while 33% live outside urban areas. This disparity suggests a possible concentration of services and resources for caregivers in urban environments, whereas those living outside major cities may face additional challenges in accessing support and assistance.

These results are also undoubtedly influenced by the fact that most health-related associative movements are primarily located in major urban centres.

Type of Relationship with the Person with Dementia

This question made it possible to identify how participants are connected to the PwD. Connections ranged from being the primary informal caregiver within the family to having a more distant relationship. The questionnaire also included the possibility of professional caregivers caring for a PwD.

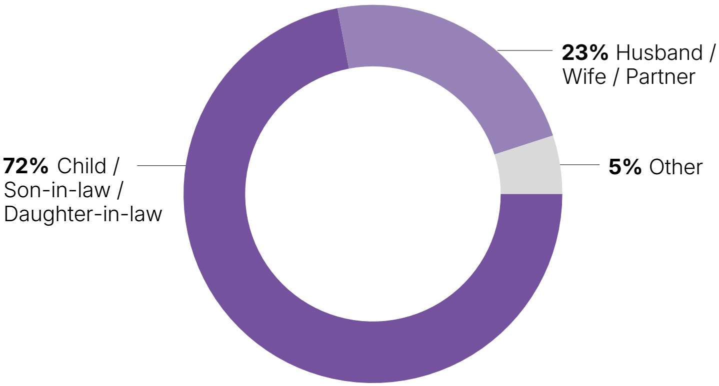
In the case of family caregivers, respondents were asked to specify their degree of kinship with the person they care for or cared for.

Nearly all participants (305) identified themselves as family members and informal caregivers of a PwD. Only two participants classified themselves as professional caregivers responsible for a PwD, and two participants declined to answer this question. For the purposes of the present study, professional caregivers were not considered, as their number was insufficient for meaningful analysis.

Type of Relationship with the Person with Dementia

It was important to determine next the degree of kinship. Internationally, two major groups assume most caregiving responsibilities and disease management: children (and similar close relatives) and spouses.

Figure 5. Degree of kinship between the participant and the PwD.



The “Other” category includes siblings, grandchildren, in-laws, and nephews/nieces, as none of these categories appeared frequently enough to justify creating separate groups.

The pattern of kinship found reflects what would be expected: care for a PwD is overwhelmingly provided by the immediate family—primarily children and spouses. This aligns fully with the existing scientific literature, which indicates that most caregivers are adult children, daughters-in-law, or sons-in-law (13). This occurs not only because some willingly take on the role but also because, at times, there is simply no alternative.

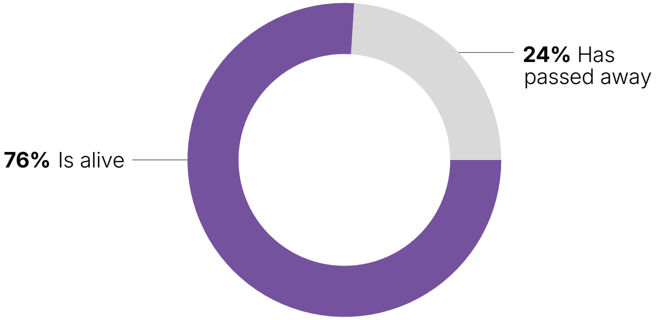
The only noteworthy element is the percentage of spouses in the sample when compared with international averages, which range from 20% to 55% across studies (14).

Determining Whether the PwD Addressed in the Survey Is Still Alive

Identifying whether the PwD the respondent cares for or cared for is still alive is extremely important, as it helps determine whether the responses represent current experiences or reflections marked by time. In a larger dataset, this information could help assess whether there has been evolution in dementia care provision in Portugal.

The clinical status of the PwD has a significant impact on the experiences and challenges faced by informal caregivers. Those currently caring for a PwD deal with the complexities of day-to-day care, while those who cared for a PwD who has passed away faced different challenges, particularly the grieving process and restructuring of life after the loss.

Figure 6. Status of the PwD addressed in the survey.

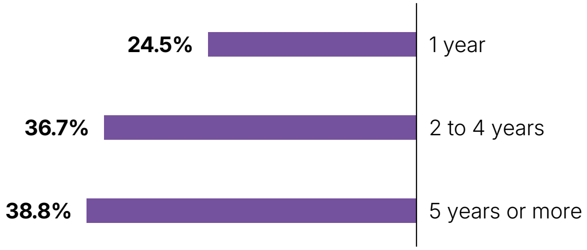


Of all validated responses, 76% indicated that the PwD is still alive, while 24% reported that the PwD has passed away.

For PwD who had passed away, participants were asked to answer based on their memory of the final years of the disease, as dementia is characterised by significant progression over time. This restriction was intended to avoid mixing memories from very different disease stages and to ensure comparability with responses referring to PwD who are still alive and for whom caregivers naturally focus on the present stage of the disease.

The study then sought to analyse the distribution of deaths over time in order to understand whether the information provided reflects distant or relatively recent events.

Figure 7. Number of years since the PwD passed away.



There was a balance across the response categories created, allowing an understanding of how care was provided to the deceased person without restricting the analysis to the immediate period of grief.

Connection to Alzheimer Portugal Association

Alzheimer Portugal (AP) is, ultimately, the primary beneficiary of this work. As the representative association for people living with Dementia and their families, it must have access to robust knowledge so that its advocacy efforts are supported by facts and quantification.

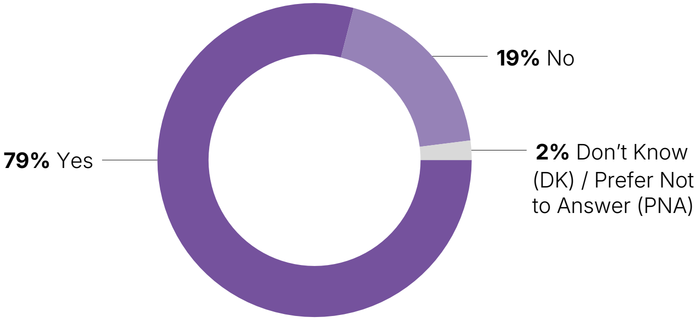
For this reason, it was essential to ask participants about their affiliation with AP—especially because, as noted earlier, the study was also disseminated on social media, reaching individuals who are not members.

Simply knowing whether the needs of non-members are perceived similarly to those of members makes it possible to determine whether the urgency and nature of unmet needs differ—or are even greater—among non-members. This is particularly important considering that the vast majority of informal caregivers of PwD in Portugal are not affiliated with AP.

The predominance of AP members in the study is a natural consequence of AP being the entity that launched the survey and, by definition, its members having a clear commitment to the Dementia cause. Their participation reflects not only this commitment but also a desire to contribute to research and to a deeper understanding of the disease and its surrounding context.

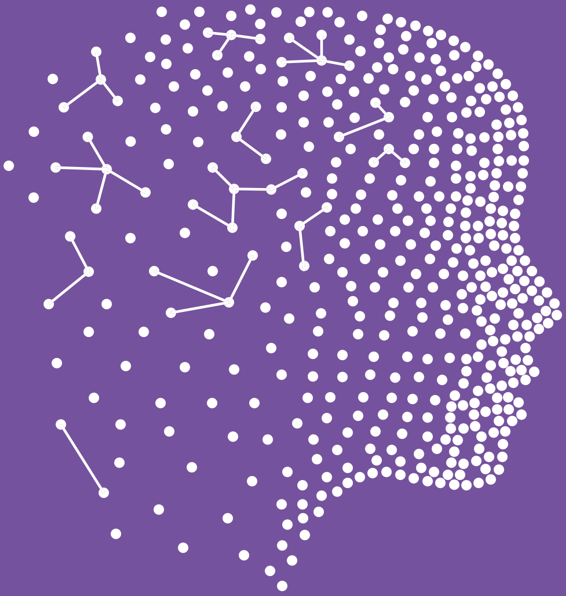
The number of non-members who participated is noteworthy, especially because their involvement was due solely to AP's public dissemination. These respondents should not be confused with the "average non-member caregiver" in Portugal, as they were, in some way, predisposed to engage with AP's initiatives, had sufficient digital access, and so forth.

Figure 8. Participant's connection with Alzheimer Portugal Association.



The data received show that respondents also tend to have a profile characterised by higher education, residence in large metropolitan coastal areas, and being either a child or spouse of a PwD.

Therefore, projections applied to other social groups must follow the usual caution used when a sample is affected by this type of bias: what occurs across the country is almost certainly the same set of problems identified here—but amplified. The fewer resources a household has—whether economic, educational, or geographic—the greater the difficulties they will face.



PRESENTATION OF RESULTS AND DISCUSSION

«

My mother and I were always worried about how exhausted my father was. He simply wasn't resting, and his stress levels were always through the roof. One day we went for a drive and he was confusing the rev counter with something else. We tried to justify the behaviour given the circumstances. One day I went to the petrol station near his house and the attendant said to me: 'Something is wrong with your father—he comes here every day and the tank is already full.'

That was the moment when all the red warning lights went off for me.»

THE HISTORY OF THE DEMENTIA DIAGNOSIS

A caregiver's journey begins long before they take on the daily responsibilities of care. It begins at the moment when a diagnosis is sought because something is clearly not right.

Understanding the "Diagnosis Story"—how the diagnosis was perceived and experienced—is essential for interpreting the experiences of informal caregivers, as it is a crucial and often traumatic moment that shapes the course of care thereafter.

A dementia diagnosis is not just a medical label; it is the beginning of an irreversible journey that profoundly affects the life of the PwD and their loved ones.

In all diseases, the ideal scenario is to obtain a correct and timely diagnosis. Once the diagnosis is made, there are medications that can make a difference at least in the early stages of the disease (15), as well as a wide range of tools that help the PwD and the informal caregiver maintain existing abilities for as long as possible—or mobilise new potential skills.

This is not only about quality of life—though that alone would more than justify targeted public policies supporting people with Dementia. Dementias, particularly Alzheimer's disease (AD), increase mortality associated with other comorbidities. For example, among 70-year-olds with AD, the probability of dying before the age of 80 is 61%, while for those without AD the probability drops to 30% (16). Similarly, during the COVID-19 pandemic, this increased vulnerability became evident, with mortality among PwD rising dramatically (17).

At this point, we draw upon the stories shared by informal caregivers, exploring the circumstances surrounding the diagnosis and the emotional responses triggered by it. We examine the role of the information and support provided at the time of diagnosis, and how these early experiences influence the way informal caregivers navigate the challenges that follow.

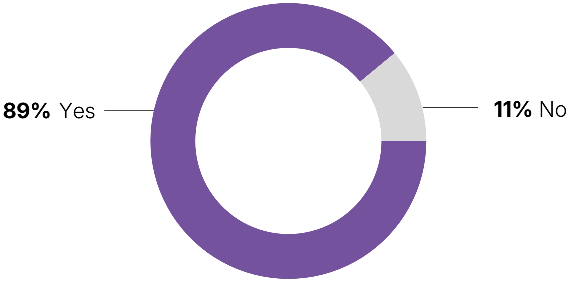
Knowledge of the Type of Dementia of the Person Being Cared For

The caregiver's ability to identify the type of Dementia is an important indicator of involvement and preparedness. It suggests not only the level of knowledge they possess but also the nature of their relationship with healthcare professionals. It also offers preliminary—though limited—clues about the distribution of Dementia types in Portugal, bearing in mind that participation in the study was voluntary and digital.

It is essential to recognise that this type of question often triggers social desirability bias: informal caregivers sometimes feel that admitting they do not know a technical detail may be perceived by others as a lack of attention, a failure, or disinterest. As a result, some may select one of the available options rather than indicate that they do not know. This behaviour is itself an indicator of the emotional burden they carry. As with all survey items in this study, no documentary confirmation was required—for example, no verification of the medical diagnosis was requested.

While literacy levels among participants were notably high and participants were motivated enough to be members of AP, it is also true that dementia diagnoses are sometimes made by exclusion. Thus, the proportion of respondents who claim to know the exact type of Dementia is considered unusually high. What follows reflects what was declared:

Figure 9. Knowledge of the type of Dementia of the PwD.



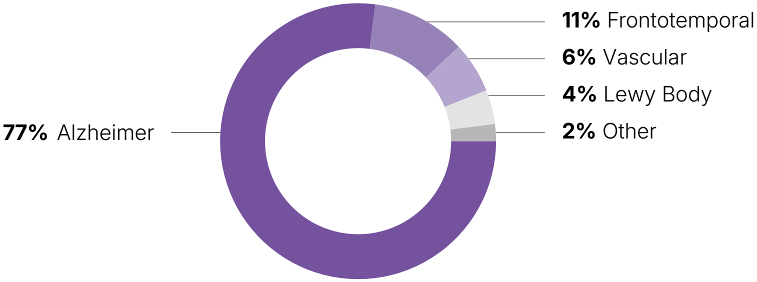
More than double what was reported by the Alzheimer's Association (USA) in 2015 (18).

Among the participants whose responses were considered valid, 89% reported being aware of the specific type of Dementia affecting the person under their care, while 11% stated that they did not have this knowledge.

We tested whether the consistency of responses was influenced by any socio-demographic qualification of the respondent, and no statistically significant differences were found—even in variables where one might expect them, such as educational attainment. It is therefore reasonable to assume that, in some cases, the response reflects a desire to "answer correctly" rather than actual knowledge.

If the caregiver knew the type of Dementia, they were asked to indicate it by selecting one of the following options: Alzheimer's, Vascular Dementia, Frontotemporal Dementia, Lewy Body Dementia, or Other.

Figure 10. Type of Dementia of the PwD.



The values observed in the sample are close to international averages (19,20), with the exception of Frontotemporal Dementia, which appeared more frequently than expected.

Among those who reported knowing the specific type of Dementia, the majority (77%) indicated Alzheimer's disease (international mean (IM): 60–80%) (17), followed by Frontotemporal Dementia (11%, IM: 2–10%), Vascular Dementia (6%, IM: 5–15%), Lewy Body Dementia (4%, IM: 5–10%), and, to a lesser extent, other types (2%, IM: 13%). As before, no sociocultural variable showed association with these distributions.

Even accounting for social desirability bias, the overall profile of responses could approximate what might be expected from a clinically observed distribution based on international averages.

Awareness and Understanding of the Dementia Diagnosis by the Person with Dementia

Whether the PwD should be informed of their diagnosis—at least in the early stages—is a controversial issue, and strong arguments exist on both sides.

Every person has the right to know their diagnosis, while also having the right not to be informed if they explicitly prefer not to know. In general, scientific (21) and social (22) organisations dedicated to Dementia advocate for disclosure of the diagnosis to the PwD.

If sufficient cognitive capacity exists and the diagnosis is not disclosed, feelings of uncertainty may arise and worsen over time—especially if the person later discovers that critical information about their health was withheld. This is particularly concerning because few things are more detrimental to PwD than stress, uncertainty and the loss of trust in those who care for them.

The PwD's awareness and understanding of their diagnosis is essential for acceptance and adaptation to the new condition. Involving the PwD in their own care journey, when possible, maximises remaining internal resources and helps ensure that their wishes and needs are respected. It is also an opportunity—if sufficient decisional capacity remains—to exercise rights that may become unfeasible later, such as completing an advance care directive, managing financial matters, or expressing personal preferences for future care.

Figure 11. Awareness of the Dementia Diagnosis by the PwD.

The results obtained are close to those published internationally. For example, a study conducted in the United States (23), published by the Department of Health in 2020, found that 46.8% of people living with Dementia were unaware of their condition. It is assumed that informal caregivers generally know whether the PwD has been informed of their diagnosis, though one cannot entirely rule out situations where the PwD was informed but did not disclose this to the caregiver.

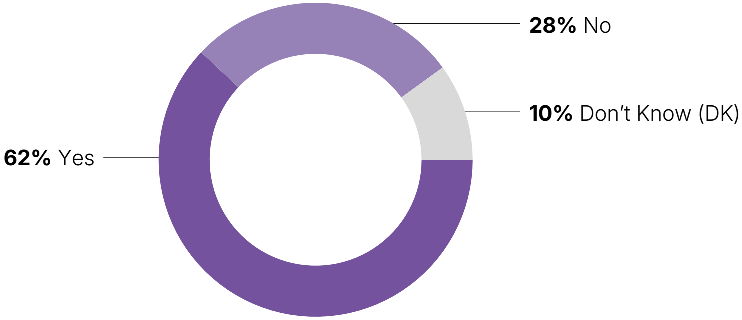
Across respondent subgroups, differences were not dramatic. Caregivers under the age of 50 were more likely to report that the person they care for knows their diagnosis, compared with older caregivers ($p<0.060$).

The most substantial difference emerged depending on whether the PwD was alive or deceased. PwD who are currently alive showed a significantly higher probability of having been informed of their diagnosis than PwD who have since passed away ($p<0.021$). This likely reflects a broader international trend: increasing transparency in communicating the diagnosis to PwD.

In simple terms, among PwD who are alive, the likelihood of having been informed of the diagnosis is double that observed, on average, 5–10 years ago. Despite this progress, there remains considerable room for improvement, as many individuals still do not know their diagnosis.

We aimed to go a step further by determining, when the PwD was aware of having Dementia, whether they also knew the specific type of Dementia they had. The purpose was not to assess technical knowledge or its direct impact on the PwD's future, but rather to use this as an indicator of engagement and of the quality of the information provided to them. It is important to note that, beyond the cases in which diagnosis is made by exclusion, a PwD may be diagnosed at an advanced stage, preventing communication and, consequently, limiting any management of diagnostic knowledge.

Figure 12. Awareness of the type of Dementia by the PwD.



Among PwD who were aware of their diagnosis—that is, those who were cognitively able to know—most reportedly possessed this more detailed information. Overall, the response pattern mirrors the previous question: the only intragroup difference observed was between those who had already passed away and those still living ($p<0.044$), with the latter being more likely to have known their specific type of Dementia. The percentage was also higher among PwD whose caregivers were members of Alzheimer Portugal ($p<0.021$), likely reflecting the association's educational initiatives directed at its members.

Here too, the values are surprisingly high. Only an in-person assessment with the PwD could clarify whether this reflects social desirability bias or a truly distinct profile of the sample.

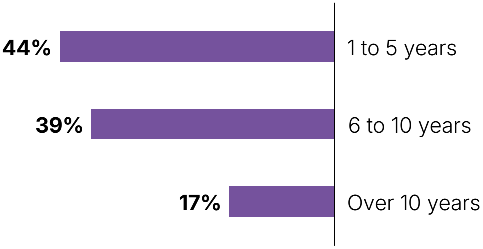
Time Elapsed Since the Dementia Diagnosis

We sought to understand how long caregivers had been dealing with the challenges of Dementia. Given the considerable number of respondents who had cared for a PwD who has since passed away, it is natural that the timeframes would be long.

Participants were asked to select one of the following options:

- "Less than one year" (and specify the number of months)
- "One year or more" (and specify the number of years)

Figure 13. Time elapsed since the Dementia diagnosis.



This measure is strongly influenced by historical effects. As expected, there is a marked difference between the timeframes reported by respondents whose relative had already passed away—tending to reflect long-past cases—and those caring for someone currently alive (p<0.001).

Ninety-one percent of participants indicated that the PwD had been diagnosed at least one year ago, 5% reported less than one year, and the remaining 4% stated they did not know. It is understandable that few cases fall within the "less than one year" category, as this is typically a period of family adjustment and exploration of available resources, including the support of Alzheimer Portugal.

Another interesting finding concerns the progressive increase in the involvement of men in informal caregiving over the years, despite women still being the majority in caregiving roles.

Among older cases, the ratio of female to male caregivers was 9:1. For cases diagnosed 5 to 10 years ago, this shifted to 3:1. In the most recent cases, the ratio is 2:1.

This trend towards gender equalisation—already noted when analysing task distribution between male and female caregivers—suggests that Portugal (at least within this highly distinctive sample) has moved from ratios well below those reported internationally to levels comparable to, or even better than, those of other developed countries.

We do not believe these results can be directly extrapolated to the entire Portuguese population, as male involvement in caregiving remains strongly shaped by cultural norms related to education, urban context and age. Still, the findings indicate that gender equality in caregiving is gradually advancing in this domain as well.

The narrowing of the gender gap in the likelihood of providing informal care for PwD reinforces the need to design non-formal and informal training content that aligns with the specific needs of both men and women.

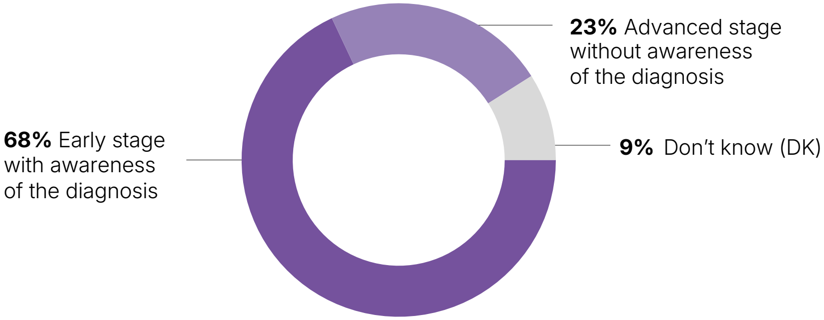
Stage of Dementia at the Time of Diagnosis

To place both the Person with Dementia (PwD) and the informal caregiver within the disease progression, participants were asked to select one of the following options:

- "Early stage of the disease, in which it was/would have been possible to have awareness of what dementia is", or
- "Advanced stage, which prevented them from having awareness of what dementia is."

It is important to highlight once again that this assessment is declarative, reflecting the caregiver's perception rather than clinical records.

Figure 14. Stage of the disease at the time of diagnosis.



Most respondents reported that the diagnosis was made at an early stage of the disease. Interestingly, only 9% reported not knowing. No significant differences were found across most sample subgroups.

It would be expected that people with higher levels of education or living closer to major health-care centres would have received a diagnosis earlier. However, this was not the case. Instead, a significant difference emerged according to the caregiver's relationship with the PwD:

When the caregiver is a spouse, the likelihood of receiving a diagnosis in the early stage is higher than when the caregiver is a child (or equivalent) ($p < 0.001$). This pattern is consistent with the fact that spouses generally share daily life more closely, with greater intimacy, making them more capable of noticing subtle changes and seeking medical help earlier.

Intervention by adult children often occurs only when spouses are absent or unable to act.

Diagnosis Timeline: Interval Between First Symptoms and Dementia Diagnosis and Medical Consultations During that Period

The time between noticing that something is wrong and receiving a confirmed diagnosis can be lengthy and involve multiple steps. One indicator of these difficulties is the number of doctors consulted before reaching a dementia diagnosis.

A long diagnostic timeframe also means lost opportunities for early pharmacological intervention, stimulation, and preservation of existing skills.

Scientific literature identifies three potential periods of delay that work against the PwD (24): The time between realising something is wrong and speaking to someone about it; The time between speaking to someone and seeking medical help; Delays caused within the health-care system itself.

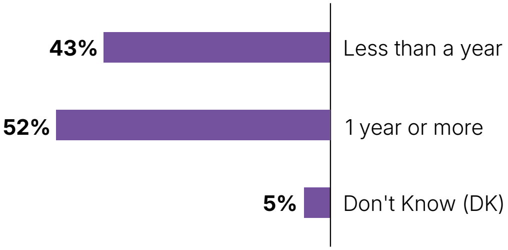
Since it would be unreasonable to expect participants to accurately recall events that may have occurred long ago, the focus was placed on the third phase. In a UK study (ibid.), the first two phases lasted on average about two years, and the third around 35 weeks, with 90% receiving a diagnosis within eight weeks.

It is difficult to extrapolate these numbers to Portugal, as the contexts differ and the UK sample was small. In another large US study (25), the third phase was extremely long: about three years, with delays even greater for disadvantaged groups. A more recent US study (26) found that PwD waited 12–20 months for a specialist appointment and an additional 6–12 months for diagnostic confirmation if in the early stage. The study also warned that, given the shortage of specialists and population ageing, waiting times may reach 40 months within a decade.

To determine how long ago the PwD had received their dementia diagnosis, participants were asked to select one of the following:

- “Less than one year” (and, if so, indicate the number of months), or
- “One year or more” (and indicate the number of years).

Figure 15. Time elapsed from first symptoms to diagnosis.



It is noteworthy that almost half of the diagnoses were made within one year, compared with US studies—another indication of the strong proactivity of respondents and their ability to seek solutions.

Among these, nearly half received the diagnosis in under six months.

Figure 16. Months elapsed until diagnosis.

Nonetheless, the reality in Portugal is highly asymmetric, both regarding access to care depending on where one lives, and depending on the family's resources—educational, financial, and social. However, in this sample no statistically significant differences emerged among subgroups.

This absence of differences is likely due to the fact that more vulnerable populations are generally excluded from social listening—they tend not to participate in digital surveys or voluntary research.

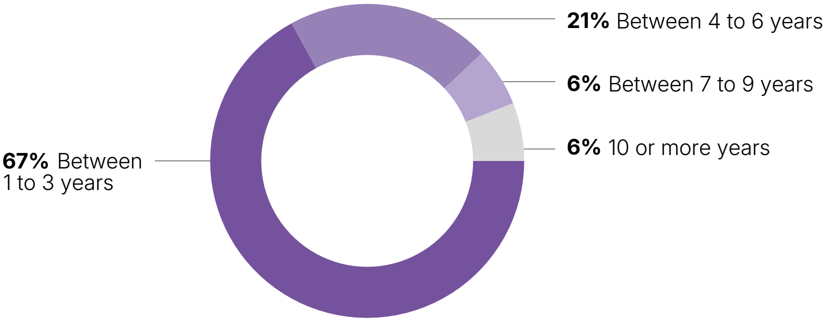
Among those who waited more than a year for a diagnosis (43%), the majority received it between one and three years after symptoms began.

Some cases extended far longer. Since answers were declarative rather than verified against medical records, inaccuracies—especially in very long time frames—are to be expected. People often report perceived time, not chronological time.

Several factors contribute to prolonged diagnostic processes, starting with the inherent complexity of diagnosing dementia, which is often a diagnosis of exclusion.

Early-stage disease may also complicate definitive diagnosis, often requiring a period of continued observation.

Figure 17. Years elapsed until diagnosis.



Considering all responses, the average reported diagnostic time was 22.3 months, with a median of 10.5 months. The large difference between the mean and the median is explained by the standard deviation of 28.8 months, which strongly suggests that the longest reported times may reflect perceived time rather than objective time. No significant differences were found across the various sample subgroups.

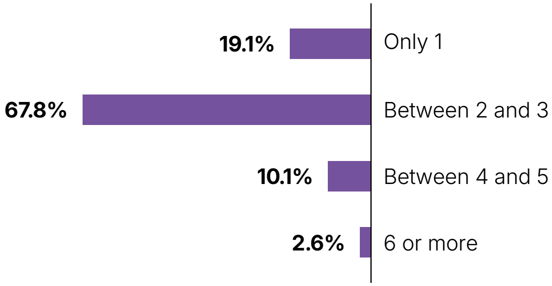
Pathway to Diagnosis: Medical Specialties Involved Until the Official Dementia Diagnosis

Identifying the specialties of the professionals involved in the diagnostic process helps clarify the routes and approaches commonly used to diagnose dementia.

Participants were asked to select all applicable options from the following list: General Practice/Family Medicine, Neurology, Psychiatry, and Other.

A first analytical step is to determine whether patients were taken directly to dementia-related specialists. During the first phase of the study (in-depth interviews), it was often reported that the initial step was to speak with the family doctor or another specialist routinely consulted by the person with dementia for unrelated reasons.

Figure 18. Number of physicians consulted before the diagnosis.



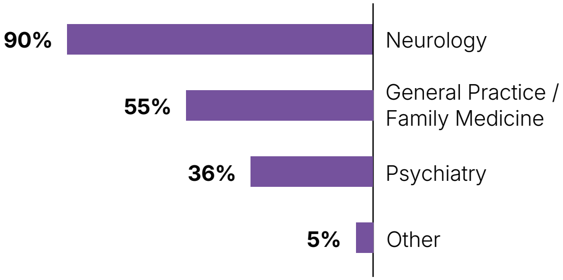
The diagnostic pathway typically involved several steps, with an average of 2.38 physicians consulted before receiving the diagnosis. Fewer than one in five individuals received their diagnosis from the first doctor they saw. The vast majority obtained it from the second or third physician.

Based on interview reports, the usual sequence is that the person with dementia is first taken to a general practitioner, who then refers them to neurology or psychiatry. However, additional steps are frequently required.

Discomfort or uncertainty regarding an initial diagnosis also increases the number of medical consultations, as seeking a second opinion is the patient's right. Multiple caregivers reported that the first doctor(s) consulted dismissed early symptoms by saying things like "It's normal for older people to forget things or take longer to complete tasks," prompting families to pursue further evaluations.

As symptoms progress and the burden on both the person with dementia and the caregiver increases, families tend to seek "something" that can help—often a diffuse effort to minimise strain and mitigate the emerging limitations.

Figure 19. Medical specialties visited prior to diagnosis.



Other specialties mentioned included: cardiology (4), ophthalmology (3), urology (1), rheumatology (1), neuropsychology (1), pulmonology (1), oncology (1), immunology (1), orthopaedics (1), and endocrinology (1)—most likely due to prior medical follow-up unrelated to dementia.

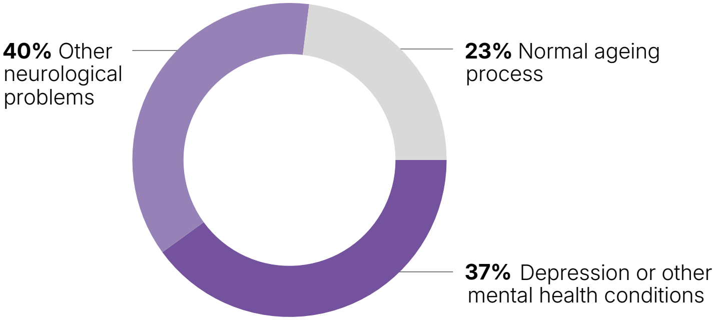
A remarkably high percentage of physicians involved were qualified to diagnose dementia. This figure is notably higher than in several countries far wealthier than Portugal, where most diagnoses are made by non-specialists (27).

Analysis of Preliminary Diagnoses Prior to the Official Confirmation of Dementia

Before receiving a dementia diagnosis, many respondents reported that they had been given other diagnoses. This occurred in 247 out of the 305 informal caregivers surveyed.

Based on what emerged most frequently during the qualitative phase of the study, participants were asked to select one of the following options: “Depression or other mental health conditions,” “Normal ageing process,” or “Other neurological problems” (in which case they were asked to specify which).

Figure 20. Diagnoses received prior to the official dementia diagnosis.



The results show considerable variation in how early dementia symptoms were perceived and interpreted—something that should not be confused with diagnostic error. Receiving an alternative diagnosis does not exclude the presence of dementia, which can easily coexist with or mimic other conditions.

The data reveal three important points:

1. Depression or other mental health conditions (40%). These may represent early signs of dementia or comorbidities that complicate differential diagnosis.
2. Dementia symptoms dismissed as “normal ageing” (37%). This finding suggests that dementia symptoms continue to be interpreted as part of natural ageing, leading to delays in diagnosis and appropriate intervention. The results underline the need for improved training among medical professionals outside neurology and psychiatry, so that referrals for specialist assessment occur as quickly as possible.
3. Other neurological problems (23%). This category reflects recognition of neurological symptoms that may overlap with dementia. Although too few cases were reported to create separate categories, the most frequent included ataxia, mild cognitive impairment, dyskinesia, Parkinson’s disease, memory loss, among others. It is essential to emphasise that these responses reflect the participants’ perceptions and the communication they received, not clinical information exchanged between healthcare professionals.

This section also highlights a clear area for caregiver training—equipping informal caregivers with the knowledge needed to better understand and navigate the diagnostic process, secondary and tertiary prevention, and the full range of care that must be provided.

History of Institutionalisation: Assessment of Prior Care Experience and Social Support Responses

Whenever possible, efforts are made to ensure that people with dementia (PwD) remain in their own homes for as long as possible, as this provides structure and reduces anxiety. However, the progression of the condition sometimes makes temporary or permanent institutionalisation necessary. Two major factors contribute to this decision: 1) the need for respite for the informal caregiver, given that providing dementia care can be exhausting; 2) the caregiver’s inability to manage complex situations that require round-the-clock supervision.

Other, less frequent factors may also require placing a PwD outside their home—such as the absence of an available informal caregiver (often occurring when children live abroad), illness or death of a spouse, or specific family circumstances.

This section sought to understand how institutional placements occurred, which types of services were sought (or found), and what the needs of informal caregivers and PwD were in this process.

Figure 21. Placement of PwD in Nursing Homes, Day Centres, Long-Term Care Units, or similar.

If the answer was "Yes", participants were asked to indicate the type of social support service accessed by choosing among: "Specialised for PwD", "Not specialised, but with dementia-specific competencies", or "General nursing home or similar (non-specialised)".

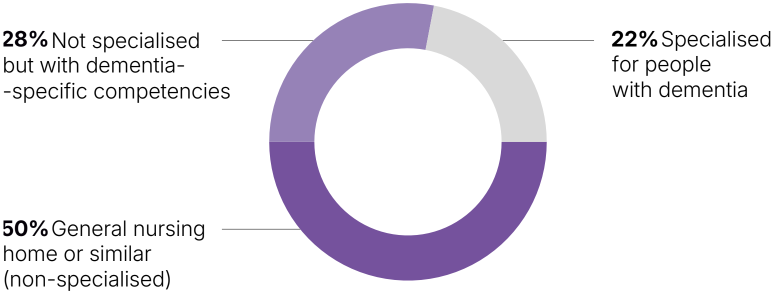
Almost half of all PwD represented in this survey have been or currently are in some form of institutional care (43%), whether in a Nursing Home, Day Centre, or Long-Term Care Unit.

The greatest difference in institutionalisation rates was associated with the caregiver's relationship to the PwD. When the informal caregiver was a spouse, the likelihood of institutionalisation at some point was 22%, whereas for adult children (or equivalents) it rose to 48%—a statistically significant difference ($p < 0.001$). The most plausible explanation lies in generational differences and the varying availability of time.

There were also differences between families of PwD who are still alive and those whose loved one has passed away. However, this simply reflects the comparison between an ongoing trajectory and one already completed—where final stages of illness naturally tend to involve higher institutionalisation rates.

Among respondents who had experienced at least one episode of institutional placement, we examined the type of dementia-related competencies available in these institutions.

Figure 22. Type of social care service.



It is well established that PwD obtain better outcomes when placed in facilities with dementia-specific care. A recent study in the United States, covering nearly 14,000 nursing homes and 3.2 million residents (28), found that generalist facilities may have between 10% and 90% of residents living with dementia, yet fewer than 5% of PwD were placed in specialised dementia units. Specialised care leads to better outcomes, such as more effective specialised nursing, which in turn reduces emergency episodes—events associated with significant distress and cost.

Studies also show (ibid.) that even in generalist facilities, a high concentration of PwD improves staff expertise through informal and non-formal learning, resulting in higher overall care quality. Comparable studies have not been conducted in Portugal, meaning these correlations cannot yet be confirmed in the national context.

Technically, “specialised dementia care” has a specific definition. As in many other countries, a higher density of PwD within a nursing home often leads to the perception that the home is “specialised,” which may not be accurate. True specialisation requires trained and prepared staff, appropriate equipment, and in many cases dedicated interior and exterior layout adaptations.

The present study reveals several noteworthy elements, especially considering the already-demonstrated over-representation of highly skilled respondents relative to the national population. It is also important to note that “specialisation” is a declarative term here—based on caregiver perception. Key findings include:

1. Half of informal caregivers who resorted to institutional services chose facilities that were not specialised in dementia. This strongly suggests limited availability of specialised options, insufficient awareness among caregivers, or financial constraints.
2. Approximately one-fifth (22%) of PwD were in specialised facilities. This value is much higher than figures observed in wealthier countries, as noted earlier. However, this must be interpreted cautiously given that respondents include members of an association that offers specialised services, as well as the unique characteristics of the sample.
3. 28% were in facilities that are not exclusively for dementia but have some specialised competencies. This may reflect integrated care approaches or attempts by general facilities to incorporate dementia-specific support within broader structures.

These findings underline that informal caregivers could benefit from more training and information about available care options, enabling them to make more informed decisions about institutional placement. A well-informed caregiver is better equipped to select, demand, and evaluate care quality. In addition, care-providing institutions may require further resources and staff training to develop specialised dementia competencies. Portugal already shows a significant shortage of specialised care options, with a likely worsening of this gap as the number of PwD increases in the coming decades.

The results may also reflect shortcomings in the planning and provision of health and social care services for PwD, pointing to an opportunity for public policy investment aimed at expanding specialised resources and infrastructures. Such investment would help ensure that all individuals living with dementia receive the level of care necessary to live with dignity and quality, while also ensuring that caregivers receive appropriate support to manage the complex daily demands of caregiving.

> «We started with the family doctor, who prescribed medication for nerves and said it was normal to lose abilities with age. After some time, he referred us to a specialist. In the NHS we had to wait a very long time. In the private sector it was quicker, but we had to pay. It took more than two years before we got the diagnosis. (...)
>
> At the beginning we were not told it was dementia, only that he had frontotemporal disease and needed to take some pills and use a patch. The doctor only told me — my mother never knew he had dementia.
>
> When I looked up what frontotemporal disease was, it was a shock, even though the disease was still in its early stages (...). Gradually we become more aware of what it really means.»

HOW THE DIAGNOSIS WAS COMMUNICATED

The way a dementia diagnosis is communicated has a profound impact on the life of the person with dementia (PwD) and their informal caregivers. It is a moment that can remain vividly etched in memory, carrying emotions that may range from confusion to sadness, anger, and acceptance. How health professionals approach and deliver the diagnosis plays a crucial role in how the news is received and processed (29). It is always a complex step for the PwD and for the family, potentially generating anxiety and depression, and it must therefore be carefully thought out in advance.

In the past decade, several approaches have been discussed and some progress has been made in recommendations. In summary, it is advised that both the PwD and a trusted companion — ideally the future informal caregiver — be present. Pre-counselling should be considered, as well as scheduling multiple follow-up sessions with the PwD and the family/caregiver. The communication of dementia as a potential risk was not part of this study and follows its own specific guidelines (30).

The goal here was to understand the "Way in Which the Diagnosis Was Given." How professionals handle this critical moment influences how the PwD and caregiver perceive dementia, as well as their future engagement with strategies and support to manage the disease.

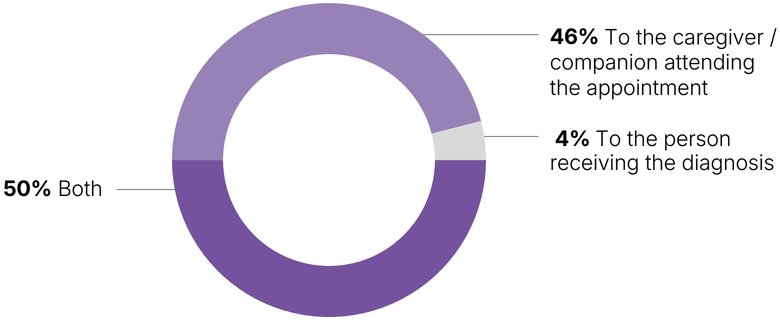
Diagnosis Moment: Identification of the Initial Recipient of the Diagnosis

Knowing who first received the dementia diagnosis is key to understanding how the news was initially conveyed and who was present at the time.

Participants were asked to select one of three options:

- “The person being diagnosed”
- “The caregiver/companion present at the consultation”
- “Both the person and the caregiver were present”

Figure 23. Who first received the diagnosis.



In almost half of the cases, the PwD was not present. Certainly, in some situations the PwD may already have been too impaired to attend the consultation, but the results show that in a substantial number of cases the PwD was excluded from the process. The trend, however, is decreasing in more recent cases. This exclusion occurs less frequently when the accompanying person is the spouse ($p<0.001$).

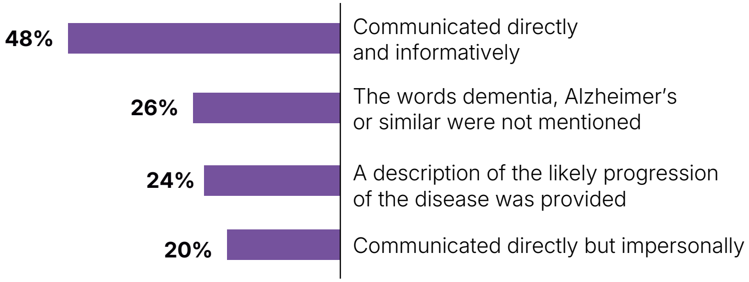
Mode of Communication of the Diagnosis

The way the diagnosis is communicated also affects the emotional experience of both the PwD and the informal caregiver. Understanding these details helps assess the sensitivity and empathy perceived during the process.

Participants could select all options that applied:

- "In a direct and impersonal manner"
- "In a direct and informative manner regarding dementia"
- "Diagnosis was given without mentioning the words dementia, Alzheimer's or similar"
- "A description of the expected progression of the disease was provided"

Figure 24. How the diagnosis was communicated.



Delivering such impactful news requires transparency, objectivity, and empathy. Since the responses are declarative and not validated by an external observer, they reflect personal perceptions — accurate or not, they represent what remained with the caregiver.

The results show significant room for improvement: explaining the progression of the disease is essential for planning the future, yet this occurred in only a quarter of cases. Likewise, clearly naming dementia — regardless of the subtype — is important to reduce uncertainty.

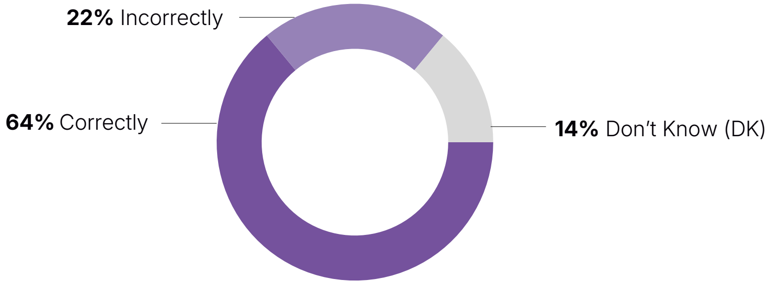
No major differences were found across sociodemographic groups.

Assessment of the Adequacy of Diagnostic Communication

Assessing whether the diagnosis was communicated appropriately, from the respondent's perspective, is important to determine whether the information was delivered in a clear and respectful manner—elements that directly influence acceptance and understanding of the diagnosis.

Participants were asked whether they felt the diagnosis had been communicated in a way they considered appropriate, with the response options "Yes", "No", and "I don't know". This third option is necessary because most people are unlikely to know what the technically recommended procedure is. In essence, what is being assessed is a lived experience that is felt more emotionally than cognitively.

Figure 25. Perceived appropriateness of diagnostic communication.



Most respondents reported feeling comfortable with the way they learned that dementia was the condition they would have to deal with. The 22% who expressed the opposite view overlap strongly with those who said the diagnosis had been communicated in an impersonal manner. Empathy is the key dimension at stake. It is also noteworthy that one in seven people selected "I don't know", which can be interpreted as a broadly positive perception with room for improvement.

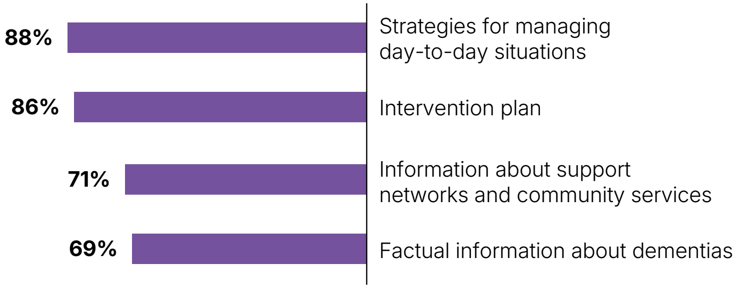
Some differences emerged between sexes ($p<0.040$): women appeared less satisfied than men and expressed more doubts about the adequacy of the diagnostic communication. Age was also a factor, with respondents under 60 reporting lower levels of satisfaction ($p<0.015$).

Critical Aspects in Communicating the Diagnosis

Identifying the information considered important at the moment of diagnosis helps determine the expectations and needs of PwD and their caregivers, contributing to a more effective communication process.

Participants were asked to select all options that applied, based on the categories identified in the qualitative phase as the most relevant from the perspective of informal caregivers: “Factual information about dementias,” “Intervention plan (which medication or appropriate therapies),” “Strategies for managing day-to-day situations,” and “Information about support networks and community services.”

Figure 26. Information considered important when the diagnosis was communicated.



All categories received substantial weight, confirming the relevance of the selected options.

The greatest difference emerged between members and non-members of Alzheimer Portugal (p<0.001): those who are not members feel a stronger need for information, clearly highlighting the important role that the Association already plays—and can play even more if its reach expands—in providing education and guidance.

People confronted with a new condition about which they know little—especially regarding what comes next and how—need information that helps them create a coherent framework that makes sense to them (31,32). Informal caregivers value information about the nature of the disease, its stages, symptoms, and expected progression. This reflects their search for understanding and preparation for the challenges ahead, consistent with what patient associations (33,34) and health systems provide in many countries.

The option “Strategies for managing day-to-day situations” was the most selected (88%), highlighting the need for practical guidance. Caregivers seek concrete advice for dealing with everyday challenges, including behavioural management, communication techniques, and strategies for handling functional and cognitive difficulties in PwD.

The category “Intervention plan” was the second most selected (86%). It reflects a search for clear information on how the disease will be managed—medication, therapies—indicating a proactive stance towards treatment and disease management.

Next came “Information about support networks and community services” (71%), showing that caregivers recognise the need for external support. They seek information about available resources such as support groups, health and social services, reflecting an understanding that the caregiving journey is demanding. Simply knowing that a support network exists—and that they are not alone—reduces anxiety about the unknown.

The category “Factual information about dementias”, selected by 69% of respondents, reflects the need to understand the nature of these diseases.

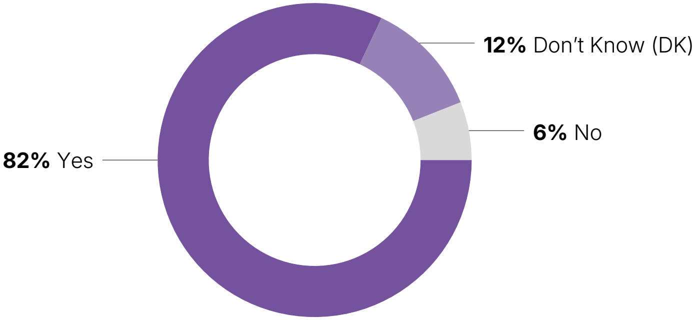
These results are fully consistent with the scientific literature from other countries and with the experience of dementia organisations supporting patients and caregivers.

The findings show that information management for both the PwD and the informal caregiver is a fundamental component of the disease-management process and should be placed at its centre. Diagnostic communication protocols must be shared with both the caregiver and the PwD, if the latter wishes to receive them. New communication approaches should be adapted to socially vulnerable groups, which the literature consistently identifies as individuals with language barriers, unemployed people, those with low literacy, and isolated individuals.

The Importance of Access to Diagnosis from the Perspective of PwD

Assessing informal caregivers' opinions on whether PwD have the right to know their own diagnosis raises questions about autonomy and consent. As discussed earlier, major scientific, social, and policy organisations related to dementia support the right to know—if the person wishes—while also defending the right not to be informed, should that be their choice.

Figure 27. Perception of diagnostic knowledge as a right of PwD.



Overall, the vast majority agree that PwD should have the right to know their diagnosis. However, nuances exist: older respondents tend to agree less, especially above age 70; individuals aged 50–70 express more uncertainty; and below 60, agreement is overwhelming, with only one caregiver under 50 disagreeing. By collinearity, the caregiver's role (child/equivalent vs. spouse) also shows differences ($p<0.037$). Unsurprisingly, the issue appears more complex in older cases in which the PwD is already deceased.

Critical Assessment of Diagnosis Communication: Positive Highlights and Identified Challenges

Identifying positive and negative aspects of diagnostic communication provides valuable insight into the experience of PwD and caregivers. This helps pinpoint areas needing improvement and recognise successful elements in how the diagnosis was delivered.

Participants were offered an open-text option to share **opinions or testimonies**. Hundreds of responses were received—both positive and negative—and several representative examples were selected.

The moment the diagnosis is delivered often eases anxiety and resolves lingering uncertainty, which may already have been causing significant distress:

The positive part was finally understanding what was actually happening.

Communicating the diagnosis directly ensures the information is conveyed accurately. There is an initial shock, but in my opinion it allows for faster acceptance.

We finally had a diagnosis.

The manner in which the diagnosis was communicated greatly shaped caregivers' perceptions. When well delivered, it became a source of inner reassurance:

The most positive aspect was the help it gave the family in understanding the problem.

I highlight how well the explanation was given.

The best part was that the diagnosis was not delivered in an alarmist tone.

When poorly delivered, it intensified the shock and added emotional burden. These responses formed the strongest criticisms:

The diagnosis was given only to my mother, who was caring for my father, but she always felt abandoned, with no guidance on how to care for him or where to seek more information.

The doctor gave the diagnosis and nothing else was said or done, not even a referral to supportive services.

The first neurologist was terrible, saying there was nothing to be done and that the hospital had nothing more to offer.

Although the focus is often on the PwD, **the accompanying person is also under immense pressure and deserves specific support**:

I don't know what the doctor said; it's as if I refused to hear what she told us.

Nothing is positive when one receives a diagnosis like this.

I became prepared for the future of the patient.

The importance of the physician's empathy—towards both PwD and caregiver—was highlighted by most informal caregivers. It was praised when present and strongly criticised when lacking:

The worst part was the impersonal way in which the diagnosis was communicated.

The doctor's kindness was the most positive aspect.

Cold treatment—the diagnosis was only given because I insisted.

The doctor stressed the need for affection, support and attention for the patient—very good.

Finally, the **idea of the future is vital**. Caregivers emphasised how important it is to discuss what lies ahead in what is, undeniably, a one-way journey:

The second doctor explained everything, from medication to disease progression. That was the most positive element.

The most negative part was that the future was not addressed; medication was simply prescribed.

What was most helpful was the explanation of the disease, the future, and how it was communicated.

«

I quickly lost hope. No one showed us the glass half full. As informal caregivers, we need a lot of help, even if we are educated people, because we simply don’t know what to do. Even when they go to the hospital, they want to send them back home right away. I had to study all the legislation on my own just to understand what I was entitled to.»

TRAINING TO DEAL WITH THE DISEASE

Dealing with dementia is a complex and demanding task, filled with nuances and unforeseen challenges. Caregivers often face situations that leave them overwhelmed and full of doubts, particularly when confronted with the progression of dementia in its various forms, in a process of continuous decline.

The empowerment of informal caregivers plays a crucial role in the quality of care provided and in the quality of life of the person with dementia (PwD). Dementia manifests differently in each individual, and successful care strategies require a wide range of skills—from managing specific symptoms to understanding the physical and psychological needs of the PwD.

Exploring the availability of training and assessing its effectiveness in preparing caregivers is essential for a full understanding of the situation and for identifying potential solutions.

Since dementia is a progressive condition with challenges that differ across stages, continuous learning and adaptation by the informal caregiver are key components of successful care.

Informal and non-formal training, when suited to each target population segment, is a decisive factor in reducing the perceived burden of the problems—namely by reducing caregiver stress and equipping caregivers with tools to handle difficulties—ultimately improving both caregiver quality of life and PwD well-being (35,36).

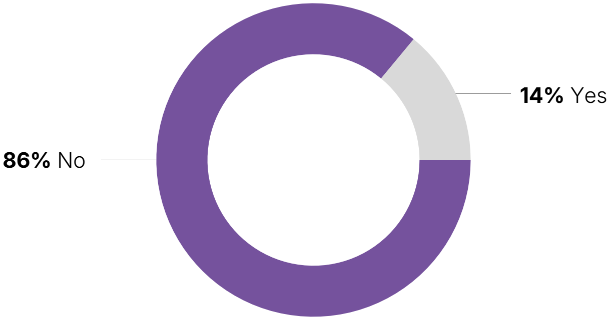
This section examines the experiences of informal caregivers regarding the training they received to face dementia. It discusses how training influenced their care practices, their confidence in their caregiving role, and their ability to provide effective support. It also presents the resources and training types most frequently mentioned by caregivers.

Post-Diagnosis Training: Involvement and Target Groups in the PwD Care Context

From the moment a dementia diagnosis is given, informal and non-formal training plays a role in empowering informal caregivers—usually family members—and may even be extended, in early stages, to co-workers. No distinction was made between different training formats, as people generally do not perceive such differences.

The first step was to identify whether any form of training had been provided. Participants could answer “Yes” or “No”.

Figure 28. Training to deal with Dementia provided to PwD or to close contacts



Overall, respondents reported not having received any training, and this absence is consistent across all sample subgroups. The only difference found was that AP (Alzheimer Portugal) members had received some form of training in 15% of cases, while non-members reported receiving training in only 7%.

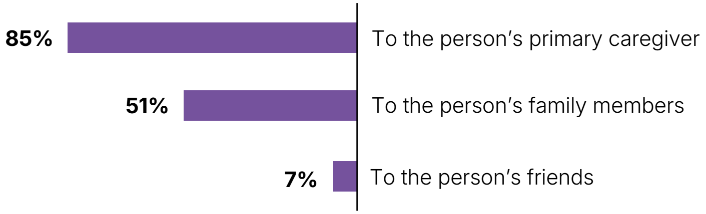
This reveals a vast untapped resource that could benefit everyone:

- The PwD, who would receive better care;
- The caregiver, who would improve their physical and mental health;

- The immediate family, who would be better prepared to understand and manage dementia;
- The health and social care system, since a well-supported PwD relies less on emergency and high-cost services.

If the respondent had answered “Yes”, they were then asked to select all applicable options regarding who received training: “The main caregiver”, “Family members”, “Friends”.

Figure 29. Who received training to deal with dementia.



As shown in Figure 29, those who received training were mostly the primary caregivers. Only a little over half of respondents indicated that family members also received training—revealing a significant gap in preparing families for the specific challenges of dementia care, and thus in the support they are able to provide. No participant indicated that supervisors or colleagues at the workplace (in cases where the PwD was still working) had received training.

This allows one clear conclusion: virtually everything remains to be done in terms of training, a particularly concerning finding given that this sample is already highly advantaged and engaged.

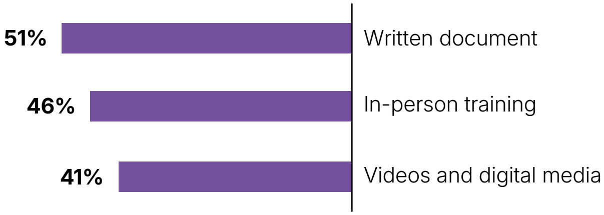
Below, some details are presented regarding the types of support and training content received, although the group comprises only about fifty people.

Training for Caregivers: Types of Support and Content for Dealing with Dementia

If the participant had previously reported having received training, they were asked to indicate the type of support through which that training was provided. They could select all applicable options:

- Videos and digital media (Internet, webinars, recorded courses, etc.)
- Written materials (PwD guide, caregiver guide, or others)
- In-person training (workshops, practical sessions, etc.)

Figure 30. Types of training support received to deal with dementia.



Although none of the formats had significant prevalence, the low use of digital resources was particularly surprising given the widespread use of online tutorials and training tools, which have shown positive results for caregivers in various dimensions (37,38).

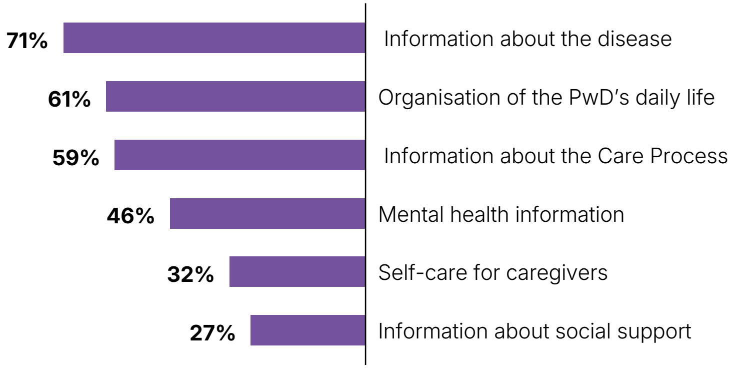
The "Other" category was nearly nonexistent, and due to the small number of respondents in each category, no subgroup analysis was performed.

Understanding the topics covered in training is essential for evaluating its comprehensiveness. The next question listed the areas most commonly addressed in caregiver training.

Participants were asked to select all applicable options among the following:

- Information on mental health issues
- Information on organising the PwD's daily life
- Information about the disease
- Information on social support
- Information about the caregiving process
- Self-care for caregivers
- Other

Figure 31. Topics covered in training for dealing with Dementia.

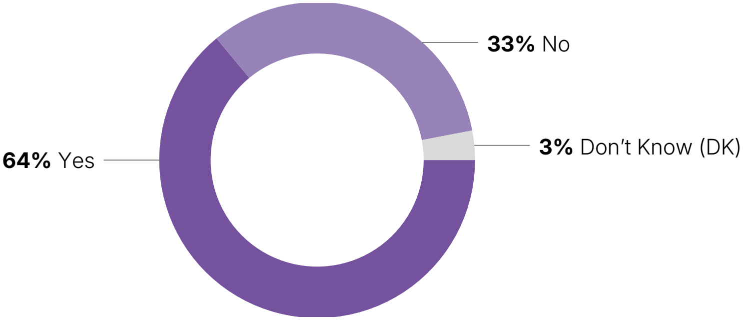


The training accessed by caregivers addresses the immediate needs of what must be done: understanding what Dementia is, how to provide care, etc. It is noteworthy that—even within an already small proportion of participants who received any training—the component dedicated to caregiver self-care is even lower, despite the well-known physical and emotional demands involved in caring for a person with Dementia.

Training Provided by Dementia Associations: Involvement and Impact on Caregivers

Training delivered through associations for people with dementia (PwD) is a valuable source of support and knowledge. This question aims to identify whether caregivers turn to such associations—primarily, in Portugal, the Alzheimer Portugal Association—for training.

Figure 32. Provision of training to deal with the disease through a PwD Association.



Among respondents who indicated having received training to deal with the disease, more than half (64%) reported having received it through an Association for People with Dementia.

«

At first, we were in shock.»

REACTIONS TO THE DIAGNOSIS

A diagnosis of dementia goes far beyond a medical label—it is a life-changing event that profoundly affects both the person living with dementia (PwD) and the informal caregiver. Reactions to the diagnosis vary, but they are almost always negative (29). They may include acceptance—sometimes even relief at finally having an explanation for what was happening—or shock, denial, or fear. Other common reactions include a sense of commitment to future care and concern about how the PwD will react (39).

When decades of life have been shared, when the couple lives together 24 hours a day, and when age is already more advanced than that of the average informal caregiver, everything tends to be lived more intensely (40). Understanding how these early reactions evolve over time and how caregivers navigate such complex emotions is essential for providing effective support.

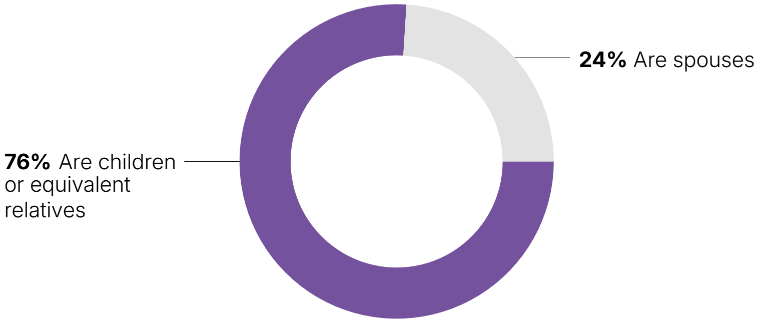
This section explores the personal and emotional stories of informal caregivers, highlighting how initial responses to the diagnosis shape the relationship between the PwD and the caregiver, as well as their ability to face the challenges that emerge thereafter.

Relationship with the Person Being Cared For: Dual Roles as Spouse/Partner and Informal Caregiver

Informal caregivers are often the spouse of the PwD. This dual role has profound implications on both the caregiving experience and how the caregiver perceives their responsibilities.

This type of relationship tends to be more challenging than when the caregiver has a different degree of kinship (41), mainly because the couple shares the same living environment day and night. Spousal caregivers have fewer opportunities to introduce emotionally restorative elements into their daily routine. They tend to sleep worse and experience more social isolation than other types of caregivers (ibid.), making them more vulnerable to the demanding emotional landscape of dementia.

Figure 33. Percentage of participants who are spouses/partners and caregivers of a PwD



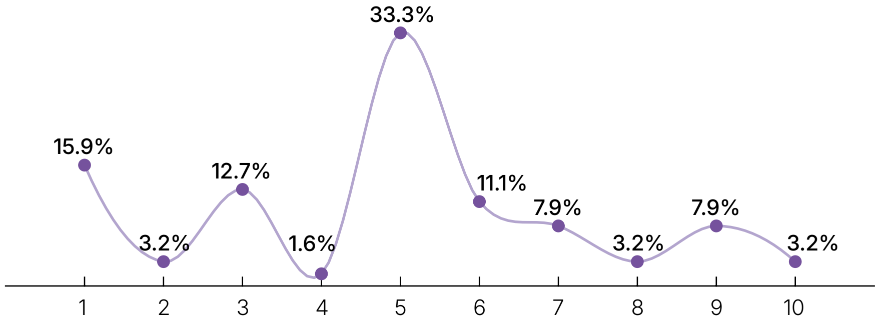
There is naturally a strong association between being a spouse and belonging to a certain age group. What stands out most, however, is that spousal respondents were more often men than women ($p<0.001$), even though epidemiological studies worldwide show that women continue to be the majority of spousal caregivers—although the difference is decreasing.

Several factors may help explain this finding: older women in Portugal have significantly lower digital literacy and are therefore under-represented in online surveys; men who become caregivers often need to develop skills traditionally not performed by older generations of men, leading them to seek more support resources, including through associations. Regardless of the reasons, the sex distribution among spouses is a structural element that must be considered when interpreting these data.

Reaction of the Spouse/Partner to the Dementia Diagnosis of the Person Being Cared For

Spouses were asked to rate their reaction to the diagnosis on a scale from 1 = "Very negative reaction" to 10 = "Very positive reaction."

Figure 34. Distribution of responses to the spouse's reaction to the diagnosis.



1: Very negative reaction   10: Very positive reaction

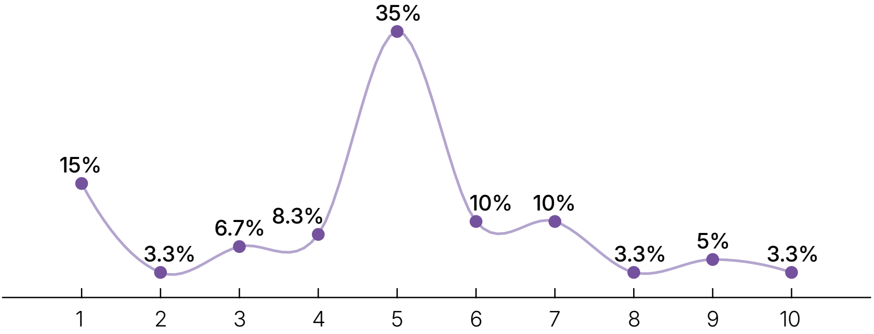
The distribution spans the entire scale. As expected, negative reactions were the most frequent, resulting in an average score of 4.8/10 with an SD of 2.5.

It is important to note that answers to this type of question often contain some degree of positive bias due to social desirability: people tend to want to appear strong or optimistic when facing adversity. Nonetheless, it is entirely possible for positive and negative feelings to coexist—for example, finding renewed purpose in caring for a loved one.

Family Reaction to the Dementia Diagnosis of the Person Being Cared For, from the Perspective of the Spouse

Spouses were also asked to assess how the family reacted to the diagnosis, using the same scale from 1 (very negative) to 10 (very positive).

Figure 35. Distribution of family reactions to the diagnosis (as perceived by the spouse).



1: Very negative reaction   10: Very positive reaction

The results closely mirror those from the previous question. The average again remained at 4.8, with an SD of 2.37.

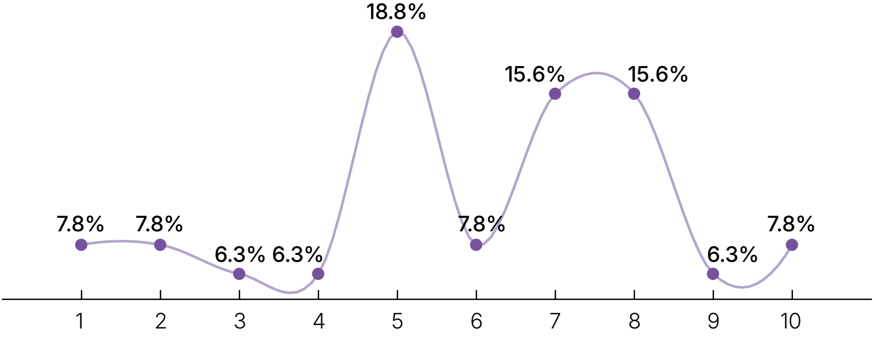
This similarity is particularly notable given the known divergence of roles that emerges throughout disease progression, often requiring increasing time, effort and physical demand from the spouse (40).

Adaptation of the Spouse/Partner to the Reality of Dementia in the Person Being Cared For

How the spouse learned to manage the realities of dementia is critically important for the well-being of the PwD and for the caregiver's own physical and mental health.

Participants rated their adaptation on a scale from 1 = "Copes very poorly" to 10 = "Copes very well."

Figure 36. Distribution of responses on how spouses adapted to dementia.



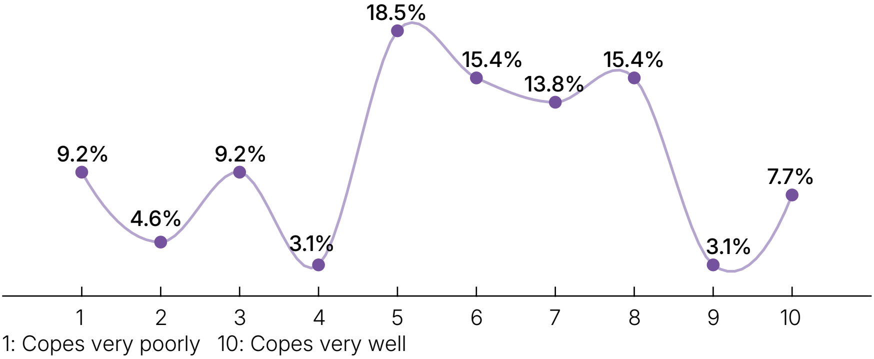
1: Copes very poorly 10: Copes very well

Reported adaptation in the period following diagnosis was more positive than the initial reaction to receiving the diagnosis. Again, two forms of positive bias must be considered:

- This sample includes individuals with higher literacy and proactive attitudes;
- Many respondents may engage in positive reframing.

The mean score increased to 5.77, with an SD of 2.60. There were no major differences across socioeconomic or demographic subgroups, except for a slight trend: individuals with higher education tended to report coping better than those with lower education—an expected result, as they may mobilize more resources.

Figure 37. Distribution of responses on how the family adapted to dealing with Dementia, from the spouse's perspective.



Feeling that the family is coping well with the challenges of Dementia is extremely important for the spouse-caregiver, as this perception provides social support, reduces involuntary loneliness, and reinforces their own ability to face difficulties.

Once again, a similar pattern appears, with comparable mean and standard deviation values (5.57 and 2.52, respectively). No differences were found across subgroups.

> «She was an extremely independent woman, did everything she needed without asking for help from children or grandchildren. Then she began to require my intervention even for simple tasks, and toward the end we were all helping — and even that was not always enough.»

CHANGES IN THE LIFE OF THE PERSON WITH DEMENTIA

Dementia not only affects the lives of informal caregivers, but also brings profound changes to the life of the diagnosed individual. This section does not discuss clinical variables, but rather caregivers' perceptions of the person, based on what they previously knew about them and how they attribute changes to Dementia.

The section begins with "Behavioural changes caused by Dementia," examining how behavioural symptoms influence the relationship between the person with Dementia (PwD) and the caregiver, as well as their home environment.

It then addresses changes observed in work life, where applicable, offering insight into how Dementia affected the person's ability to continue working and how employment-related decisions were made.

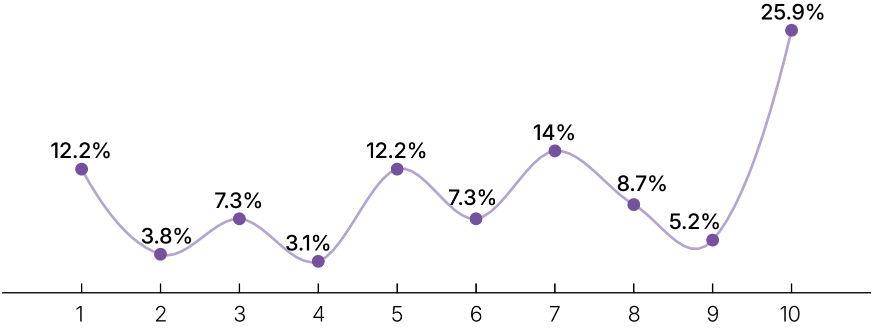
Finally, the section explores changes in leisure activities — social, cultural, and physical.

Behavioural changes caused by Dementia

Caregivers were asked to evaluate several behavioural dimensions: sadness, apathy, isolation, loss of interest in social and/or family activities, loss of interest in self-care or previously enjoyed activities, and changes in sleep or eating behaviour. All assessments reflect the caregiver's subjective perception.

A scale from 1 to 10 was used, where 1 indicated complete absence of the behaviour and 10 indicated strong expression of it.

Figure 38. Distribution of responses regarding the degree of sadness manifested by the PwD.



1: Did not show sadness 10: Showed significant sadness

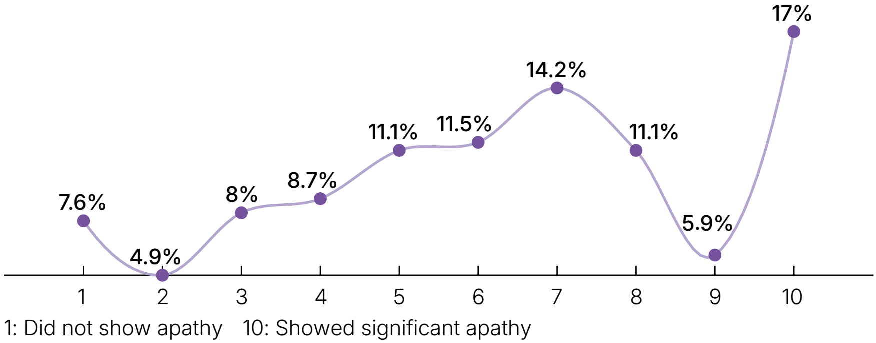
Across the sample, respondents reported the presence of sadness, with a mean score of 6.33 and a standard deviation of 3.1. Notably, a high proportion of participants (25.4%) selected the maximum value on the scale.

Looking more closely, additional elements emerge. Women reported significantly more sadness in the person they care for than men did (p<0.004). It is unclear whether this reflects greater emotional sensitivity among women or a greater manifestation of depressive symptoms in the male PwD for whom they provide care. The scientific literature on this topic is still limited. What is known, based on a meta-analysis (42) on sex differences among informal caregivers, is that women tend to have poorer physical health and are particularly more sensitive to depressive phenomena, reaching rates twice as high as those observed in men (43). This condition may influence their perception and recognition of sadness in the PwD.

Age also played a role: participants aged between 50 and 70 years—especially women—reported higher sadness scores than the rest of the sample (p<0,003), with many opting for the extreme end of the scale.

The analysis then moved to caregivers' perception of apathy in the PwD. In this dimension, no differences were observed across any subgroup of the sample.

Figure 39. Distribution of responses regarding the degree of apathy manifested by the PwD.



A similar pattern emerged, with many participants choosing the negative extreme of the scale. The mean apathy score was 6.1 (SD = 2.76). No sub-segment differentiations were observed.

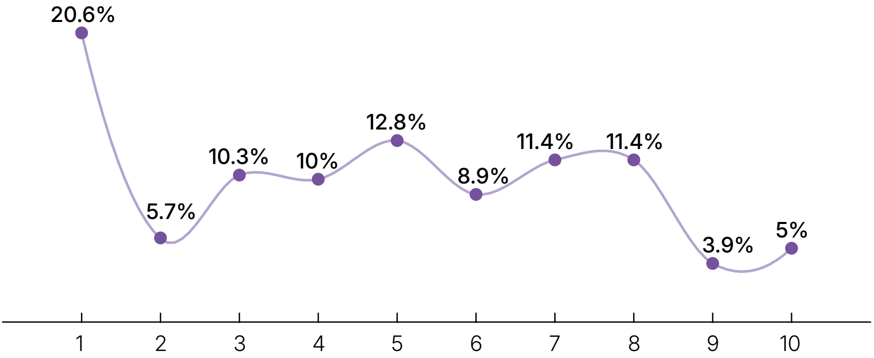
The next variable assessed was perceived isolation in the PwD following diagnosis. The question did not distinguish whether isolation stemmed from loss of functional abilities or emotional decline. Informal caregivers are generally not trained to make such distinctions, and even professionals may find them challenging.

A meta-analysis of 20 studies on emotional changes after Dementia diagnosis found apathy in 54% of mild cases, 59% of moderate cases, 43% of severe cases (44). If all negative-side scores in this study's scale are considered, 71% of the Portuguese sample showed isolation—potentially exceeding the ranges reported in the meta-analysis. While extrapolation to the national population is not appropriate due to the voluntary and digitally-mediated nature of the sample, the result warrants attention for future research.

The next item measured was the degree of isolation perceived in the PwD after diagnosis. A previous study (45) reported isolation present in 30% of cases, extremely present in 5%, and not influenced by marital status nor different from values observed in people of the same age without Dementia. The study also highlighted the scarcity of research on this topic.

Despite the methodological reservations — self-report, distinct observer profiles, and varying contexts — the results found in this Portuguese study suggest a somewhat different pattern.

Figure 40. Distribution of responses regarding the degree of isolation of the PwD after diagnosis.



1: Not isolated at all 10: Completely isolated

Regarding the stratification of the sample, few differences were observed. Individuals with higher levels of education reported less isolation after the diagnosis than those with lower educational levels ($p<0.040$), with a more polarised distribution.

Next, it was important to understand the PwD's relationship with social and family activities. The decline in interest in such activities cannot be attributed solely or directly to dementia. Among older adults, a reduction in interest in family activities is common when depression is present (46), a condition that frequently co-occurs with dementia. Dementia also involves difficulty dealing with the future and planning ahead, leading the person to prefer activities that provide immediate emotional gratification (47). The decline in interest in family and social activities will therefore depend on whether activities are adjusted to the PwD's reality, whether depressive symptoms are present, and on the type of family bonds established within each household.

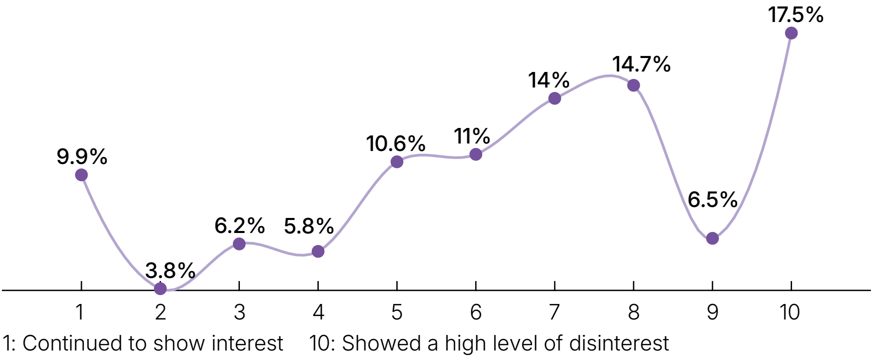
This study does not aim to judge anyone nor to specify in detail which activities are provided. It merely recognises existing conditions and identifies potential needs. These may include family training, increased mental health support for the PwD and the informal caregiver, among others.

According to informal caregivers, PwD showed a marked loss of interest in social and family activities after diagnosis. The distribution of responses was highly polarised. For example, the highest point of the scale was chosen far more frequently than the immediately adjacent category.

The mean score was 6.27 (SD = 2.83), suggesting opportunities to improve several dimensions that may mitigate the loss of interest in these activities, as recognised by informal caregivers.

Again, the only differentiation occurred between those with a university degree or higher and those with lower levels of education ($p<0.016$). Individuals with lower literacy reported a greater degree of withdrawal than those with higher education.

Figure 41. Distribution of responses regarding the PwD's degree of disinterest in social/family activities.

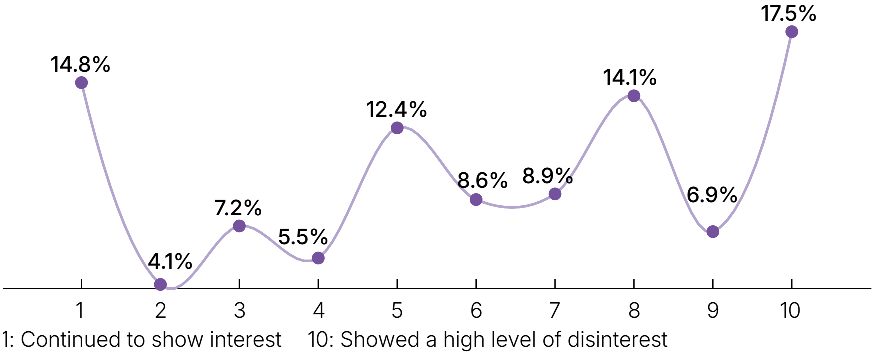


Self-care activities and individual tasks tend to be affected in both PwD and informal caregivers once dementia is established (48), depending on the degree of social vulnerability and the burden of disease they must manage. This is relevant because it may affect some respondents themselves and, consequently, their perception of the PwD's capabilities.

Self-care must always be addressed as a dyadic condition. The PwD's ability to care for themselves depends on their functional capacity at each moment, which will gradually decrease and eventually become impossible (49). This raises questions about the safety of carrying out self-care activities and the need for supervision at an early stage, followed by substitution when the person is no longer able to perform them safely.

Efforts should focus on helping the PwD maintain self-care skills for as long as possible and ensuring that disease progression occurs without safety gaps and with the least burden possible for the informal caregiver.

Figure 42. Distribution of responses regarding the PwD's degree of disinterest in individual and self-care activities.



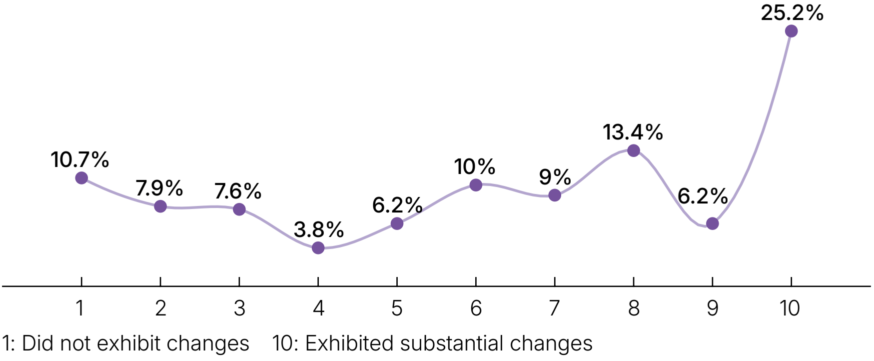
The pattern observed in previous questions is repeated here. The mean score was 5.9, with an SD of 3.0. Again, the only intergroup difference was related to education: those with a university degree or higher reported less decline than those with lower levels of education. This may reflect a perception effect; however, scientific literature consistently shows that individuals with higher literacy resources tend to experience a lower burden of disease as caregivers and often have greater capacity to manage dementia. The results are therefore aligned with expectations.

International data (ibid) indicate that at least 85% of PwD present some degree of self-care impairment. This percentage highlights the significant opportunity to promote informal caregiver training and capacity-building to prevent avoidable strain, facilitate the transition between self-care and dependence, and ultimately enable PwD to receive the best possible care.

The next analysis focused on factors that most impact family dynamics and informal caregiving: sleep and eating habits. Given the length of the questionnaire, these aspects were not examined in detail, as the aim is to capture the caregiver–PwD dyadic experience.

Sleep is very frequently a disturbed element, even being used in the establishment of the diagnosis. Eating is the social act that is usually most often performed together within the family. However, it is necessary to highlight a few ideas in this regard. Eating-related changes in Dementia may occur throughout the entire process, from the purchase of food to the way the body reacts to the digestive process. Eating-related changes in Dementia are therefore strongly associated with the stage of disease progression (50).

Figure 43. Distribution of responses regarding manifestations of sleep or eating behaviour disturbances in the PwD.



1: Did not exhibit changes 10: Exhibited substantial changes

In the earliest phase, when the PwD has not yet been diagnosed or, although diagnosed, is still in a phase of autonomy, it is common to record changes in shopping patterns, because they forget some of the food items they intend to buy or the way to prepare them (51). In later stages, the person may forget that they have eaten and present over-eating, or simply skip meals and not eat, with the inherent malnutrition. Dementia interacts strongly with depression, mutually exacerbating each other in the eating domain.

In advanced stages of Dementia, problems of swallowing control arise, which may even lead to fatal choking accidents.

Inadequate eating behaviours may also occur, ranging from the inability to eat at the table using cutlery, to ingesting non-food items, and handling other diners' food (52).

As can be seen in the figure, the vast majority of individuals showed some manifestation of sleep or eating changes, resulting in a mean value of 6.2 and an SD of 3.1. Differentiation by subgroups only showed adult children reporting greater differences compared with the preceding stage than spouses ($p<0.050$).

Work-Related Changes Observed (When Applicable)

Dementia, being a progressive and debilitating disease that affects memory, cognitive capacity, orientation, and the ability to perform daily tasks, not only compromises individual autonomy but also has a profound impact on all aspects of a PwD's life, including the work domain, if applicable.

When receiving a diagnosis of Dementia, due to age, most people are no longer working; only 10 to 20% of people diagnosed with Dementia still maintained some form of work activity (53). Therefore, the first question asked whether they were retired or receiving a pension.

The labour world is usually associated with the skills of those who engage in it and with early or intermediate stages of adult life. However, the progressive ageing of the workforce and the continual rise in retirement age mean that more older people are now in the workplace and, consequently, the likelihood increases that conditions such as Dementia may be present within the labour force.

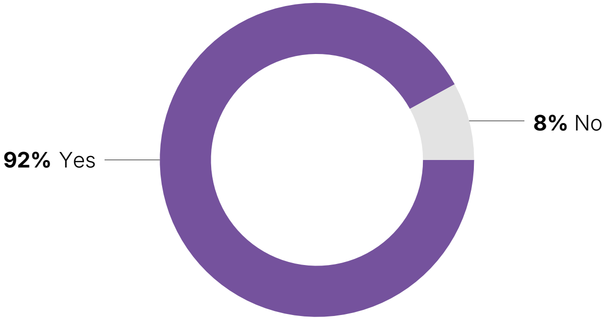
In turn, Dementia promotes a decline in the capacity to cope with the workload, especially in the early stages of the disease, when a pathological pattern is not yet visible. Forgetfulness of commitments and the reduction in the volume of work produced accumulate, which can easily be misinterpreted by supervisors and colleagues as negligence, age-related incapacity, or incompetence (54).

When a person is deprived of working as a result of their condition, in addition to the inherent financial loss, they also suffer other harms: social, self-esteem, etc., which are not usually associated with the issue of Dementia.

This study seeks to document, in the sample analysed, the transformations that a Dementia diagnosis imposes on the professional sphere of affected individuals, if applicable, based on the premise that the capacity to work is one of the pillars of a person's identity and independence.

The questionnaire, in line with the rest, is restricted to the changes reported by the PwD's informal caregiver. Analysing these changes is important for developing policy strategies for inclusion, as well as for providing support and adaptation in the workplace for as long as this is possible. In this effort, occupational health companies that certify fitness to work and those providing adaptive training should also be involved.

Figure 44. Determination of whether the PwD is (was) retired or receiving a pension at the time of diagnosis.



Of the participants, 92% responded affirmatively, which may be considered close to the international value mentioned of 10 to 20% in a work situation at the time of the Dementia diagnosis.

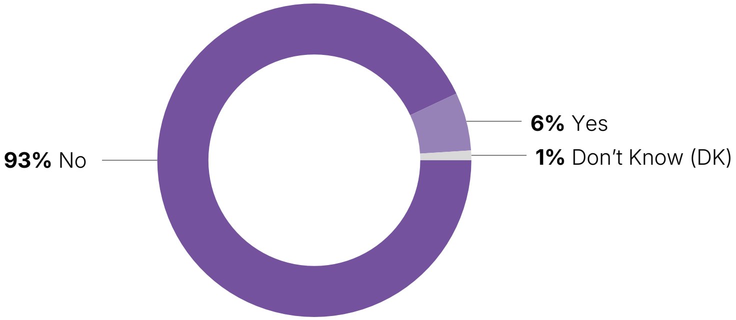
This finding reinforces the idea that it is important, also for labour-related reasons, to obtain the diagnosis as early as possible, as well as the need for capacity-building measures and workplace adaptation for as long as feasible. By prolonging work activity, if that is the choice of the PwD and the accompanying team, the person may maintain a broader social network, a better retirement or pension at the time of work cessation, and greater self-esteem.

Within this framework, the issue arises of legal protection, as well as the need to equip supervisors and colleagues so that expectations and the adaptation of the workplace and required skills may be aligned with the actual capacities that the PwD is able to offer.

When asked whether the PwD had any work activity after the diagnosis, a relatively high value was found (6%), which is positive.

The PwD's work does not have to be exclusively related to the functional aspects previously described. There is an "aspirational self" that the person may work towards and obtain results for, with (extreme) examples of taking part in the production of scientific publications (55).

Figure 45. Determination of whether the PwD works or has worked in the period after the Dementia diagnosis.



The inclusion of the PwD in work means that this activity should neither be a source of stress nor an externally imposed reframing (which leads to frustration), but rather a constructive and adapted form of productivity.

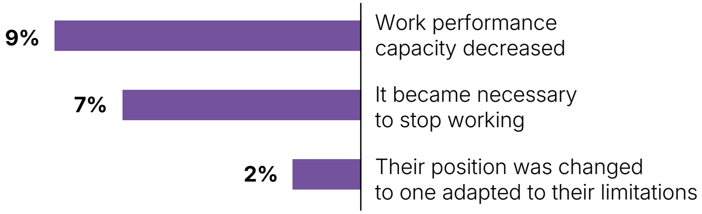
The remaining participants (93%) indicated that the person they care for did not work or had stopped working after the diagnosis, which highlights the difficulties that Dementia imposes through restrictions in work activities. The possibility of working or returning to work is limited to people whose stage of the disease is still in its early phase.

Finally, 1% responded that they did not know whether the PwD worked or had worked in the post-diagnosis period.

It was then important to understand the impacts on work following the diagnosis, naturally only for those who still had professional activity.

From the qualitative phase of the study, the following response hypotheses were created for the question "What consequences did Dementia have on the PwD's employment?": "There were never any problems", "Work performance capacity decreased", "The supervisor changed their position to one adapted to their limitations", "It became necessary to stop working", "Other", "Don't Know (DK)", and "Prefer Not to Answer (PNA)".

Figure 46. Consequences of Dementia on the PwD's employment.



It is clear that all, without exception, experienced problems, which reinforces the need for labour reframing policies. The results of the responses to that question reflect the reality of a specific subsample composed of the 18 PwD who were in a work situation. Seven people had to face the need to stop working, leaving it unclear whether this need resulted from the absence of socio-occupational support or from actual cognitive impairment. Two people had their work position adapted to their limitations. As would be expected, no one stated that they had never encountered any type of problem or obstacle in their job.

Changes in leisure activities

It is commonly accepted that social leisure practices are important for all humans and, by extension, for PwD, and therefore their recommendation is useful in the context of prevention strategies (56) and for cognitive preservation (57).

Recent scientific literature has, however, added complexity to the issue, suggesting that it may not be the existence or absence of these activities that holds predictive value, but rather the decrease in the frequency of leisure activities in the phase preceding the Dementia diagnosis (58), as indicated in the Whitehall II study, which followed a large group of thousands of people over 18 years. The type of activity does not appear to have a differentiating impact. Even if this is the case, it does not diminish the general importance of these fundamental activities.

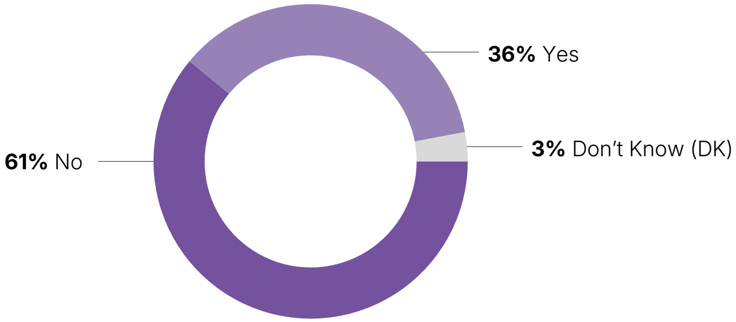
The survey therefore included a section assessing changes recognised in the leisure activities of PwD, widely acknowledged as fundamental for the well-being and quality of life of individuals after diagnosis. Since informal caregivers may be less aware of the pre-diagnosis phase, which may be long, the focus was placed solely on the post-diagnosis period.

The first question in the block sought to assess whether the leisure activities of the PwD remained the same after the diagnosis. A total of 36% of informal caregivers indicated that the leisure activities of the PwD under their care remained unchanged despite the challenges imposed by Dementia.

Sixty-one per cent recognised that PwD experienced changes after the diagnosis, which may vary from reduced participation in activities to complete discontinuation.

The remaining 3% of informal caregivers stated that they did not know whether the PwD’s leisure activities had remained unchanged or had undergone changes.

Figure 47. Determination of whether the leisure activities of the PwD remained the same after the diagnosis.



To explore the topic further, the survey sought to assess the existence of changes in leisure activities caused by Dementia across four distinct areas:

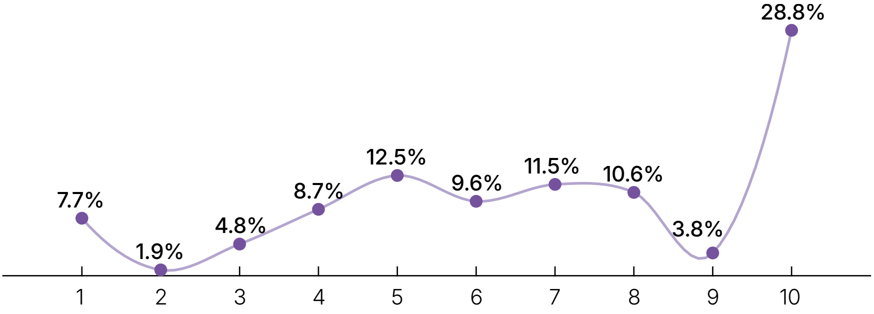
1. Domestic activities;
2. Social activities;
3. Cultural activities;
4. Physical activities.

For each of these areas, informal caregivers were asked to assign a score on a scale ranging from 1 (fully maintained the activity in question) to 10 (stopped carrying out that activity). This approach enabled a more detailed assessment of changes in the leisure activities of PwD, highlighting the areas that may have been most affected by Dementia.

It is debatable whether domestic activities constitute leisure. In fact, they may or may not be, depending on the individual's enjoyment in carrying them out. They were included in this context because, at the very least, they are structuring activities and may even be recreational, such as preparing specific dishes, lacework and crochet, tidying, etc.

Ceasing a routine or discontinuing an activity that brings pleasure almost always indicates the presence of an inhibiting problem.

Figure 48. Distribution of responses regarding the consequences of the disease on domestic activities.



1: Fully maintained 10: No longer carried out

The majority of individuals, more than 90%, recorded a decline in the performance of domestic activities after the diagnosis. About one third reported a total or near-total decline (the 9/10 pattern, as seen in this and the other scales, is strongly associated with and used as a superlative). The mean value of the reduction in activity frequency was 6.68, with a standard deviation of 2.81.

Men showed a slight tendency towards a smaller decline, which, given the social roles in Portuguese society, may simply mean that they had fewer domestic activities and therefore had less scope for decline. The remaining differentiators used in the study showed no differences.

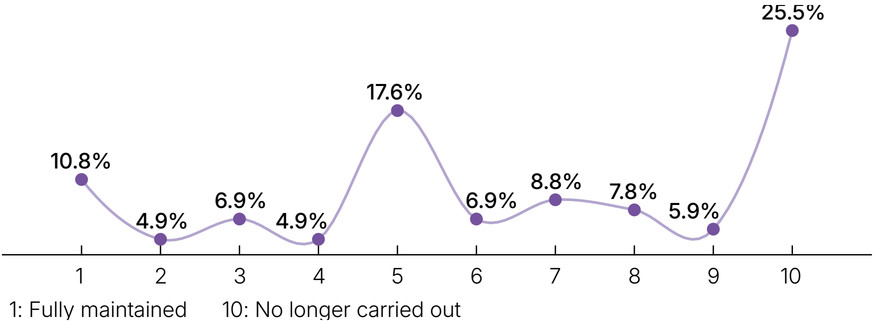
It must be borne in mind that each task previously carried out by the PwD and no longer performed means that the informal caregiver, or whoever replaces or assists them, must take it on, adding that workload to the burden already present.

The decline in social activities is less marked than in domestic ones. However, an alert should be made: the educational level of the PwD is highly important in determining the impact on social and volunteering activities. Individuals with low educational attainment who are strongly involved in social activities may (on average) even show cognitive improvements, whereas those with higher educational levels show no cognitive fluctuation (59).

In this study centred on the informal caregiver, it was not within scope to measure the educational level of the person being cared for, only that of the caregiver, which, as seen, is on average much higher than that of Portugal as a whole.

Among social activities, a wide diversity may be carried out depending on the PwD's preferences. Survey respondents were reminded of some possibilities. Most of these activities are beneficial to the PwD, as widely illustrated in the scientific literature: listening to music (60), social interaction (61), or even considering social activities generically (62).

Figure 49. Distribution of responses regarding the consequences of the disease on social activities.



A central concentration of responses was recorded, alongside extreme negative polarisation, resulting in a mean value of 6.2 and an SD of 3.1. In other words, informal caregivers report, in a considerable proportion of cases, an almost complete cessation of the PwD's social activities and, in the remaining cases, a more or less pronounced decline.

Caregivers up to the age of 50 report less decline in this type of activity among PwD (p<0,003). It is unclear whether this results from an external perspective — given that they are mostly adult children or equivalents — or from reduced daily contact compared with spouses.

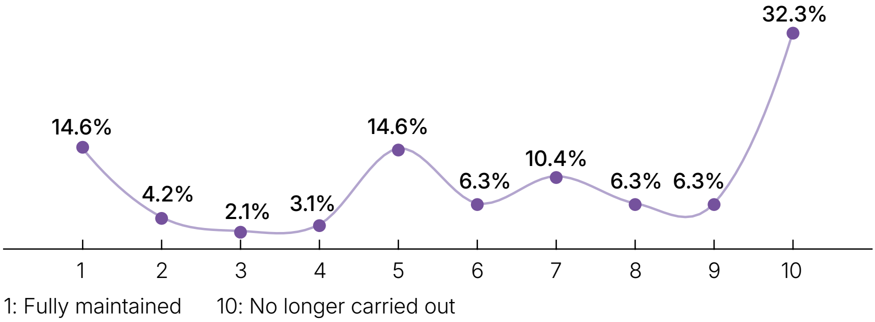
Whatever the underlying reason for this difference, it highlights the need to alert younger informal caregivers to the risk of decline in the PwD's social activities and to the importance of promoting and facilitating them.

Contact with cultural activities is highly beneficial for the PwD in the early and moderate stages, as it improves subjective well-being through the evocation of memories, the rehearsal of meanings, and social inclusion. In the more advanced stages of Dementia, there are no conditions that allow the PwD to engage in such activities.

Experiences have been developed with very interesting results, in which visits to museums are promoted for small groups of PwD, provided they fall within the aforementioned stages. In these visits, beyond the usual tour, direct contact with objects that allow handling is provided (63).

When cultural activities are understood more broadly, very positive contributions for the PwD are also recorded, improving their engagement with activities (64). Music stands out among cultural activities for its capacity to combat depression and improve subjective well-being. It is beneficial whether through simple listening or, preferably, through collective singing (65). Playing music is also possibly beneficial, although studies clearly demonstrating this are still lacking.

Figure 50. Distribution of responses regarding the consequences of the disease on cultural activities.



The distribution pattern is very similar to the remaining assessments in this group of questions: the majority registered moderate or very strong decline, and a minority indicated little or no change. The resulting mean was 6.54, with an SD of 3.67. No stratifier of the sample showed any distinction.

The most salient element of this question is the low number of responses (less than half of the sample), which suggests a low frequency of this type of activity, fully aligned with what is known about cultural consumption in the Portuguese population.

There is, therefore, a need to strongly encourage the use of cultural activities for various purposes: preservation of the PwD's capacities, prevention of mental health problems in both PwD and informal caregiver, and general improvement of subjective well-being. This is a resource with enormous room for growth and a tool to be added to the care protocol of most PwD.

Physical activity is endogenous to the human condition and therefore indispensable for the preservation of physical and mental health. It becomes even more important in various diseases, with Dementias included in this group, which is why it is incorporated into Dementia management procedures (66). In the PwD's care plan, physical activity should be incorporated as a regular activity, for as long as this is possible, and also for the caregiver, to preserve their own physical and mental health.

The effort to provide physical activities to the PwD must be continuous and attentive, because PwD with Dementia are more sedentary than comparable individuals without Dementia (67). The benefits of physical activity also show potential to improve cognition in the early and moderate stages of the disease (68).

Caregivers are not always motivated or equipped to provide such activities. In Portugal[2], one of the European countries where sedentarism is most prevalent, habits are deeply rooted, and only the incorporation of exercise into the PwD's care protocol, the training of the informal caregiver, and their empowerment to carry it out will enable the advantages of regular physical activity to be enjoyed.

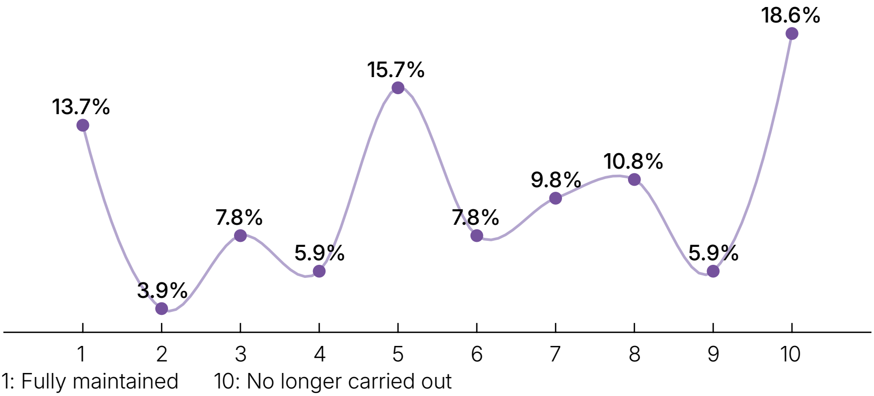
The most salient element in this question is the low number of responses (only one third of the sample), which aligns with the regularity of physical exercise in Portugal.

---

[2] *The 2022 Eurobarometer on physical activity in Europe indicates that 73% of Portuguese people do not engage in physical exercise.*

Among those who responded, a less negative distribution pattern was observed compared with the rest of the group, resulting in a mean of 5.9 and an SD of 3.0, which may be circumstantial and simply reflect that those most attentive to physical activity were the ones who responded. None of the independent variables proved to be discriminative.

Figure 51. Distribution of responses regarding the consequences of the disease on physical activities.



The questionnaire also addressed changes in holiday activities and similar moments, recognising the importance of these periods of rest and relaxation in the lives of PwD and their informal caregivers.

Very little scientific research has been developed so far on the specific issue of holidays of and with PwD. The few existing studies on the subject focus on the need for informal caregivers to forego holidays (69).

Holidays and similar moments for those who care for a PwD are a dyadic experience, even when the person is not present. It involves an entire logistics process that must be prepared in advance, with remote monitoring, etc., which does not mean that it cannot simultaneously be a break and a moment to regain strength.

If the PwD accompanies the informal caregiver on holiday, the need for preparation is even greater, as the person must be supported in an unfamiliar environment, with the inherent risks of getting lost or reacting negatively, to the point that holidays and breaks are often abandoned (70).

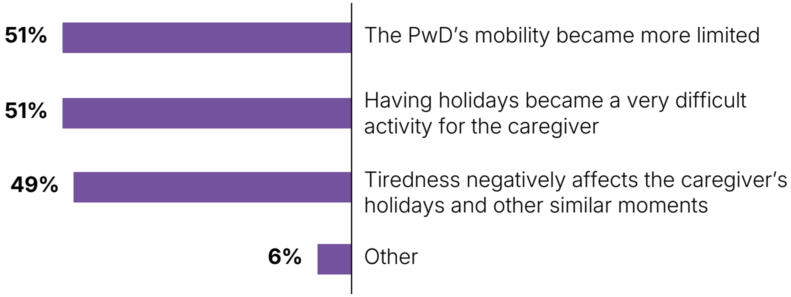
The issue was explored through the question: "Have holiday activities and similar moments become different from what they were before Dementia?".

A large majority, corresponding to 86% of informal caregivers, stated that holiday activities and similar moments became different after the PwD's Dementia diagnosis.

On the other hand, 10% of informal caregivers — the usual number — reported that holiday activities and similar moments remained unchanged, indicating that some PwD are still able to maintain a level of continuity in their leisure experiences, presumably because they are in an early stage.

A small percentage of informal caregivers (4%) stated that they did not know whether holiday activities and similar moments had changed.

Figure 52. Circumstances that led to changes in holidays and similar moments due to Dementia.



The results show that:

1. Mobility became more limited (51%). The reduction in the PwD's mobility played an important role in changing holiday activities, making them more challenging.

2. Having holidays became a very difficult activity for the caregiver (51%), suggesting that the demands and responsibilities of informal caregivers may hinder the organisation and taking of holidays for PwD.

3. Tiredness negatively affects the caregiver's holidays and similar moments (49%), indicating that caregiver fatigue may negatively influence the quality of and availability for participation in holiday and leisure activities with PwD.

A further 6% of participants indicated other reasons not included in the response options, namely the PwD's difficulty in leaving their routine, the PwD's lack of interest in such activities, the increased logistical difficulty of taking a PwD on holiday, and financial constraints, since expenses often increase due to the disease.

Adult children are more sensitive than spouses to the impact on their rest periods ($p<0{,}001$), which is understandable because spouses are usually already in a retirement phase in which the concept of holidays tends to become diluted, whereas the younger generation, still in the labour force, tries to manage access to rest more carefully.

These results emphasise the complexity of changes in the holiday and leisure activities of PwD after the Dementia diagnosis and highlight the need to develop support strategies for these moments, in areas such as mobility, care of the PwD during the caregiver's holiday period, and the informal caregivers' own well-being.

«

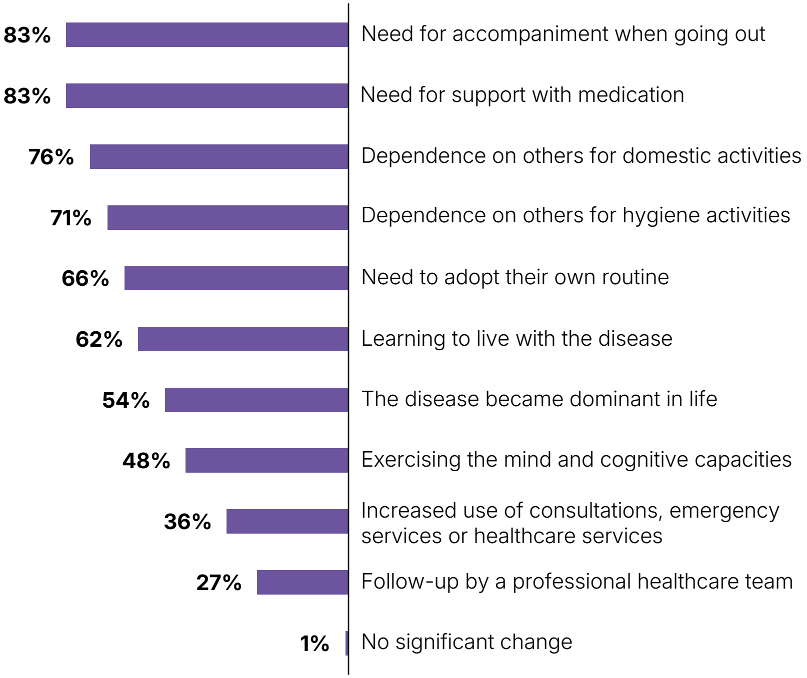
My father managed everything for four years. Then the house began to smell of urine, and we had to hire a lady to help with bathing and to put on his diaper. In terms of food, there were also countless changes: meals increasingly easier to eat and chew. The first thing to be abandoned was the knife, then the fork. In the end even water had to be gelified, otherwise he would choke.»

DAILY LIFE OF THE PERSON WITH DEMENTIA

Dementia is not only a medical condition; it is a complex life experience that profoundly affects the identity and daily routine of the person diagnosed. How is this transformation perceived by those who provide care? How has family dynamics been reshaped?

To understand the changes in the daily routine of PwD caused by the disease, multiple-choice response options were provided, offering a comprehensive overview of the perceived changes in the lives of PwD.

Figure 53. Changes observed in the PwD's routine due to the disease.



The results of this analysis are presented below:

1. **Need for accompaniment when going out:** 83% of PwD in the studied group require(d) accompaniment when leaving home, reflecting the need for supervision and safety, as well as the preparation required on the part of the informal caregiver.

2. **Need for support with medication:** 83% of PwD require(d) support with medication administration. It is presumed that the remaining individuals correspond to those in the early stage of the disease.

3. **Dependence on others for domestic activities:** For 76% of PwD, there came to be a dependence on others for domestic activities, highlighting the difficulty of carrying out these tasks independently.

4. **Dependence on others for hygiene activities:** Similarly, 71% of PwD came to depend on others for the performance of their personal hygiene needs, demonstrating a significant impact on autonomy in highly intimate situations and, again, the need to train those who care to be able to manage such situations.

5. **Need to adopt a specific routine:** For 66% of PwD, it became necessary to adopt a specific routine to manage the challenges of Dementia more effectively.

6. **Learning to live with the disease:** Around 62% of PwD and their informal caregivers reported learning to live with the disease. The immediate question that arises is how the remaining 38% are coping.

7. **The disease became dominant in life:** 54% of informal caregivers reported that Dementia became a dominant part of the PwD's life, indicating that the disease exerts a significant influence on their daily activities.

8. **Exercising the mind and cognitive capacities:** 48% of PwD are/were involved in activities aimed at exercising cognitive capacities to slow disease progression. If projected to the national population, this would mean that more than half of PwD are without this essential support. Worse still, given what has already been identified, the present sample is highly advantaged compared with national indicators, meaning overall values would be worryingly low.

9. **Increased use of consultations, emergency services or healthcare services as a result of Dementia:** For 36% of PwD, there was an increase in the use of medical consultations, emergency services, or healthcare services, demonstrating the high costs for the person with Dementia. It should be recalled that if the PwD and the informal caregiver are not sufficiently supported, the average cost per case becomes higher. The value found here is below international benchmarks, which may indicate that PwD are/were not receiving all the assistance they might need.

10. **Follow-up by a professional healthcare team:** 27% of PwD receive follow-up from a professional healthcare team, indicating that only around one quarter of the PwD in the sample has access to specialised care.

These results highlight the complexity and variety of challenges faced by PwD and their informal caregivers.

«

It is very difficult for me to reconcile life as a teacher with that of a caregiver for someone with Dementia. I go to teach in the morning and at lunchtime I have to come home; then I return to the school, but as soon as possible I go to my mother's house.

No one taught me everything I had to learn on my own.»

DAILY LIFE OF THE CAREGIVER

The experience of caring for someone with Dementia is profoundly multifaceted and challenging. The daily routine of the informal caregiver is affected across several dimensions, from physical to emotional and financial (21). If the intention is to place the patient at the centre of care, in the case of Dementia it is essential that the informal caregiver is also placed at that centre, given that there is a patient–caregiver dyad (71).

Informal caregivers deal with feelings of stress, emotional overload, anxiety and sadness as they witness the progression of the disease. This enormous burden can be reduced through access to various forms of support programmes (72).

The financial dimension is an important part of this equation. Caring for a PwD results in additional expenses, such as medical costs, home adaptations and loss of income due to possible reduction in working hours or even withdrawal from the labour market. Meanwhile, the PwD’s resources do not increase significantly through social mechanisms, resulting in potential situations of financial fragility, even in families where this did not previously exist (73).

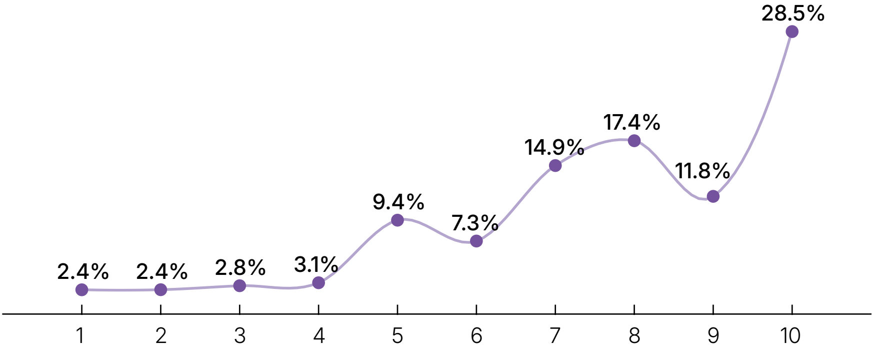
Information was collected on physical and emotional fatigue, as well as on financial impact. Scales were provided with values ranging from 1 (total absence of the manifestation of the element in question) to 10 (strong manifestation of the same).

Physical fatigue

At times it is difficult to distinguish where physical fatigue begins and emotional fatigue ends, as both are closely associated, especially when situations of burnout are recorded — a condition not at all rare among informal caregivers of PwD (73).

The issue of physical fatigue per se is still underexplored, although almost everyone recognises it as a central element. It was therefore important to measure it in Portugal.

Figure 54. Distribution of responses regarding the caregiver's level of physical fatigue.



1: Equally tired as before   10: Exhausted

As shown in Figure 54, practically all individuals reported some degree of fatigue, and many assigned very high values. If we restrict the analysis to those who gave 8+ on the scale (people experiencing very high fatigue), we obtain nearly 60% of respondents.

Women prove to be much more affected than men (p<0,001). In the remaining partitions of the sample, there are no differences, indicating that this is a common feeling. The mean value was 7.52 and the SD was 2.36.

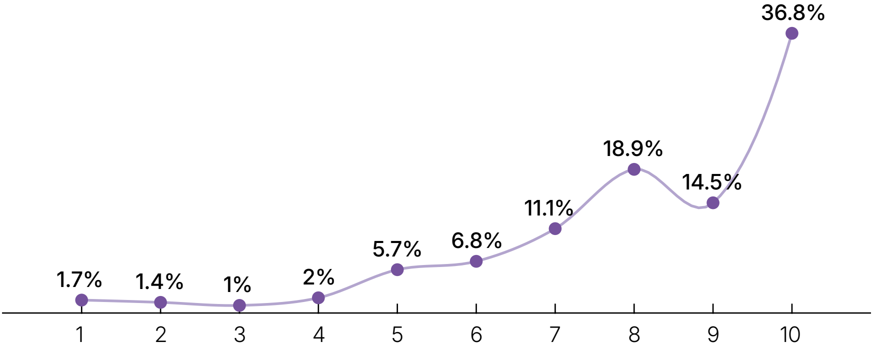
The values found require reflection on what can be done to mitigate such an intense condition.

Emotional fatigue

Unlike physical fatigue, the emotional exhaustion of informal caregivers has long been studied and documented (21,74), whether through meta-studies or through direct evidence gathered using a wide range of methodologies.

As mentioned previously, emotional fatigue often heightens physical fatigue. Therefore, it is important to contain emotional exhaustion and preserve mental health in order to avoid acute conditions such as burnout.

Figure 55. Distribution of responses regarding the caregiver's level of emotional fatigue.



1: Equally tired as before 10: Exhausted

Regarding emotional fatigue, responses were even more extreme than in the account of physical fatigue, with a mean value of 8.13 and an SD of only 2.10, resulting in approximately 70% expressing very high or extreme fatigue.

Women report much higher levels of burden than men, although men also show high values (p<0,001). It is not clear whether this difference stems from the social roles typically performed by older men in contrast with those traditionally carried out by women, or whether it is due to men, also for cultural reasons, being socially pressured not to expose their difficulties, especially when related to emotional issues.

Likewise, a tendency can be seen for sons and daughters to show greater exhaustion than spouses (p<0.044). The remaining descriptors of the sample did not show differentiating capacity.

Financial effort

Almost always, the presence of Dementia within a family unit represents an increased financial burden. The situation tends to be more complex when one belongs to a socially vulnerable group or has lower educational attainment (75), which leads to substantive differences in access to health and social care.

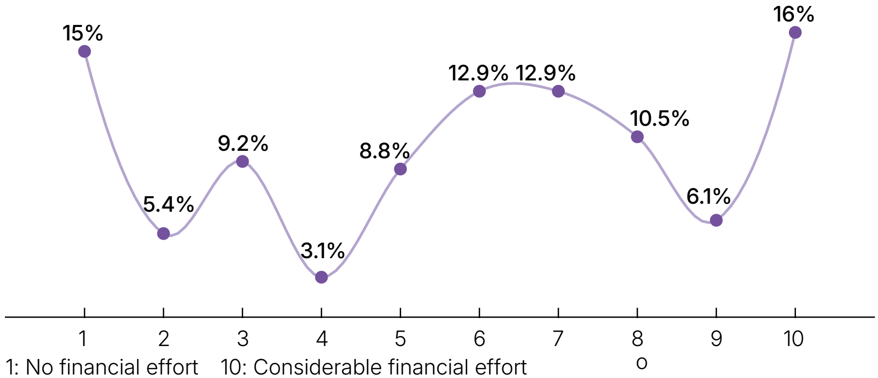
The sample used in the present study proved to be highly differentiated in terms of educational level, which in Portugal is strongly correlated with general living conditions. Likewise, the digital literacy required to complete the survey is correlated with education and income. In sum, with very high certainty, it can be stated that the sample participating in the study is financially far above the national average in Portugal.

Costs for families are borne in multiple ways: diapers and related items, temporary or permanent placement in an ERPI, medication, adapted food, home adaptations to adjust the space to the person, hours of work not undertaken, and family caregiving leave, to name only the most frequent expense categories.

In the present study, the burden of expenditure was considered differentially, that is, compared with the period prior to diagnosis, to what extent there had been an increase in financial effort.

The values recorded are quite striking, even taking into account the differentiation of the sample. Only one fifth of respondents stated that they had no impact or that it was very small, whereas nearly 60% reported a high or very high effort. If educational level and corresponding income in Portugal are adjusted for, the figure exceeds 80% in terms of families experiencing a strong financial impact.

Figure 56. Distribution of responses regarding the caregiver's level of financial strain.



In the direct data, the average effort reported by the sample was 5.77/10, with an SD of 3.0. None of the sample differentiators stood out in this question.

> «Dementia has been a constant challenge for my father's oncological condition. Many times he refuses medication and we have to be present so that he does not throw away the tablets. Even so, once we found dozens and dozens of tablets hidden under the sofa.»

RELATIONSHIP WITH DEMENTIA

In this section of the survey, respondents were asked to share the nature of the PwD's relationship with the disease, particularly how Dementia interacts with other medical conditions the PwD may have had.

Multimorbidity (two or more clinical conditions) in PwD is extremely common, among other reasons because of the age at which Dementia is most prevalent. In a study conducted in the United Kingdom (76) among PwD, it was found that 91.7% had one or more diseases concurrent with Dementia, and in another study involving tens of thousands of PwD, 35% had five or more conditions (77).

Multimorbidity in Dementia is a major problem because health systems are organised by organ and not transversally according to the PwD's overall condition. To address the various situations, the PwD and the informal caregiver most often have to consult multiple specialists, which increases polypharmacy from various sources and, by inference, the risks associated with taking medication. The PwD is left with multiple protocols to follow, in which inconsistencies may arise and the informal caregiver may find it difficult to manage them.

Behavioural changes in the PwD also promote the more pronounced development of osteoporosis, meaning that the same falls represent an increased risk and greater difficulty in recovering from fractures compared with people without Dementia (78).

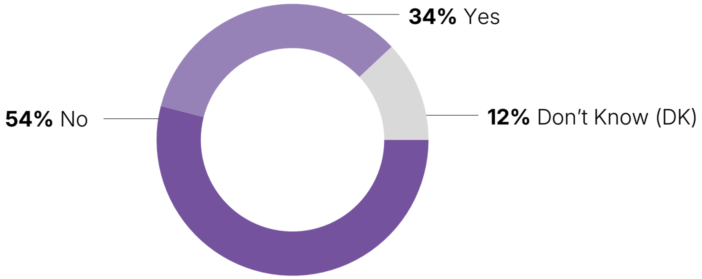
By exploring the interactions between Dementia and other health conditions, it is possible to identify patterns that help informal caregivers to manage the PwD's needs more effectively.

The results found were surprisingly below expectations. Only one third of respondents opted for the positive response, and a further 12% stated that they did not know whether there was interference. Response patterns were highly consistent across all groups studied.

This raises the issue of how the question was interpreted: whether it was understood as referring to a physical interference with another disease, or interference in a broader sense, which was what was being sought.

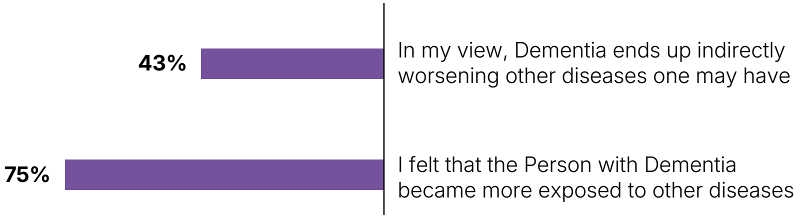
It became apparent that the very concept of interference between diseases may not even have been considered by informal caregivers. It is, therefore, an element of capacity-building to be included in future training for informal caregivers.

Figure 57. Interference of Dementia with other illnesses that the PwD has/had.



For those in the sample who answered "Yes" (34%), further detail was sought based on what had been collected in the qualitative phase of the study: "In what way does Dementia interfere with these diseases?". The response options provided were: "I felt that the PwD became more exposed to other diseases" and "In my view, Dementia ends up indirectly worsening other diseases one may have". A multiple-choice format was used, with the option to add further information, which occurred in a number too small to justify aggregation.

Figure 58. Interference of Dementia with other illnesses that the PwD has.



The results indicate:

1. In the perception of 43% of this sample of informal caregivers, the PwD became more exposed to other diseases as a result of their behaviours, general frailty, and reduced capacity to adopt preventive behaviours.

2. In the sample, 75% of informal caregivers reported that, in their view, Dementia indirectly worsens other diseases already present in the PwD.

What informal caregivers stated is fully aligned with what scientific research indicates and only errs by underestimation.

The extremely high frequency of multimorbidity among PwD justifies strengthening integrated responses in which the informal caregiver is a partner, but where they must simultaneously deal with care plans that are easy to manage, coherent, and where the safety of the PwD is a central dimension. What training response exists for this issue in Portugal? There is a lack of capacity-building for informal caregivers to deal with the problem and a lack of integration into personalised care frameworks.

> «It is difficult to get everyone on the same page. You speak to the neurologist, who says one thing, the family doctor says another, and we are caught in the middle. For example, medication for Dementia: if it is prescribed by the family doctor, it does not have the same reimbursement.»

RELATIONSHIP WITH HEALTHCARE PROVIDERS

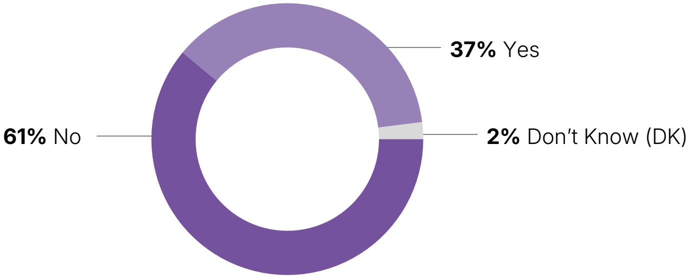
The quality of the relationship between the PwD, the informal caregiver, and healthcare professionals is a factor that significantly influences the degree of well-being and the quality of care provided. It is important that this relationship is flexible and holistic, while also personalised, in order to keep the person at home for as long as possible, considering the health conditions of both the PwD and the caregiver.

The scientific literature shows (79) that the best approaches are person-centred, where once again the training of the PwD and the informal caregiver is emphasised. Training for healthcare professionals in working with the caregiver–PwD dyad should also be considered, particularly for those whose work places them more peripherally in relation to Dementia and who must nonetheless interact with dyads.

To characterise this relationship from the perspective of the informal caregiver, a series of questions was formulated. The first concerned the perception of whether healthcare services available were sufficient. Normally, the perspective heard is that of service providers, not service users; it is therefore important to listen to what informal caregivers have to say.

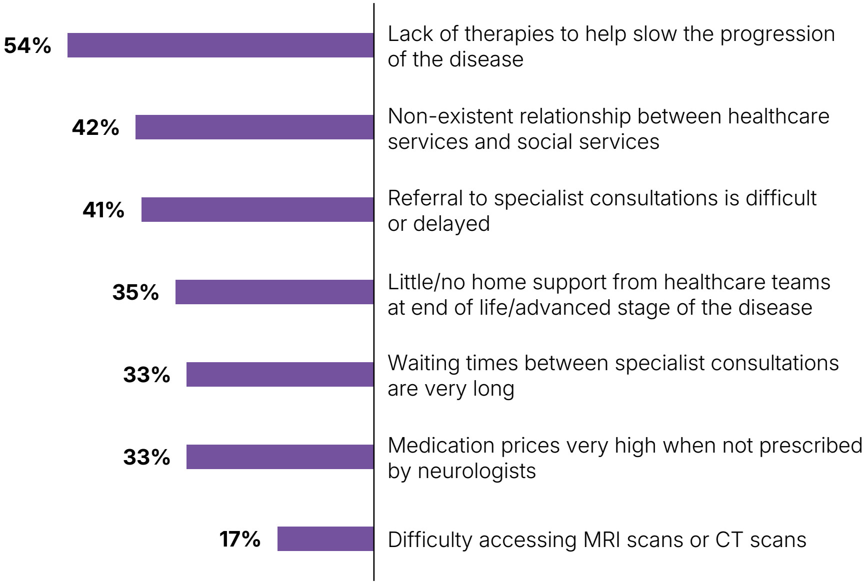
As shown in the figure below, the majority of people feel that they do not have access to as many services as they believe they need. Again, it must be emphasised that, as this is a differentiated and predominantly urban sample, access to healthcare services is easier in every sense: physical proximity, economic capacity to find alternatives if the solutions encountered are not quick enough, ability to search for formal responses, etc.

Figure 59. Whether the PwD has/had access to the health services they need/needed.



No subgroups showed differentiation. To specify what is lacking, those who answered that services were insufficient were able to provide details. Seven categories identified in the qualitative phase were presented, including the option to specify another category if desired.

Figure 60. Determination of what is considered to be lacking for the PwD to receive adequate support from health services.

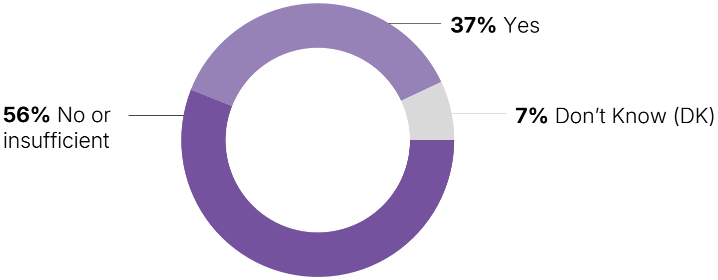


The category that received the greatest number of selections was the lack of availability of services that may help slow the progression of the disease, such as cognitive stimulation, physiotherapy and psychological support. This was followed by the difficulty in the relationship between health and social services, which was frequently expressed in personal interactions, particularly regarding the challenge of achieving an integrated response.

The remaining categories also follow, all with relevant frequency. Only three per cent of participants mentioned other factors.

Next, the aim was to explore access to physiotherapy, an important element (80), which had been described in the qualitative phase as difficult and which often had to be supplemented through private provision, or was not undertaken when financial conditions did not allow it.

Figure 61. Determination of whether the PwD has/had access to physiotherapy or similar services.



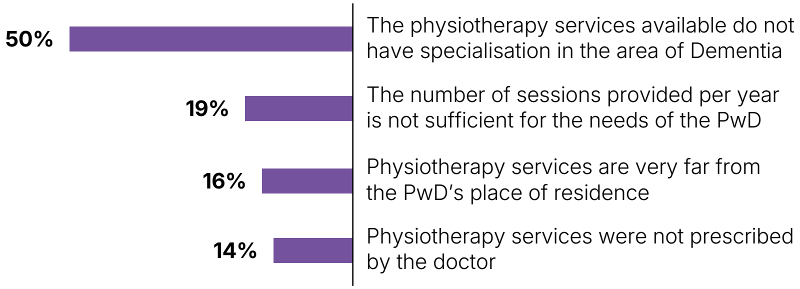
The feeling of lack of access is predominant and spans all the groups studied. Six participants chose not to answer this question.

If the response was "No or insufficient" (56%), respondents were asked what they considered to be the barriers to accessing physiotherapy and similar services for the PwD.

What stands out is the difficulty in finding someone to provide physiotherapy treatment to the PwD with some form of specialisation. This aspect is important because the mode of interaction used by the physiotherapist influences the PwD's receptiveness to treatment (81).

The condition of Dementia tends to restrict outcomes, particularly in the moderate and advanced stages (82); therefore, the physiotherapist's knowledge of the specificities of the Dementia stages has been shown to be a highly important element in achieving the full potential of the intervention.

Figure 62. Determination of barriers in accessing physiotherapy and similar services for the PwD.



In the "Other" response option, there was a significant prevalence (18 responses) of "It was never prescribed", which led to the creation and addition of a new response category entitled "Physiotherapy services were not prescribed by the doctor".

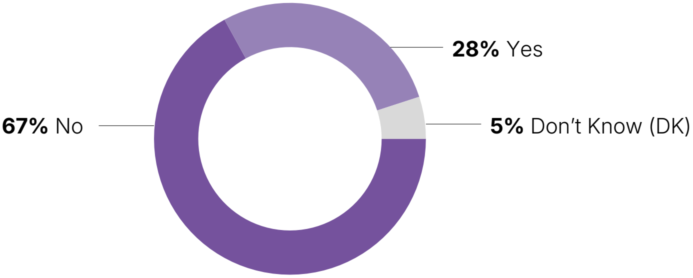
Next, the aim was to determine the existence of and ease of access to psychology and mental health support services for the informal caregiver.

First, it was asked whether the informal caregiver has access to psychological support. Given the burden to which caregivers are subjected, its use is strongly recommended. In this investigation, it is considered that such support should always be potentially available, with the decision to make use of it depending on each person, at each moment. In a meta-study (83) that analysed 46 psychological intervention programmes targeting informal caregivers of PwD, reductions in subjective burden, reductions in depressive symptoms, and other benefits were identified among those who participated.

Two thirds of respondents reported a lack of access to psychological services, and 5% did not know whether they had access, clearly illustrating how much remains to be done in this area.

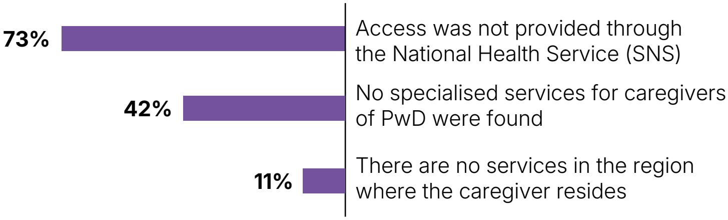
It was found that men reported greater access than women to psychological support (p<0.032), though it should be recalled that the men who participated here were those most likely to share their condition as informal caregivers of PwD, thus not representing the average Portuguese man. Aside from this, no group differentiation was found in any stratum – all groups studied reported a lack of access.

Figure 63. Whether the caregiver has/had access to psychological and mental health support services.



Secondly, for those who answered negatively, respondents were asked what they considered to be the barriers to accessing psychological services and mental health support for the informal caregiver.

Figure 64. Barriers to accessing psychological and mental health support services for the caregiver.



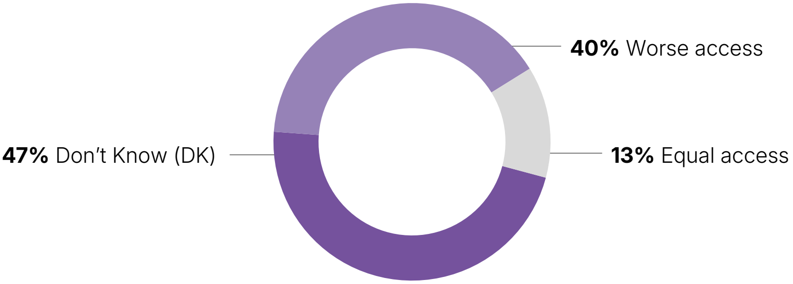
By far, the strongest emphasis was on the lack of access within the National Health Service (SNS), which forces families to incur additional expenses that are not within everyone's reach. Equally highlighted was the need for support from psychologists who are prepared to deal with the specific situation of the informal caregiver of a PwD.

Although the sample is predominantly urban, the lack of equity across the national territory was evident, in line with what had been recorded in other questions reflecting this theme. The values would surely be much higher if the sample did not essentially reflect the major urban areas. The very low number of responses from inland districts prevents normalisation between urban/rural contexts. Nonetheless, the message is clear: people living in inland areas feel much greater lack of access to health services than those in large cities. Considering that inland regions have population ageing rates far above those of the coastal areas, and that there are towns and villages where most inhabitants are older adults, the immense need for better access to psychological care becomes evident.

It was also important to hear from participants who described themselves as living in small localities regarding the equity of access to health care in these areas when compared with large cities.

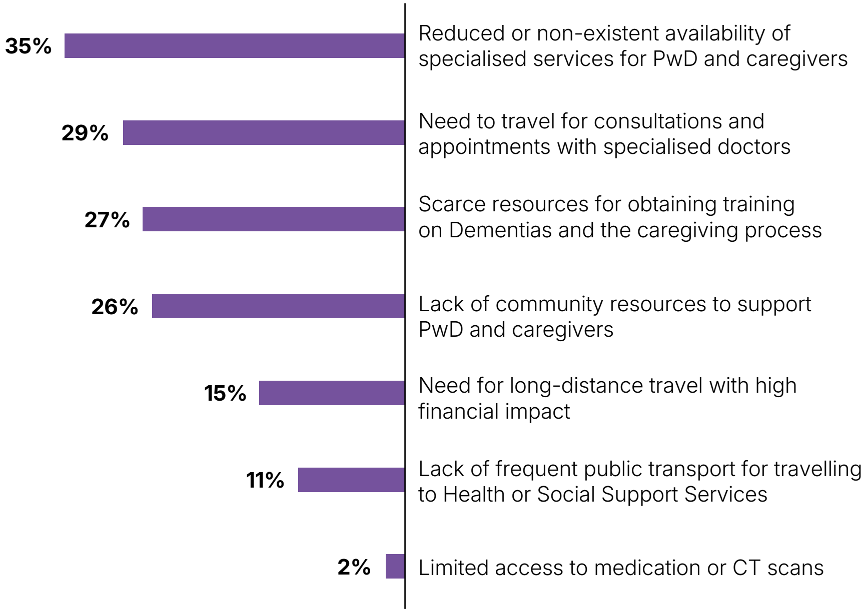
As expected, a very small number (13%) expressed having equal access.

Figure 65. Perception of equity in access to healthcare services for PwD by informal caregivers living in smaller towns.



Participants who responded negatively to the previous question were then asked to indicate which aspects they considered to be lacking, preventing the PwD from receiving good support from healthcare services in small localities.

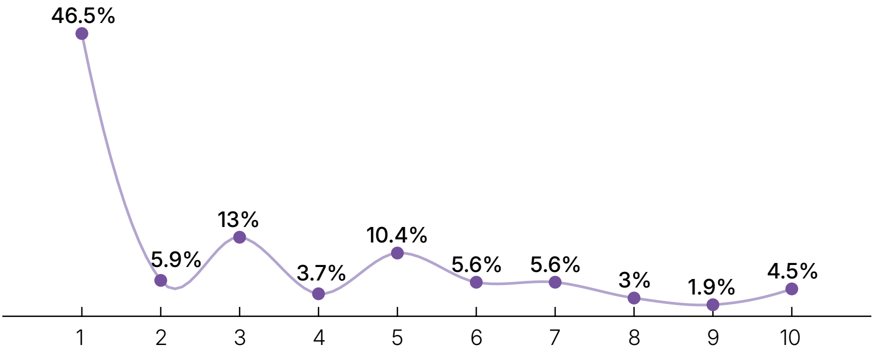
Figure 66. Differences in support for PwD who do not live in large cities.



The aim was to capture caregivers' perceptions of service coordination and the level of bureaucracy within health processes related to the PwD.

Regarding the perception of coordination between healthcare services in general, it is important to emphasise that the evaluation provided by the sample corresponds to their personal experience, not to an organisational assessment — the interpretation by the services themselves would likely be different. What mattered here was to record how informal caregivers feel and deal with the issue.

Figure 67. Distribution of responses regarding the level of coordination between healthcare services in general.



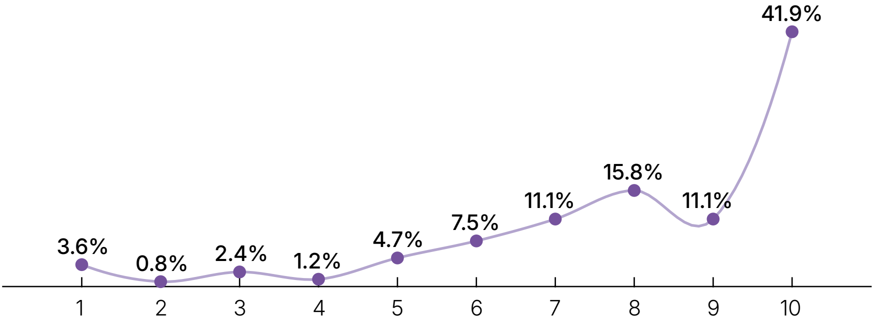
1: No coordination exists 10: Good coordination exists

The result shows that, in a very consistent way, without any intergroup differences, the response is extreme — one could say almost emotional — with the majority choosing the negative end of the scale. The mean value was one of the lowest (3.26), with an SD of 2.7.

Any action aimed at improving the coordination of services will be welcomed by those who care for PwD, and it is widely known that improving coordination between healthcare services increases system efficiency in its various dimensions.

The next step, believed to be correlated with coordination, concerned the perception of bureaucracy in processes related to the PwD. Again, responses were polarised towards the negative end of the scale. The mean value was 8.08, with an SD of 2.33.

Figure 68. Distribution of responses regarding the level of bureaucracy in processes related to the PwD.



1: No bureaucracy exists 10: There is a high level of bureaucracy

Adult children are more critical than spouses (p<0.001). Whether this reflects different patterns of expectation, or results from being more involved in administrative processes — even in situations where the spouse is the primary informal caregiver — is not known. Objectively, there is a very substantial subjective burden on everyone. The remaining differentiators did not show significantly different variances.

«

The medical board was not easy either — a year waiting, and then it seemed as though they doubted what they were being told. The reimbursement for diapers is another nonsense: all it takes is having a very small pension and they offer no help, while every day money is spent on diapers and bed pads»

«I practically went to war with the Hospital Social Services to have my father admitted to a Long-Term Care Unit close to home. I was forced to study the legislation.»

RELATIONSHIP WITH SOCIAL SUPPORT SERVICES

The network of social support services available to the PwD and the informal caregiver, if functioning well, provides support of enormous importance. The challenge lies in understanding what constitutes social support specifically for Dementia and how its outcomes are measured.

Even from a theoretical standpoint, the analysis of results is far from clear. What types of social supports should be promoted? Do they "only" improve well-being, or do they actually have an impact on the health of the PwD and the informal caregiver? If they do, which ones? A meta-study on these issues (84) indicated that when the intervention does not involve direct financial allocation, it impacts four areas of intervention, but measuring those impacts is extremely difficult.

Another meta-study (85), conducted in 2020, also presented four axes of need for social interventions:

1. Being supported: this domain is very broad and includes home-based services such as hygiene care, meals, housekeeping, etc., as well as support directly centred on the informal caregiver, for example, respite periods;

2. Receiving accessible and personalised information: Dementia progresses through various stages, and the type of support needed changes markedly over time. Interventions must therefore closely accompany changes in the condition of the PwD and of the caregiver so that they can easily access available support and know how to obtain it;

3. Being trained and educated to care for the PwD: the skills needed at one moment differ from those required later;

4. Finding a balance between providing effective care and maintaining one's own life: this balance is especially difficult when the caregiver cohabits with the PwD.

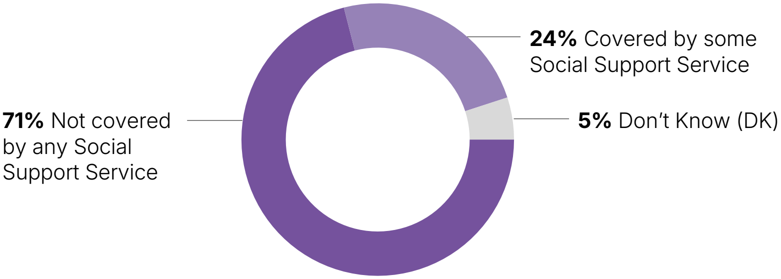
Layered onto this already complex equation is the issue of how each person perceives their relationship with social services — for example, understanding what these services communicate, which is crucial in more vulnerable populations; or the inclusion of the informal caregiver in the digital world, where solutions to bureaucratic challenges increasingly reside.

This section makes it possible to explore how the informal caregivers who participated in the study perceive the accessibility, effectiveness and adequacy of social support services to their specific situation, as well as how this relationship can affect their level of stress, satisfaction and the quality of care provided.

In principle, any Portuguese citizen, regardless of their circumstances, is potentially eligible or able to be integrated into a social support programme if they care for a PwD.

If respondents' answers are accurate, everyday life does not unfold as ideally framed in the Portuguese reference system.

Figure 69. Determination of whether the PwD addressed in the survey is/was covered by any form of Social Support Service.



In a large majority of cases, caregivers reported that the PwD under their care was not linked to any Social Support Service. This suggests either the effective absence of such services or a lack of awareness of their existence. Both scenarios are worrying.

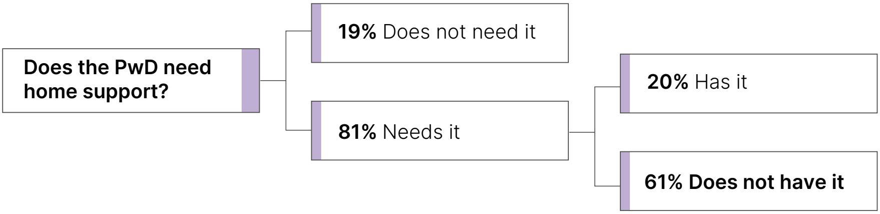
When adult children assume the role of informal caregiver, the frequency of being covered by social support increases (25%), whereas when spouses are the caregivers, the frequency drops to 13%, resulting in a marked differentiation ($p<0.001$). No other stratification remained significant once the collinearity effect between age and kinship was discounted.

The next set of questions focused on identifying concrete needs of the informal caregiver/PwD dyad.

It began with the need for home support. Such support has been controversial, if understood in the clinical sense as a mechanism to reduce the informal caregiver's mental health risk. Multiple studies have produced divergent results. A meta-study on the subject (86) found short-term positive outcomes, but long-term effects — including cost implications — remain uncertain.

Another way of framing the issue is in relation to the physical fatigue of the informal caregiver, who tends to consider nursing-home placement more readily when cognitive decline and/or behavioural symptoms become more demanding. In this context, there is no doubt: the greater the support, the longer the PwD can remain in their own home under the caregiver's supervision. Since many risk factors for deterioration are potentially modifiable, supports should be provided to allow the informal caregiver to keep the PwD at home for as long as possible (87).

Figure 70. Need for and access to home-based support for the PwD.



100% corresponds to n = 258
35 responses were "Don't Know (DK)", "Prefer Not to Answer (PNA)",
or were disqualified for not fitting the criteria.

Multiple factors may determine whether the informal caregiver needs home support: circumstances in which Dementia is still in an early stage, or situations where the caregiver has their own resources to rely on.

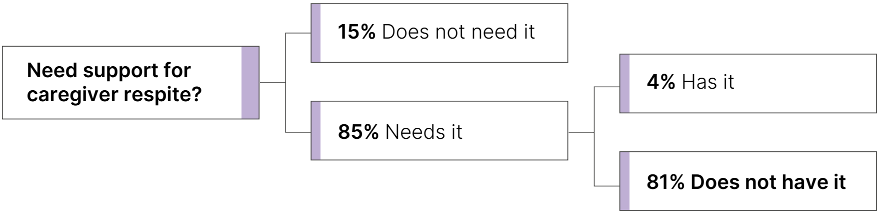
It is observed that 78% of informal caregivers state that they need/have needed home support, but only 20% have/had access to it, either through their own means or via social mechanisms. There is, therefore, room for improvement, although it has not been established whether the perceived need for home support is objective or subjective.

Taking time to “get away” is of enormous importance for the informal caregiver. “Getting away” is more than “resting a little”, although it includes that, which in itself would already justify a break. Getting away for a short period mainly means being able to refocus on relationships and interests that generate well-being, essential elements for preserving the informal caregiver’s mental health. It also means being able to devote attention to self-care, which is so often sacrificed or neglected (88).

These moments should be understood as an indispensable part of the informal caregiver’s overall stability and the PwD’s future quality of life. In theory, all informal caregivers for whom it is recommended by the attending physician should have access to such support.

Reality is not straightforward: there is strong social pressure for the informal caregiver to be omnipresent, and this is often perceived socially as “providing good care”, to the point where the caregiver internalises it, a phenomenon described as “affiliate stigma” (89). Therefore, even among those who say they do not need rest, there are cases where it would be highly advisable.

Figure 71. Need for and access to support for caregiver respite.

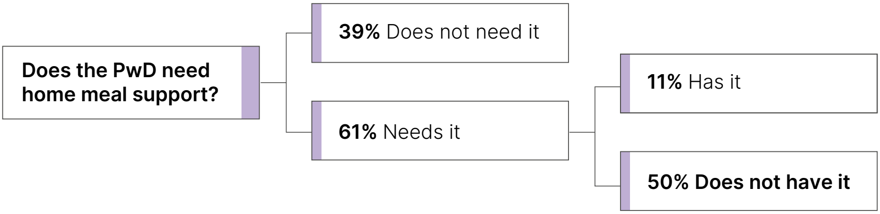


100% corresponds to n = 247
46 responses were “Don’t Know (DK)”, “Prefer Not to Answer (PNA)”,
or were disqualified due to illegibility.

The reality reported by study participants is very different from the ideal. Of the 82% who feel/felt the need for support for their rest, only 4% reported having this essential backup. In practical terms, almost everyone lacks it, and much will have to be done in the future.

There is very little knowledge, even internationally, regarding the provision of home meal support for PwD (90). This type of service can address problems that differ greatly in their origin and implementation. For example, the adaptation of food to the stage of Dementia: does the informal caregiver know how food should be modified over time? Do they have the resources to make this adaptation? In terms of preventing overload: does the caregiver have to prepare more than one type of meal? Does not having to cook relieve the burden, or does it remove a potential source of interest and diversification of activities?

Figure 72. Need for and access to home meal support for the PwD.



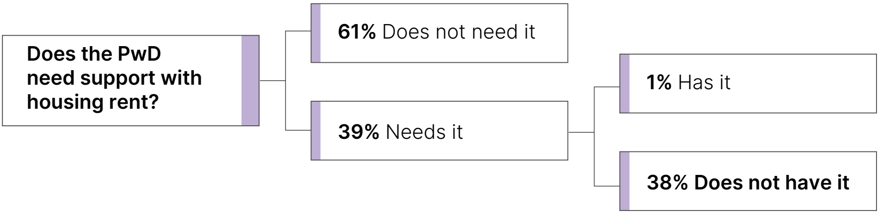
100% corresponds to n = 237
56 responses were “Don’t Know (DK)”, “Prefer Not to Answer (PNA)”, or were disqualified due to illegibility.

There is no clear answer on how to act. Much will depend on the stage of Dementia and the resources available to the informal caregiver. Several types of intervention have been developed to support the PwD’s nutrition: informational support to empower the caregiver; delivery of specially prepared meals for advanced stages of Dementia, of which the Meals-on-Wheels project is the reference, delivering frozen ready-to-eat meals adapted for PwD; delivery of standard meals as economic and respite support, etc.

In the present study, only the most generic version was considered, namely the possibility of having meals delivered to the home when necessary. The remaining possibilities are still far from being widely available in Portugal. Around half of respondents stated that they fell within the scope of potentially receiving meals at home. Only 10% reported having access.

Support with rent is purely financial support, which may be justified because informal caregivers of PwD bear a wide range of expenses related to the disease (medication, professional support or day centres, dietary changes, among many others), and sometimes have to make negative adjustments to their career paths, consequently affecting their ability to earn a more comfortable income.

Figure 73. Need for and access to rent support for the PwD's household.



100% corresponds to n = 220
73 responses were “Don’t Know (DK)”, “Prefer Not to Answer (PNA)”,
or were disqualified for not fitting the criteria.

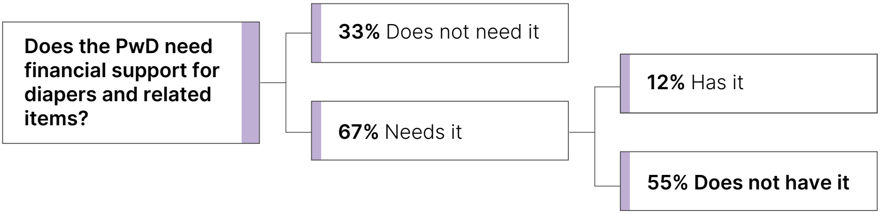
It should be noted that financial hardship may be partly due to a lack of awareness of the solutions provided for in legislation. In a study carried out in Portugal in 2020 (91), it was found that many caregivers involved in the research were unaware of the support to which they were entitled. Therefore, when someone reports not receiving support, it does not necessarily mean that they are not entitled to it, only that they are not receiving it. Another point requiring careful interpretation is when respondents state that they need support. This always reflects a personal and unilateral view that only case-by-case analysis can clarify with precision. Even so, it corresponds to how people perceive the issue.

Approximately one third of respondents stated that they needed support with rent, which was somewhat surprising given the age of most PwD and the high proportion of Portuguese households with fully paid housing. This is possibly a result of the sample being predominantly urban, where the percentage of families paying rent is higher.

None of the participants reported receiving any support, demonstrating the very limited number of situations currently benefiting from this type of aid.

Support for the acquisition of diapers and related items also tends to be a form of financial assistance, but it is more complex than that.

Figure 74. Need for and access of the PwD to financial support for diapers and related items.



100% corresponds to n = 245
48 responses were “Don’t Know (DK)”, “Prefer Not to Answer (PNA)”, or were disqualified due to illegibility.

Incontinence is often a silent reality. All parties contribute to this silence: individuals who are incontinent, while they still retain self-awareness, feel shame and embarrassment — a level of distress that has even been measured as greater than that associated with cancer (92); informal caregivers find the topic difficult to address (93), reporting a lack of training; healthcare services do not train informal caregivers to deal with incontinence; and society at large does not treat the issue as a natural aspect of caregiving.

Nevertheless, incontinence represents a substantial physical, psychological and financial burden for those caring for PwD (93). Support in this area ultimately provides assistance across all these dimensions.

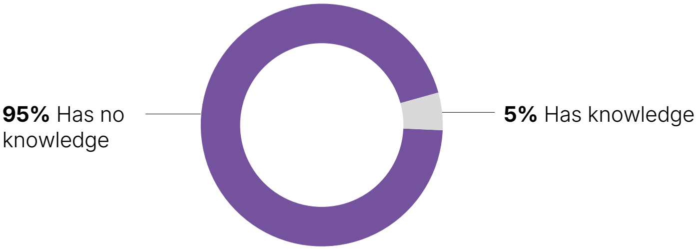
Knowing whether support is available, and what type of support exists, is often a source of subjective security for the informal caregiver. In some cases, it may be interpreted as a loss of autonomy or an external acknowledgement of fragility. International research into the reasons behind informal caregivers’ lack of knowledge about available support has identified 16 types of barriers (94).

There are various types of assistance that do not fall under this category of social support and even less so under the specification of being available at local level. However, the categorisation used can nonetheless be applied here: reasons arising from the caregiver’s lack of knowledge and difficulty seeking information; reasons linked to poor communication by the service that provides the support; and systemic reasons that may inhibit access to, or use of, the support.

Another dimension that must be considered is the distinction between "perceived social support" and "received social support". In brief, perceived social support refers to what the informal caregiver knows would be available if needed, and the quality they expect it to have. Received social support depends on the nature of the support and the frequency with which it is provided.

The subjective burden of the informal caregiver is more affected by perceived support than by received support, and this is fundamental for understanding the relationship dynamics between caregivers and care providers.

Figure 75. Knowledge of Social Security support available in the participant's area of residence.



The data speak for themselves. The vast majority of informal caregivers — even those with high literacy levels and facilitated access to services, as is the case in this sample — reported not knowing whether Social Security provides social support services in their area of residence. It is highly likely that if we were to survey the broader population, the proportion would be even higher.

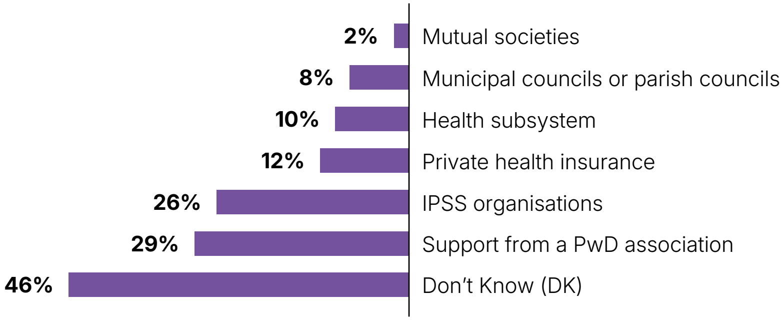
Next, the aim was to identify, among the 12 caregivers who answered affirmatively, which types of social support they were aware of. From their statements, four categories were identified: support for caregiver respite, assistance with the purchase of diapers, social assistance and benefits, and support from associations.

In legal terms, the country guarantees equal access to all public services and, in many areas, performs well by European standards. The Social Security support network has extensive territorial coverage. Therefore, such a high level of unawareness demands serious reflection on the communication of rights, the availability of support, and the proactive search for information by informal caregivers — not to mention the integration of health and social care provision.

The large number of PwD, and particularly the number expected over the next twenty years, should guide the proactive planning of policy frameworks and action. Once a new case of Dementia is identified, the mechanisms should immediately be triggered to ensure that the PwD (if still capable) and their informal caregiver are integrated into a support network. From that point onwards, the PwD–Caregiver dyad should be able to access and make use of social support whenever they deem it necessary and when eligible. As previously noted, in some cases it is not even necessary to provide the support itself — it is enough that the informal caregiver knows it exists and is easily accessible, preventing an unnecessary rise in their subjective burden.

The next step was to determine which entities, besides Social Security, are recognised as providers of support in the context of Dementia. This returns us to the notion of perceived support. Support may exist, but the informal caregiver may be unaware of it, and in some cases may not even expect a given entity to provide such assistance.

Figure 76. Other entities in the participant's geographical area providing dementia-related support.



Once again, lack of awareness of available resources is the most prominent finding. Beyond this, the associative sector (AP) is the most recognised, which is natural given that the survey largely involved its members. IPSS organisations follow, and at a considerable distance come alternative forms of health-care provision (health insurance and health subsystems), and, only residually, municipalities and mutual societies. In particular, the very low level of recognition attributed to municipalities is surprising, considering their frequent involvement in social support cases.

Other entities were mentioned, namely a local Catholic Church association and a Social and Parish Centre.

«Hiring a home-care worker for my parents has been very difficult. The support is less than €200 per month and we pay more than €1,000.»

«It's good that the medication is almost free when prescribed by the neurologist.»

«Diapers are very expensive — and that's not even talking about branded ones.»

COSTS ASSOCIATED WITH DEMENTIA

Dementia is a life condition that imposes a substantial burden of both financial and non-financial costs. Direct costs include medical expenses, medication, care in nursing homes or day centres, and other expenditures directly related to managing the condition. Indirect costs are equally significant, including loss of income due to unpaid leave by informal caregivers, additional family expenses arising from Dementia, changes in consumption patterns such as the purchase of specialised food products, and even increases in private health-insurance premiums.

During the qualitative phase of the study, informal caregivers reported great difficulty in isolating and quantifying their monthly expenses (or, in the case of deceased PwD, their past expenses). Food shopping is done jointly with the rest of the household; health subsystems reimburse some types of costs but not others; time off work is counted as annual leave; expenses are sometimes borne by other children or family members and never reported; and many other ways of managing costs lead to a diffuse perception of financial burden. Meanwhile, non-monetary costs were almost never expressed in quantitative terms.

Thus, an aggregate assessment was conducted based on the informal caregivers' perception of direct and indirect expenses, calculated after various forms of financial support.

Average monthly direct expenses varied enormously, from no additional cost (2 people) to more than €2,500 (15 people), resulting in an average monthly value of €1,042 with a very large standard deviation of over €800; indirect costs averaged €574. The median was €800 for direct costs and €300 for indirect costs. The 25th percentile was €360/€450 and the 75th percentile €1,700/€900 respectively for direct and indirect costs.

The most interesting findings emerged from the breakdown of responses by subgroup.

When analysing expenses by level of education, the differences were substantial, with $p < 0.001$ for direct costs. For indirect costs, the result was only marginally significant ($p < 0.090$), due to a considerable number of respondents in the intermediate education group reporting very low expenses.

Table 3. Average direct and indirect costs borne by informal caregivers by education level.

Education level	Average direct costs	Average indirect costs
Up to 9th grade	390€	484€
10th–12th grade	737€	334€
Higher education	1179€	650€

Although these figures reflect self-reported estimates rather than documentary evidence, it is clear that expenses increase with education level, which is consistent with Portugal being one of the European countries with the strongest correlation between education and personal/household income. These numbers imply that the vast majority of older Portuguese adults who do not have children or spouses with higher qualifications (and therefore greater economic capacity) face greater difficulty accessing dementia-related resources that entail financial costs, and consequently have a lower quality of life. In essence, one ends up living the Dementia that one's finances can afford.

However, this cannot be read too simplistically: as income rises, eligibility for certain subsidies decreases. The example of diaper support is paradigmatic — even a modest income can disqualify someone from receiving it. Several other types of support follow the same principle, meaning that higher family expenditure reflects increased resources made available, but not proportionally.

Surely, expenditure also reflects choices caregivers may make to support themselves and the PwD, such as hiring home-help or purchasing private at-home services, including physiotherapy.

When groups are separated according to relationship to the PwD, differences reappear:

Among adult children and similar degrees of kinship, the amounts tend to be higher compared with situations in which spouses assume the expenses (sig. $z < 0.016$). Certainly, pension levels are not unrelated to this issue.

Table 4. Average direct and indirect costs borne by family members of the PwD.

Relationship	Average direct costs	Average indirect costs
Children and similar	1142€	655€
Spouses	811€	368€

This raises the question of the quality of services and support the PwD receives in each case. Do they have access to the same conditions? Do financial difficulties compound the burden carried by the older informal caregiver? Probably yes: the average income of older adults in Portugal is low, at €6,735 per year, with the minimum pension in 2024 still at €319.49 per month and the survivor's pension at €191.69 per month (95).

For PwD who are already deceased, the reported values are slightly higher than current ones, even disregarding inflation. This can easily be explained by the fact that, as the disease progresses, the need for services increases—particularly placement in care homes (ERPI)—whereas living PwD span a broad spectrum of disease stages and therefore of needs.

In sum, the expenses associated with PwD under one's care are high, predominantly in direct costs, representing an increase of more than one minimum monthly wage (SMN). When combining direct and indirect expenses, this sample reached an amount close to two SMN.

It is presumed that actual expenditure may be even higher because, during the qualitative phase of the study, when discussing this matter, participants initially tended to list only ERPI costs and regular medication. After going through the various usual sources of expense relating to PwD, they identified additional items they had not previously considered. By the nature of the survey process, although several potential expense sources were mentioned in the question text, it was not possible to exhaustively cover all cost components.

«Let’s hope they discover a cure for this.»

«At least they could take away the worst part — when they no longer know who we are.»

«People with Alzheimer’s deserve more than what they currently get.»

FUTURE

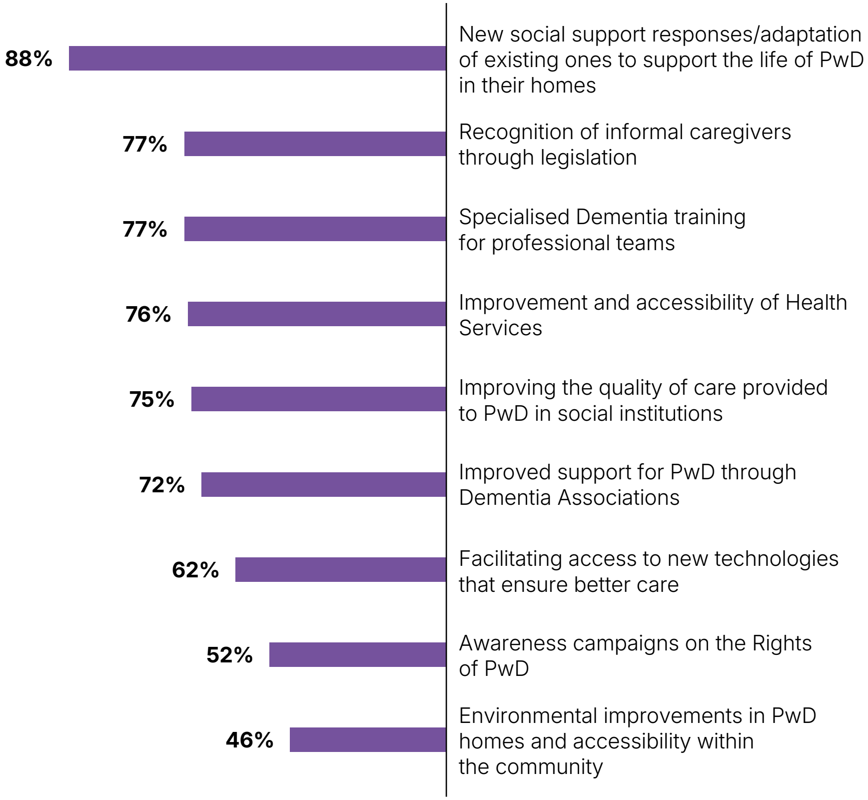
As stated at the outset, the number of cases of Dementia will increase dramatically in Portugal, in Europe, and worldwide. Something must be done now to prevent highly predictable disruptions across multiple parts of the system.

The future is a constant concern for all those dealing with Dementia—both for the person diagnosed, while still aware of their condition, and for their informal caregivers. In this study, caregivers expressed their views on how the life of the PwD could be improved.

Understanding these concerns allows for better design of future interventions and health policies focused on Dementia, making the informal caregiver a partner within the dementia-response system, rather than the almost always passive figure to which they are relegated. For this to be achievable, the caregiver must become a social actor within the health ecosystem. It will not be possible to keep people in their familiar environments for longer—thus ensuring better physical and mental comfort, reducing global costs, and fostering sustainability of the dementia-response system—without this condition of parity.

In the qualitative phase of the study, nine relevant categories of aspects to improve were identified, and these were included in the survey. Respondents were also invited to suggest additional elements.

Figure 77. Desired changes to improve the life of the PwD.



With the exception of one option, all others were chosen by the majority of participants, clearly demonstrating the consistency of the respondents' views. One could add that similar proportions were found among those involved in the first phase. The results are highly insightful.

Informal caregivers, contrary to much of vox populi, do not wish to "send the PwD off to a nursing home or similar institution." Their first choice is precisely to reinforce the conditions that allow PwD to remain in their own homes—a situation that is in everyone's best interest: families, the care system, social services, and the country. To achieve this, they highlight the need for new services—many of which have been mentioned throughout this report—as well as improvements to existing ones, where there is still significant room to increase both effectiveness and efficiency.

Secondly, caregivers frequently report that, particularly outside major urban centres, there is a shortage of health and social-care professionals trained to work with dementia. Respondents mentioned a wide range of examples: from the lack of physiotherapists and occupational therapists capable of providing dementia-adapted exercises at different stages of the disease, to psychologists trained to support informal caregivers of PwD, and staff in Day Centres and Long-Term Care Facilities—just to name the most frequently mentioned.

Thirdly, the issue of valuing informal caregivers—a topic discussed in Portugal for many years—remains far from resolved in practical terms. Caregivers want to be recognised as partners within the care ecosystem, for the social role they perform, and as citizens who provide a service to the community—one which, in their absence, would require public funding.

The remaining categories also received very high levels of endorsement, covering a wide spectrum of needs: from strengthening the capacity of organisations to perform their roles more effectively, to practical elements that could improve the quality and humanisation of care.

«

It was really good when I was able to take some time to rest — I was starting to lose control.»

«How is it possible for my 92-year-old grandfather, diagnosed with dementia for years, to have his driving licence renewed? Luckily, he barely drives anymore!»

NETWORK OF PEOPLE WITH DEMENTIA

Support networks, communities, and interactions with others who share similar experiences play an important positive role in strengthening informal caregivers and enriching their lives. They provide a sense of belonging, emotional support, and opportunities for learning. Informal caregivers who have faced similar challenges and managed to overcome them can guide and support others who are struggling and unsure how to act. The emotional component is equally important. The therapeutic value of peer-to-peer sharing of problems is widely recognised.

This principle has been demonstrated for at least fifty years across many areas of health. However, in the field of dementia, there are relatively few scientific studies, and those that exist often involve small samples or specific regions. Still, peer support is known to strengthen informal caregivers' skills (96), increase self-confidence, and reduce isolation (97).

The creation of dementia-focused communities also contributes to increasing society's positive regard for these conditions and for the policies associated with them.

Asking whether the informal caregiver–PwD dyad participates or participated in any peer community made it possible to explore the existence of such networks in Portugal. Given the strong involvement of Alzheimer Portugal and its members in this study, a degree of associational participation could be expected. Nonetheless, even with this favourable bias, it is striking that the overwhelming majority (86%) stated that they were not part of any peer community—past or present. This highlights a level of disengagement from community support that is far below what would be desirable for the mental well-being of informal caregivers.

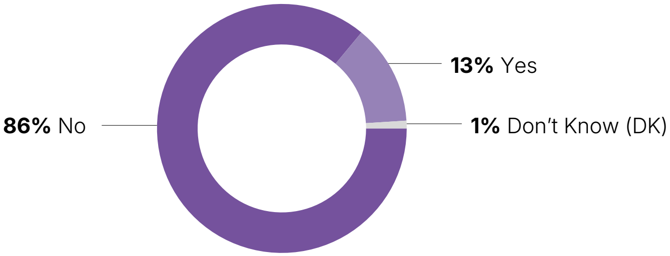
Isolation of PwD and their caregivers is widely documented. The daily demands and the environment caregivers face often lead to depressive states that encourage withdrawal. Caregivers may also isolate themselves to avoid exposing challenging behavioural symptoms of the PwD. The result is reduced participation in social relationships of various kinds, which inherently limits the potential benefits of mutual-support networks.

Creating conditions for these communities to flourish is not always easy: there must be a sufficient number of PwD in the area to form a group and ensure ongoing participation, given that international data show average absence rates of at least 50% due to the factors mentioned. A trained facilitator is also needed to lead activities, along with adequate resources.

Digital solutions have been used to include people living in areas not covered by support networks, achieving some degree of success. One of the few positive aspects of the COVID-19 pandemic was the expansion of such digital solutions. However, in-person activities cannot simply be replicated online due to the lack of resources, tools, and digital skills needed for meaningful participation.

Among those who answered "yes", the following communities were mentioned: Alzheimer Portugal Association (16), Alzheimer Portugal – Algarve (2), Alzheimer Portugal – Madeira (1), Alzheimer Portugal – Pombal (1), Café Memória (4), Casa do Alecrim (3), Day Centre (3), Marquês de Pombal Centre (1), Neuro-Intervention Complex (1), Nursing Home (2), and specialised residence for PwD (1).

Figure 78. Participation of the PwD in PwD community(ies).



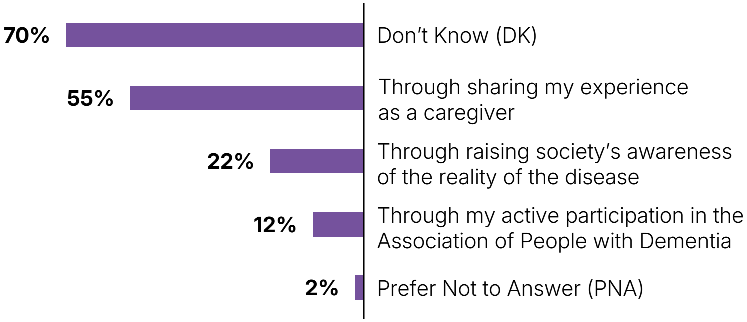
When asked to describe how they believe their experience could be useful in helping other caregivers of PwD, respondents indicated a strong sense that their personal experience carries valuable knowledge that may be shared with others in similar situations (70% of the total). This finding contains enormous potential, even though naturally there is a considerable gap between expressing willingness to contribute and the actual realisation of that willingness.

The second most selected option was contributing to increased societal awareness about dementia, which can be described as health citizenship. This reflects the potential for combating stigma and fostering societal goodwill towards the actions required to address dementia. This is another major resource that could be further explored.

The fact that actions conducted through the Alzheimer Association (AP) appear in third place suggests that, for many respondents, intervention is possible either personally or through other social agents.

The finding that twenty-two percent expressed interest in having their efforts coordinated by an Association of People with Dementia also represents a significant resource potentially available to AP. However, these numbers should be interpreted with caution: those who responded to the survey were, for one reason or another, already more motivated to engage than the broader general population.

Figure 79. Ways in which participants believe their experience could help other caregivers of PwD.



«Nothing is the same. It’s over. But I no longer let it get to me.»

INTIMATE LIFE

Exploring the topic of "Intimate Life" in this survey is a sensitive but important task. It is important to note that this section was intended exclusively for informal caregivers who are or were spouses or partners of the PwD.

If the respondent was an informal caregiver who was not a spouse or partner, they were given the option of sharing a reflection on this dimension if they wished to do so.

Respecting respondents' privacy and sensitivity, they were also given the option to decline participation in this part of the questionnaire and proceed directly to the next section.

Dementia has significant implications for the most intimate aspects of relationships between PwD and their informal caregivers, particularly when the caregiver is the spouse or partner of the person with dementia.

Sexuality in the context of dementia remains a topic that is rarely discussed and, at times, poorly accepted by some professionals—including in long-term care facilities—despite extensive scientific literature on the subject, with the exception of studies focusing on the perspectives of PwD and couples responding jointly.

It is a multidimensional issue that raises several questions:

- In a couple where one partner has dementia and they maintain sexual activity, are both parties fully aware of what they are doing?
- As dementia can lead to socially inappropriate behaviours, what implications does PwD sexuality have in terms of exposure for both the person and the informal caregiver?
- How can the sexual rights of the PwD be upheld?

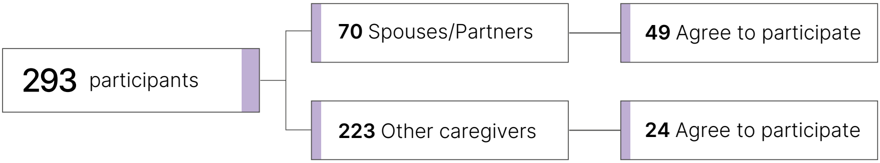
Regardless of the spouse's openness or comfort, dementia always impacts a couple's sexual life, and the more the disease progresses, the greater this impact—especially in couples where the PwD is relatively young.

Inappropriate sexual behaviours, such as disinhibition, occur in 7% to 25% of PwD (98), with increasing prevalence as dementia advances. This contributes to a higher risk of depression among informal caregivers (99).

Non-spousal informal caregivers may also be affected by the PwD's sexuality, particularly in cases of hypersexuality, which can cause discomfort or embarrassment—these being the most frequent situations reported.

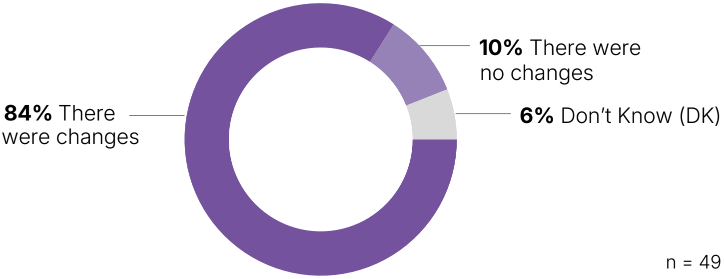
Forty-nine spouses and twenty-four informal caregivers agreed to participate in this section.

Figure 80. Participation of the informal caregiver in the section on the PwD's intimate life.



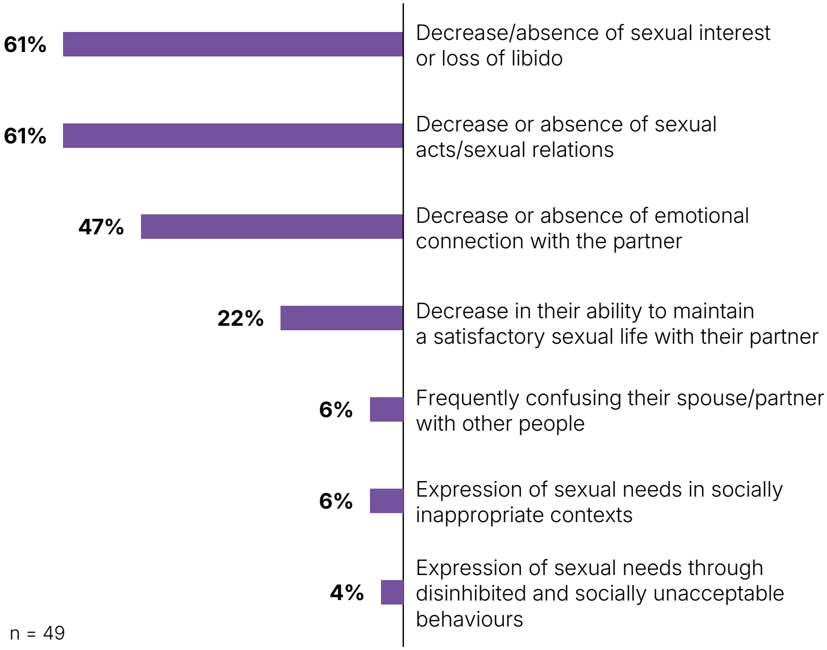
Focusing only on spouses and equivalent partners who agreed to respond, and as would be expected, the large majority reported deterioration in intimate life since the diagnosis of dementia. Among the 10% who reported the opposite, their previous situation is unknown. Those who indicated not knowing are understood as expressing a preference not to answer.

Figure 81. Worsening changes in the PwD's intimate life.



Detailing the reasons that worsened sexual life, the elements related to sexual attraction stand out: libido and the ability to engage in sexual activity, both of which decline sharply or cease to exist.

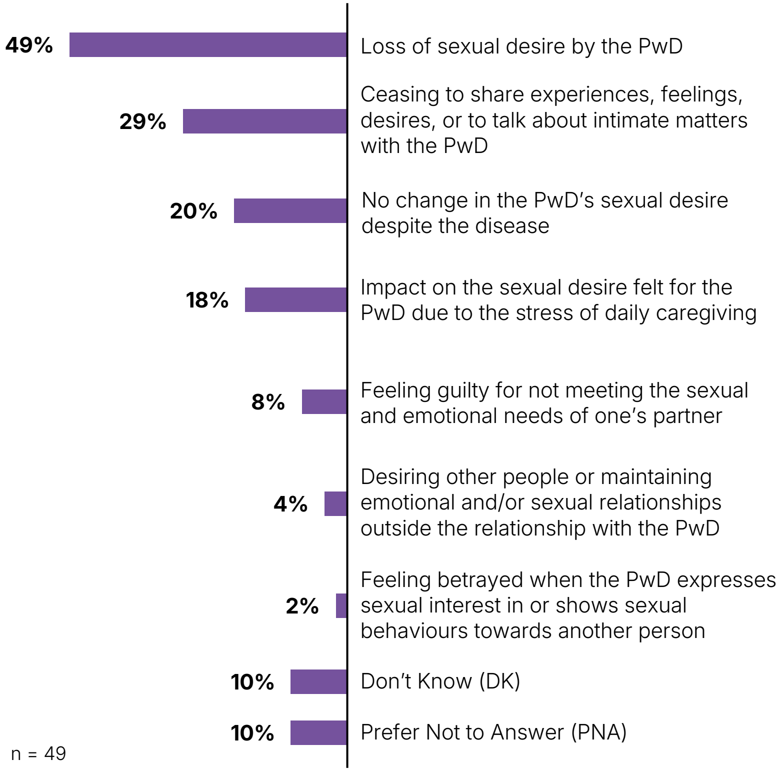
Figure 82. Changes observed in the PwD's sexual life.



No participant selected the option "Initiating sexual acts/relations without the partner's consent", which was one of the possible responses and is documented in the literature.

Regarding the impacts that the spouse/partner considers to exist in terms of intimacy and sexuality:

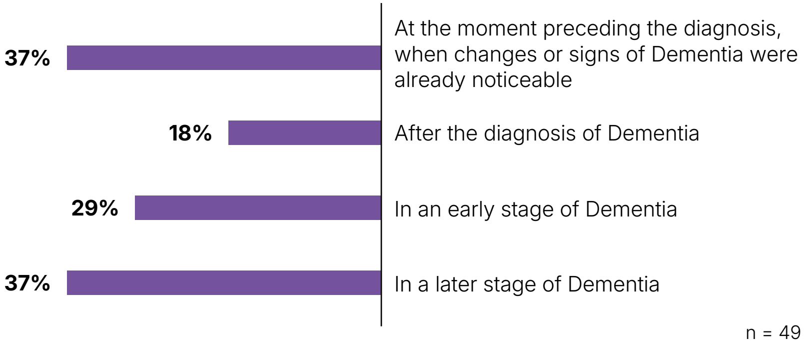
Figure 83. Impacts on the experience of intimacy and sexuality between the PwD and the spouse.



With regard to the moment when participants consider that the sexuality and intimacy of a PwD are affected by the disease, their views are shown below.

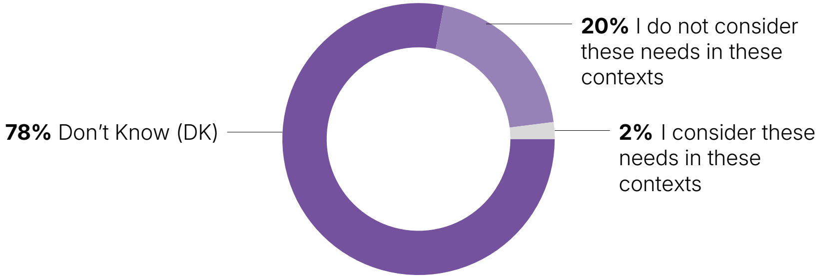
In general, residential homes/ERPI do not accept manifestations of sexuality between residents, even among people without dementia. The situation becomes more restrictive when the condition is present, which is partially understandable as a means of protecting the PwD from potentially more invasive behaviours by others. However, this should not prevent the right to sexuality when the PwD's condition allows it.

Figure 84. Moment at which the PwD's sexuality and intimacy are affected.



Informal caregivers are not always aware, nor necessarily supportive, nor feel comfortable making decisions concerning the exercise of this right, particularly when adult children may have to make intimate decisions on behalf of their parents.

Figure 85. Experience and expression of the sexual needs of PwD living in Nursing Homes/ERPI.



The 2% of participants who answered affirmatively, when asked about the reasons for their agreement, chose not to express their motives, and no responses were recorded for this question.

FINAL CONSIDERATIONS

To conclude, respondents were invited to share their final thoughts, comments and concerns, as well as highlight any dimensions not addressed in the study that they considered relevant.

Approximately 250 short texts were received, predominantly from female participants. No new dimensions emerged; rather, the reflections reinforced those discussed throughout the questionnaire.

The texts served as a space for sharing emotional experience, criticising the lack of access to what participants believe they should receive, emphasising the dimensions they found most significant, and expressing gratitude for the study. Below is a summary of these contributions, organised by major themes and accompanied by selected quotations that collectively reflect the sentiments of many.

The two central messages conveyed are the profound lack of preparation people feel in managing the dementia of someone in their care, and the state of emotional and physical exhaustion in which many informal caregivers find themselves.

The feeling of being unprepared to manage another person's dementia, combined with the perception that the health-social ecosystem assumes that each individual must self-train, is experienced by many as a form of violence. They express near-despair:

I live a day-to-day learning process, trying to deal with anomalous and inappropriate situations, outside the parameters of normality, which, causing constant stress, leads to frequent misunderstandings and, naturally, degrades the family environment.

What I miss most is support for the informal caregiver, in the sense of providing us with tools to manage the disease, as well as knowing how to handle our own emotional burden.

I needed some tools to help my husband more and to avoid feeling so tired.

The hardest part has been my lack of preparation to be a caregiver/'mother' to my mother. She also was not prepared to become 'daughter to her daughter' and accept that the daughter now makes decisions about her life.

Since dementia is a disease that affects the whole family, all family members should have specific information and training.

The **extreme exhaustion** is also frequently mentioned. Statements include:

I can't take it anymore.

I'm drained, but I have no alternative.

If not me, then who will take care of my husband?

The physical and mental exhaustion is overwhelming, which sometimes makes it difficult to stay calm when dealing with daily situations.

The caregiver's mental health becomes severely compromised. I became exhausted and mentally unwell at various points.

I felt exhausted by all the guidance/training/responsibilities that health professionals placed on me without realising that my abilities and limits were not static.

Just to mention sentiments repeated in countless ways.

It becomes clear that many **informal caregivers are in need of support for their own health**, which is itself deeply affected by the situation they are facing:

Emotional exhaustion, difficulties reconciling relationships among various family members led me to be medicated for depression.

I felt that dementia is crushing, and that as a daughter, the experience is very hard.

I felt alone, as the rest of the family withdrew.

There was a deep sense of loneliness.

I feel completely abandoned and misunderstood.

This is devastating. It destroys what is left of the family. I no longer recognise this as my Mother. I cannot accept her illness.

Alongside this, **feelings of guilt** appear frequently in the texts:

I had to place my father/mother/husband/wife in a nursing home, but I couldn't handle it anymore. I would have kept them at home if I could.

I'm doing everything I can to keep them at home, but I know I won't be able to continue without support.

Family is important in care, but sometimes too much is demanded of us!

Sometimes (other members of the nuclear family) feel jealous and blame the patient, making the caregiver feel torn.

Difficulties in dealing with administrative processes emerged as huge in this shared space—an extremely relevant issue given the high level of education among the participants. Projecting the results onto the general population, normalised for literacy and digital inclusion, the implications are alarming:

Two years to obtain a simple document.

There is a complete lack of proactivity from health and social organisations that should support us.

Bureaucracy should be reduced when people with dementia can no longer sign documents or make decisions.

Families remain alone, buried in social bureaucracy and without tangible results in daily life.

The identification of supports—whether new or strengthened versions of existing ones—was omnipresent in the texts. Several major themes stand out:

1. Different types of long-term care homes (ERPI)

Many times the discourse is: She no longer understands anything, so it makes no difference whether she is at home or in a nursing home (tied to the bed and with a feeding tube inserted)'—a statement made by the owner of a private facility where I left my mother and from which I removed her 45 days later, on the day after hearing this barbarity.

Day centres, nursing homes, health centres, hospitals are not prepared to deal with this issue; sometimes instead of helping caregivers, they force caregivers to solve problems that fall under their responsibility. Example: A person with Alzheimer's (65 years old) was not accepted at a day centre (one-month trial) because she could not remain seated for long, could not wait her turn in group activities, did not eat the second course—in other words, she needed more individualised care because she was not autonomous enough for that type of institution. This institution supposedly had training to deal with this. She was rejected because she had Alzheimer's, even after the family had explained that everyone worked and would have to quit to care for her. In the meeting, they simply said this was not their problem, but the family's.

It would be extremely important in the near future to have nonprofit organisations/nursing homes specialised in Alzheimer's patients, properly regulated.

What is most needed is an effective support service for people with dementia; there are not enough institutions, and the existing ones are always full. Unfortunately, a vacancy only opens when 'someone dies'.

Positive contrasts also emerged:

Without Casa do Alecrim it would have been impossible to care for my mother, my father, and even myself.

I wish every town had a Casa do Alecrim.

2. Better integration into health services

In general, these patients are easily marginalised and remain solely under neurology. Access to other medical specialties, physiotherapy, nursing, dental care, urology, palliative care, psychology is difficult and often denied.

Health centres should have teams that can visit PwD and their caregivers to ensure safe living conditions at home, help with practical strategies for daily life, ensure medication is taken correctly, and clarify any concerns. Sometimes communication with doctors is difficult, people fear asking questions, appointments last 15–30 minutes, and many doctors lack sensitivity—some even tell patients to 'look it up on Google' (this happened to me).

When taking my relative to appointments, I had to leave them in the waiting room while parking the car, and had to rely on strangers or security staff to ensure they didn't wander off.

There is no clinical coordination between specialists. Medical care gradually disappeared. The family doctor has not seen her for four years, perhaps due to lack of capacity or knowledge about these diseases. Social support for placing my wife in a nursing home only arrived two months ago, when she was already in an advanced stage. When I requested support from the court a year and a half ago, describing her condition, no one assessed her. The lack of coordination between social services, clinicians, and the courts is evident. I requested support because her family—siblings, nieces and nephews—abandoned her and have not visited in seven years.

3. The need for rest

There is no support network that allows caregivers periodic rest. What exists is ridiculously insufficient. A caregiver without rest becomes another ill person. Quick, non-bureaucratic respite networks would allow more people with dementia to remain within their families.

In practice, caregiver respite does not exist; it is constantly denied due to limited vacancies occupied by other types of users.

I suggest increased support for informal caregivers (psychological support, educational support, and more resources allowing the caregiver to rest).

There is no support network that allows caregivers periodic rest.

4. Strengthening existing support systems

The caregiver no longer has a social life, can no longer go to the cinema at night or simply have dinner out; the caregiver stops having a life because there is no support for anything. It is very easy to hear 'you need to find time to take care of yourself — a few minutes each day just for you', but how is that possible? Should we leave the patient alone, unattended? How do we manage this?

There is an urgent need for a stronger response from the National Health Service (SNS) and better coordination between services and entities — namely social services and local authorities.

There is an urgent need for support for informal caregivers, even if they do not explicitly request it.

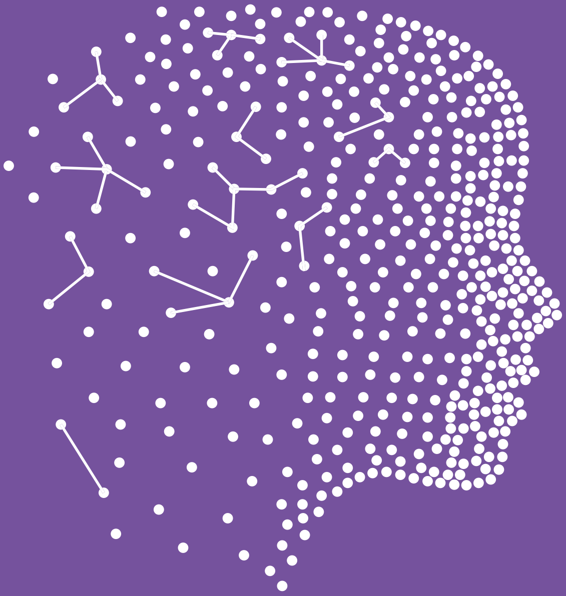
5. Strengthening the skills of professionals who work with dementia

Fifty years ago, children were left with childminders when parents went to work, and progress was made through specialised training and multi-year qualification programmes such as early-childhood educators. The same should happen regarding care for older adults. People who care for the elderly, whether in nursing homes or home-care services, should study and develop specific competencies.

More support is needed for the caregiver so that the person being cared for does not have to leave their home.

There is a need for greater training of healthcare staff to meet the needs of PwD.

Much more was said — sometimes describing highly personal situations, other times sharing difficult moments experienced throughout the caregiving journey. Nearly a quarter of a thousand statements were gathered, each corresponding to someone facing challenges, striving to overcome them, and feeling alone. A way must be found to give these people a voice. This was our contribution.



BIBLIOGRAPHIC REFERENCES

1. The Henry J. Kaiser Family Foundation. Women, Work, and Family Health: Key Findings from the 2017 Kaiser Women's Health Survey. 2018.
2. Xiong C, Biscardi M, Astell A, Nalder E, Cameron JI, Mihailidis A, et al. Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. PLoS One. 2020 Apr 1;15(4).
3. Ohno S, Chen Y, Sakamaki H, Matsumaru N, Yoshino M, Tsukamoto K. Burden of caring for Alzheimer's disease or dementia patients in Japan, the US, and EU: results from the National Health and Wellness Survey: a cross-sectional survey. J Med Econ. 2021 Jan 1;24(1):266–78.
4. World Health Organization. Cuidados de saúde primários. 2023.
5. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health. 2012 Dec 25;12(1):80.
6. Li Y, Hu L, Mao X, Shen Y, Xue H, Hou P, et al. Health literacy, social support, and care ability for caregivers of dementia patients: Structural equation modeling. Geriatr Nurs (Minneap). 2020 Sep;41(5):600–7.
7. Zhao M, Lv X, Tuerxun M, He J, Luo B, Chen W, et al. Delayed help seeking behavior in dementia care: preliminary findings from the Clinical Pathway for Alzheimer's Disease in China (CPAD) study. Int Psychogeriatr [Internet]. 2016 Feb 1 [cited 2024 Jun 20];28(2):211–9. Available from: https://pubmed.ncbi.nlm.nih.gov/26138923/
8. Lorini C, Buscemi P, Mossello E, Schirripa A, Giammarco B, Rigon L, et al. Health literacy of informal caregivers of older adults with dementia: results from a cross-sectional study conducted in Florence (Italy). Aging Clin Exp Res. 2022 Oct 19;35(1):61–71.
9. Bonaccorsi G, Pieralli F, Innocenti M, Milani C, Del Riccio M, Donzellini M, et al. Health Literacy among Non-Familial Caregivers of Older Adults: A Study Conducted in Tuscany (Italy). Int J Environ Res Public Health. 2019 Oct 8;16(19):3771.
10. Abdel Rahman TT. Health Literacy: Prevalence among Elderly Care Givers and Its Impact on the Frequency of Elderly Hospitalization and Elderly Health Related Quality of Life. Adv Aging Res. 2014;03(05):380–7.

11. PORDATA. Fundação Francisco Manuel dos Santos. 2023. Resident population aged between 16 and 89 years: total and by highest completed level of education.

12. Fundação José Neves. Estado da Nação: Educação, Emprego e Competências em Portugal – 2023. June 2023.

13. National Alliance for Caregiving in Partnership with the Alzheimer's Association. Dementia Caregiving in the U.S. [Internet]. 2017 Feb. Available from: http://www.caregiving.org/wp-content/uploads/2014/01/Dementia-

14. Garcia-Ptacek S, Dahlrup B, Edlund AK, Wijk H, Eriksdotter M. The caregiving phenomenon and caregiver participation in dementia. Scand J Caring Sci [Internet]. 2019 Jun 1 [cited 2024 Mar 27];33(2):255–65. Available from: https://onlinelibrary.wiley.com/doi/full/10.1111/scs.12627

15. Self WK, Holtzman DM. Emerging diagnostics and therapeutics for Alzheimer disease. Nat Med. 2023 Sep 4;29(9):2187–99.

16. Arrighi HM, Neumann PJ, Lieberburg IM, Townsend RJ. Lethality of Alzheimer Disease and Its Impact on Nursing Home Placement. Alzheimer Dis Assoc Disord. 2010 Jan;24(1):90–5.

17. Alzheimer's Association. 2023 Alzheimer's disease facts and figures. Vol. 19, Alzheimer's and Dementia. John Wiley and Sons Inc; 2023 Apr.

18. Leonard K. Most Alzheimer's Patients Not Told About Their Diagnosis. US News & World Report [Internet]. 2015 [cited 2024 Mar 27]; Available from: https://www.usnews.com/news/articles/2015/03/24/most-alzheimers-patients-not-told-about-their-diagnosis

19. World Health Organization. Dementia. 2023.

20. Alzheimer's Research UK. Subtypes of Dementia. 2023.

21. Lindeza P, Rodrigues M, Costa J, Guerreiro M, Rosa MM. Impact of dementia on informal care: a systematic review of family caregivers' perceptions. BMJ Support Palliat Care. 2020 Oct 14; bmjspcare-2020-002242.

22. Alzheimer's Society. Difficult questions and telling the truth to a person with dementia. 2023.

23. ASPE - Office of the Assistant Secretary for Planning and Evaluation. Individuals' Awareness of a Dementia Diagnosis Issue Brief. 2020 Feb.

24. Chrisp TAC, Thomas BD, Goddard WA, Owens A. Dementia timeline: Journeys, delays and decisions on the pathway to an early diagnosis. Dementia. 2011 Nov 7;10(4):555–70.

25. Lin PJ, Daly AT, Olchanski N, Cohen JT, Neumann PJ, Faul JD, et al. Dementia Diagnosis Disparities by Race and Ethnicity. Med Care. 2021 Aug;59(8):679–86.

26. Mattke S, Hanson M. Expected wait times for access to a disease-modifying Alzheimer's treatment in the United States. Alzheimer's & Dementia. 2022 May 27;18(5):1071–4.

27. Drabo EF, Barthold D, Joyce G, Ferido P, Chang Chui H, Zissimopoulos J. Longitudinal analysis of dementia diagnosis and specialty care among racially diverse Medicare beneficiaries. Alzheimer's & Dementia. 2019 Nov 4;15(11):1402–11.

28. Mukamel DB, Saliba D, Ladd H, Konetzka RT. Dementia Care Is Widespread In US Nursing Homes; Facilities With The Most Dementia Patients May Offer Better Care. Health Aff. 2023 Jun 1;42(6):795–803.

29. Yates J, Stanyon M, Samra R, Clare L. Challenges in disclosing and receiving a diagnosis of dementia: a systematic review of practice from the perspectives of people with dementia, carers, and healthcare professionals. Int Psychogeriatr. 2021 Nov 17;33(11):1161–92.

30. Alpinar-Sencan Z, Schicktanz S. Addressing ethical challenges of disclosure in dementia prediction: limitations of current guidelines and suggestions to proceed. BMC Med Ethics. 2020 Dec 11;21(1):33.

31. Soong A, Au ST, Kyaw BM, Theng YL, Tudor Car L. Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: a scoping review. BMC Geriatr. 2020 Dec 14;20(1):61.

32. Efthymiou A, Papastavrou E, Middleton N, Markatou A, Sakka P. How Caregivers of People With Dementia Search for Dementia-Specific Information on the Internet: Survey Study. JMIR Aging. 2020 May 19;3(1):e15480.

33. Family Caregiver Alliance. Caregiver's Guide to Understanding Dementia Behaviors.

34. Alzheimer's Society. Understanding and supporting a person with dementia.

35. Hale L, Mayland E, Jenkins M, Buttery Y, Norris P, Butler M, et al. Constructing Normalcy in Dementia Care: Carers' Perceptions of Their Roles and the Supports They Need. Gerontologist. 2020 Jul 15;60(5):905–15.

36. Dixe M dos ACR, da Conceição Teixeira LF, Areosa TJTCC, Frontini RC, de Jesus Almeida Peralta T, Querido AIF. Needs and skills of informal caregivers to care for a dependent person: a cross-sectional study. BMC Geriatr. 2019 Dec 18;19(1):255.

37. Pleasant M, Molinari V, Dobbs D, Meng H, Hyer K. Effectiveness of online dementia caregivers training programs: A systematic review. Geriatr Nurs (Minneap). 2020 Nov;41(6):921–35.

38. Egan KJ, Pinto-Bruno ÁC, Bighelli I, Berg-Weger M, van Straten A, Albanese E, et al. Online Training and Support Programs Designed to Improve Mental Health and Reduce Burden Among Caregivers of People With Dementia: A Systematic Review. J Am Med Dir Assoc. 2018 Mar;19(3):200-206.e1.

39. Champlin BE. The informal caregiver's lived experience of being present with a patient who receives a diagnosis of dementia: A phenomenological inquiry. Dementia. 2020 Feb 17;19(2):375–96.

40. Johansson MF, Mckee KJ, Dahlberg L, Williams CL, Meranius MS, Hanson E, et al. A comparison of spouse and non-spouse carers of people with dementia: a descriptive analysis of Swedish national survey data. [cited 2024 Feb 26]; Available from: https://doi.org/10.1186/s12877-021-02264-0

41. Johansson MF, McKee KJ, Dahlberg L, Summer Meranius M, Williams CL, Marmstål Hammar L. Negative Impact and Positive Value of Caregiving in Spouse Carers of Persons with Dementia in Sweden. Int J Environ Res Public Health. 2022 Feb 4;19(3):1788.

42. Xiong C, Biscardi M, Astell A, Nalder E, Cameron JI, Mihailidis A, et al. Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. PLoS One [Internet]. 2020 Apr 1 [cited 2024 Feb 26];15(4):e0231848. Available from: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0231848

43. Albert PR. Why is depression more prevalent in women? Journal of Psychiatry and Neuroscience [Internet]. 2015 Jul 1 [cited 2024 Feb 26];40(4):219–21. Available from: https://www.jpn.ca/content/40/4/219

44. Leung DKY, Chan WC, Spector A, Wong GHY. Prevalence of depression, anxiety, and apathy symptoms across dementia stages: A systematic review and meta-analysis. Int J Geriatr Psychiatry [Internet]. 2021 Sep 1 [cited 2024 Feb 26];36(9):1330–44. Available from: https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5556

45. Victor CR, Rippon I, Nelis SM, Martyr A, Litherland R, Pickett J, et al. Prevalence and determinants of loneliness in people living with dementia:

Findings from the IDEAL programme. 2020 [cited 2024 Feb 26]; Available from: https://onlinelibrary.wiley.com/doi/10.1002/gps.5305

46. Holtfreter K, Reisig MD, Turanovic JJ. Aging & Mental Health Depression and infrequent participation in social activities among older adults: the moderating role of high-quality familial ties. [cited 2024 Feb 26]; Available from: http://dx.doi.org/10.1080/13607863.2015.1099036

47. Bohn L, Kwong See ST, Fung HH. Aging & Mental Health Preference for emotionally meaningful activity in Alzheimer's disease. 2018 [cited 2024 Feb 26]; Available from: https://doi.org/10.1080/13607863.2018.1506750

48. Waligora KJ, Bahouth MN, Han HR. The Self-Care Needs and Behaviors of Dementia Informal Caregivers: A Systematic Review. Gerontologist [Internet]. 2019 Sep 17 [cited 2024 Feb 26];59(5):e565–83. Available from: https://pubmed.ncbi.nlm.nih.gov/29931147/

49. Rees J, Tuijt R, Burton A, Walters K, Cooper C. Supporting self-care of long-term conditions in people with dementia: A systematic review. Int J Nurs Stud. 2021 Apr 1;116:103432.

50. Fostinelli S, De Amicis R, Leone A, Giustizieri V, Binetti G, Bertoli S, et al. Eating Behavior in Aging and Dementia: The Need for a Comprehensive Assessment. Front Nutr. 2020 Dec 16;7:604488.

51. Lima-Silva TB, Bahia VS, Carvalho VA, Guimarães HC, Caramelli P, Balthazar MLF, et al. Direct and indirect assessments of activities of daily living in behavioral variant frontotemporal dementia and Alzheimer disease. J Geriatr Psychiatry Neurol [Internet]. 2015 Mar 13 [cited 2024 Feb 26];28(1):19–26. Available from: https://pubmed.ncbi.nlm.nih.gov/25015849/

52. O'Connor CM, Clemson L, Hornberger M, Leyton CE, Hodges JR, Piguet O, et al. Longitudinal change in everyday function and behavioral symptoms in frontotemporal dementia. Neurol Clin Pract [Internet]. 2016 Oct 1 [cited 2024 Feb 26];6(5):419. Available from: /pmc/articles/PMC5100706/

53. Silvaggi F, Leonardi M, Tiraboschi P, Muscio C, Toppo C, Raggi A. Keeping People with Dementia or Mild Cognitive Impairment in Employment: A Literature Review on Its Determinants. International Journal of Environmental Research and Public Health 2020, Vol 17, Page 842 [Internet]. 2020 Jan 29 [cited 2024 Mar 12];17(3):842. Available from: https://www.mdpi.com/1660-4601/17/3/842/htm

54. Evans D. An exploration of the impact of younger-onset dementia on employment. Dementia [Internet]. 2019 Jan 1 [cited 2024 Mar 12];18(1):262–81. Available from: https://journals.sagepub.com/doi/full/10.1177/1471301216668661

55. Williams J, Richardson S, Draper E. A Beginning and not the End: Work After a Diagnosis of Dementia. https://doi.org/101177/0950017017737493 [Internet]. 2017 Nov 20 [cited 2024 Mar 12];32(1):219–29. Available from: https://journals.sagepub.com/doi/full/10.1177/0950017017737493

56. Krell-Roesch J, Feder NT, Roberts RO, Mielke MM, Christianson TJ, Knopman DS, et al. Leisure-Time Physical Activity and the Risk of Incident Dementia: The Mayo Clinic Study of Aging. Journal of Alzheimer's Disease. 2018 Jan 1;63(1):149–55.

57. Almeida-Meza P, Steptoe A, Cadar D, Almeida-Meza P. Is Engagement in Intellectual and Social Leisure Activities Protective Against Dementia Risk? Evidence from the English Longitudinal Study of Ageing. Journal of Alzheimer's Disease [Internet]. 2021 Jan 1 [cited 2024 Mar 14];80(2):555–65. Available from: https://content.ios

58. Sommerlad A, Sabia S, Livingston G, Kivimäki M, Lewis G, Singh-Manoux A. Leisure activity participation and risk of dementia: An 18-year follow--up of the Whitehall II Study. Neurology. 2020 Nov 17;95(20):E2803–15.

59. Park S, Choi B, Choi C, Kang JM, Lee JY. Relationship between education, leisure activities, and cognitive functions in older adults. Aging Ment Health [Internet]. 2019 Dec 2 [cited 2024 Mar 14];23(12):1651–60. Available from: https://www.tandfonline.com/doi/abs/10.1080/13607863.2018.1512083

60. Särkämö T. Music for the ageing brain: Cognitive, emotional, social, and neural benefits of musical leisure activities in stroke and dementia.

61. Saito T, Murata C, Saito M, Takeda T, Kondo K. Influence of social relationship domains and their combinations on incident dementia: a prospective cohort study. J Epidemiol Community Health [Internet]. 2018 Jan 1 [cited 2024 Mar 14];72(1):7–12. Available from: https://jech.bmj.com/content/72/1/7

62. Wang Z, Marseglia A, Shang Y, Dintica C, Patrone C, Xu W. Leisure activity and social integration mitigate the risk of dementia related to cardiometabolic diseases: A population-based longitudinal study. Alzheimer's & Dementia [Internet]. 2020 Feb 1 [cited 2024

Mar 14];16(2):316–25. Available from: https://onlinelibrary.wiley.com/doi/full/10.1016/j.jalz.2019.09.003

63. Camic PM, Hulbert S, Kimmel J. Museum object handling: A health--promoting community-based activity for dementia care. J Health Psychol [Internet]. 2019 May 1 [cited 2024 Mar 14];24(6):787–98. Available from: https://journals.sagepub.com/doi/full/10.1177/1359105316685899?casa_token=Dya0SN8dkJoAAAAA%3AjnwQEsjtuMKJGARzPhleqGo_V3XXTE69XIGyc8f-k69_ehQGPfh4KstOUEft56PHqk27Mb4vN2A2

64. Bethell J, Rostad HM, Bloomberg LS, Babineau J, Grinbergs-Saull A, Wighton MB, et al. Patient engagement in research related to dementia: A scoping review Martine Puts. Dementia. 2018;17(8):944–75.

65. Daykin N, Mansfield L, Meads C, Julier G, Tomlinson A, Payne A, et al. What works for wellbeing? A systematic review of wellbeing outcomes for music and singing in adults. Perspect Public Health [Internet]. 2018 Jan 1 [cited 2024 Mar 14];138(1):39–46. Available from: https://journals.sagepub.com/doi/full/10.1177/1757913917740391

66. Arvanitakis Z, Shah RC, Bennett DA. Diagnosis and Management of Dementia: A Review. JAMA [Internet]. 2019 Oct 10 [cited 2024 Mar 14];322(16):1589. Available from: /pmc/articles/PMC7462122/

67. Hartman Esther GA Karssemeijer YA, van Diepen Marcel GM Olde Rikkert LA, Thijssen DH. Dementia Patients Are More Sedentary and Less Physically Active than Age-and Sex-Matched Cognitively Healthy Older Adults. Dement Geriatr Cogn Disord [Internet]. 2018 [cited 2024 Mar 14];46:81–9. Available from: www.karger.com/demwww.karger.com/dem

68. Moniruzzaman M, Kadota A, Akash MS, Pruitt PJ, Miura K, Albin R, et al. Effects of physical activities on dementia-related biomarkers: A systematic review of randomized controlled trials. 2020 [cited 2024 Mar 14]; Available from: https://doi.org/10.1002/trc2.12109

69. Qiu D, Hu M, Yu Y, Tang B, Xiao S. Acceptability of psychosocial interventions for dementia caregivers: A systematic review. BMC Psychiatry [Internet]. 2019 Jan 14 [cited 2024 Mar 14];19(1):1–14. Available from: https://link.springer.com/articles/10.1186/s12888-018-1976-4

70. Woodford J, Farrand P, Watkins ER, LLewellyn DJ. Clinical Gerontologist "I Don't Believe in Leading a Life of My Own, I Lead His Life": A Qualitative Investigation of Difficulties Experienced by Informal Caregivers of Stroke Survivors Experiencing Depressive and Anxious Symptoms "I Don't Believe in Leading a Life of My Own, I Lead His Life": A Qualitative

Investigation of Difficulties Experienced by Informal Caregivers of Stroke Survivors Experiencing Depressive and Anxious Symptoms. 2017 [cited 2024 Mar 14]; Available from: https://doi.org/10.1080/07317115.2017.1363104

71. Chin NA, Dinsmore D, Gonzales T, Groves B, Johnson D, Napolitano J, et al. Alzheimer's Disease - Anti-Amyloid Medications, Early Detection, and Screening. N Engl J Med [Internet]. 2024 Mar 7 [cited 2024 Jun 25];390(10). Available from: https://pubmed.ncbi.nlm.nih.gov/38446673/

72. Reed C, Belger M, Andrews JS, Tockhorn-Heidenreich A, Jones RW, Wimo A, et al. Factors associated with long-term impact on informal caregivers during Alzheimer's disease dementia progression: 36-month results from GERAS. 2019 [cited 2024 Mar 14]; Available from: https://doi.org/10.1017/S1041610219000425

73. Oba H, Kadoya Y, Okamoto H, Matsuoka T, Abe Y, Shibata K, et al. The Economic Burden of Dementia: Evidence from a Survey of Households of People with Dementia and Their Caregivers. International Journal of Environmental Research and Public Health 2021, Vol 18, Page 2717 [Internet]. 2021 Mar 8 [cited 2024 Mar 14];18(5):2717. Available from: https://www.mdpi.com/1660-4601/18/5/2717/htm

74. Gérain P, Zech E. Informal Caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. Front Psychol [Internet]. 2019 Jul 31 [cited 2024 Mar 14];10(JULY):466359. Available from: www.frontiersin.org

75. Aranda MP, Kremer JD IN, Hinton L, Zissimopoulos J, Whitmer RA, Huling Hummel DMin C, et al. Impact of dementia: Health disparities, population trends, care interventions, and economic costs. 2021 [cited 2024 Mar 14]; Available from: https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.17345

76. Browne J, Edwards DA, Rhodes KM, Brimicombe DJ, Payne RA. Association of comorbidity and health service usage among patients with dementia in the UK: a population-based study. BMJ Open [Internet]. 2017 Mar 1 [cited 2024 Mar 14];7(3):e012546. Available from: https://bmjopen.bmj.com/content/7/3/e012546

77. Mondor L, Maxwell CJ, Hogan DB, Bronskill SE, Gruneir A, Lane NE, et al. Multimorbidity and healthcare utilization among home care clients with dementia in Ontario, Canada: A retrospective analysis of a population--based cohort. PLoS Med [Internet]. 2017 Mar 1 [cited 2024 Mar

14];14(3):e1002249. Available from: https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002249

78. Welsh TJ. Multimorbidity in people living with dementia. Case Rep Womens Health. 2019 Jul 1;23:e00125.

79. Kim SK, Park M. Effectiveness of person-centered care on people with dementia: A systematic review and meta-analysis. Clin Interv Aging [Internet]. 2017 Feb 17 [cited 2024 Mar 14];12:381–97. Available from: http://dx.doi.org/10.2147/CIA.S117637

80. Yokogawa M, Taniguchi Y, Yoneda Y. Qualitative research concerning physiotherapy approaches to encourage physical activity in older adults with dementia. PLoS One [Internet]. 2023 Jul 1 [cited 2024 Mar 15];18(7):e0289290. Available from: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0289290

81. Lord S, Rochester L. Role of the physiotherapist in the management of dementia. In: Dementia. 5th ed. CRC Press; 2017.

82. Kowalska J, Mazurek J, Kubasik N, Rymaszewska J. Effectiveness of physiotherapy in elderly patients with dementia: a prospective, comparative analysis. Disabil Rehabil [Internet]. 2019 Mar 27 [cited 2024 Mar 15];41(7):815–9. Available from: https://www.tandfonline.com/doi/abs/10.1080/09638288.2017.1410859

83. Wiegelmann H, Speller S, Verhaert LM, Schirra-Weirich L, Wolf-Ostermann K. Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – a systematic literature review. BMC Geriatrics 2021 21:1 [Internet]. 2021 Feb 1 [cited 2024 Mar 15];21(1):1–17. Available from: https://link.springer.com/articles/10.1186/s12877-021-02020-4

84. Dam AEH, De Vugt ME, Klinkenberg IPM, Verhey FRJ, Van Boxtel MPJ. A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? Maturitas. 2016 Mar 1;85:117–30.

85. Bressan V, Visintini C, Palese A. What do family caregivers of people with dementia need? A mixed-method systematic review. Health Soc Care Community [Internet]. 2020 Nov 1 [cited 2024 Mar 18];28(6):1942–60. Available from: https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.13048

86. Reilly S, Miranda-Castillo C, Malouf R, Hoe J, Toot S, Challis D, et al. Case management approaches to home support for people with dementia. Cochrane Database of Systematic Reviews [Internet]. 2015 Jan

5 [cited 2024 Apr 1];2017(6). Available from: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD008345.pub2/full

87. Toot S, Swinson T, Devine M, Challis D, Orrell M. Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. Int Psychogeriatr [Internet]. 2017 Feb 1 [cited 2024 Apr 1];29(2):195–208. Available from: https://www.cambridge.org/core/journals/international-psychogeriatrics/article/causes-of-nursing-home-placement-for-older-people-with-dementia-a--systematic-review-and-metaanalysis/62B350693121CB1E1B109714A58CD343

88. Waligora KJ, Bahouth MN, Han HR. The Self-Care Needs and Behaviors of Dementia Informal Caregivers: A Systematic Review. Gerontologist [Internet]. 2019 Sep 17 [cited 2024 Apr 5];59(5):e565–83. Available from: https://dx.doi.org/10.1093/geront/gny076

89. Vasileiou K, Barnett J, Barreto M, Vines J, Atkinson M, Lawson S, et al. Experiences of loneliness associated with being an informal caregiver: A qualitative investigation. Front Psychol [Internet]. 2017 Apr 19 [cited 2024 Apr 5];8(APR):261780. Available from: www.frontiersin.org

90. Papachristou I, Hickey G, Iliffe S. Dementia informal caregiver obtaining and engaging in food-related information and support services. http://dx.doi.org/101177/1471301215583148 [Internet]. 2015 Apr 22 [cited 2024 Apr 5];16(1):108–18. Available from: https://journals.sagepub.com/doi/full/10.1177/1471301215583148?casa_token=1zyWlckgLCEAAAAA%3ANH89Gj-fxfJdWXgPe2gIclbevdB6kSPTXOrOitkUu_r502B59uch7npdMh2AEE_SanZ3JNDIzmSe

91. Lindeza P, Virgolino A, Santos O, Guerreiro M, Rosa M. Facing Costs With Dementia: Daily Lives Perspectives From Informal Caregivers. 2020 Nov 24 [cited 2024 Apr 5]; Available from: https://www.researchsquare.com

92. Elenskaia K, Haidvogel K, Heidinger C, Doerfler D, Umek W, Hanzal E. The greatest taboo: Urinary incontinence as a source of shame and embarrassment. Wien Klin Wochenschr. 2011 Oct;123(19–20):607–10.

93. Talley KMC, Davis NJ, Peden-McAlpine C, Martin CL, Weinfurter E V., Wyman JF. Navigating through incontinence: A qualitative systematic review and meta-aggregation of the experiences of family caregivers. Int J Nurs Stud. 2021 Nov 1;123:104062.

94. Stephan A, Bieber A, Hopper L, Joyce R, Irving K, Zanetti O, et al. Barriers and facilitators to the access to and use of formal dementia care:

Findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. BMC Geriatr [Internet]. 2018 Jun 4 [cited 2024 Apr 1];18(1):1–16. Available from: https://link.springer.com/articles/10.1186/s12877-018-0816-1

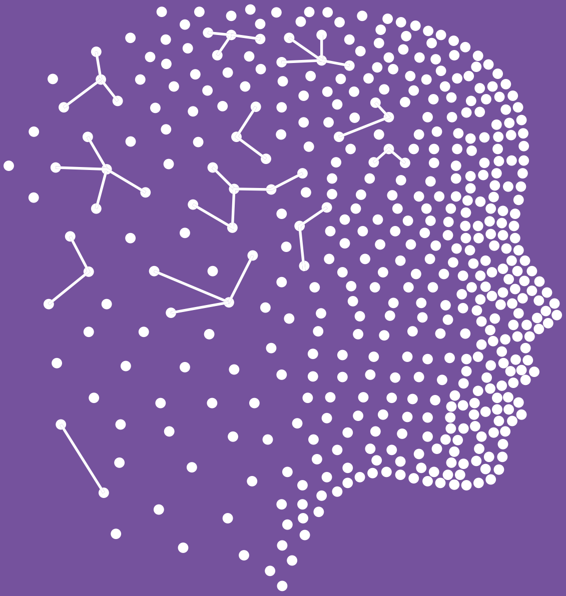
95. PORDATA. Fundação Francisco Manuel dos Santos. 2023 [cited 2024 Jun 12]. Valor mínimo mensal das pensões do regime geral da Segurança Social: pensões de velhice, invalidez e sobrevivência. Available from: https://www.pordata.pt/portugal/valor+minimo+mensal+das+pensoes+do+regime+geral+da+seguranca+social+pensoes+de+velhice++-invalidez+e+sobrevivencia-103

96. Worrall H, Schweizer R, Marks E, Yuan L, Lloyd C, Ramjan R. The effectiveness of support groups: a literature review. Mental Health and Social Inclusion. 2018;22(2):85–93.

97. Varik M, Medar M, Saks K. Launching support groups for informal caregivers of people living with dementia within participatory action research. Action Research [Internet]. 2021 Jun 30 [cited 2024 Apr 9]; Available from: https://journals.sagepub.com/doi/10.1177/14767503211023135

98. De Giorgi R, Series H. Treatment of Inappropriate Sexual Behavior in Dementia. Curr Treat Options Neurol [Internet]. 2016 Sep 1 [cited 2024 Apr 9];18(9):1–15. Available from: https://link.springer.com/article/10.1007/s11940-016-0425-2

99. Ilik F, Büyükgöl H, Kayhan F, Ertem DH, Ekiz T. Effects of Inappropriate Sexual Behaviors and Neuropsychiatric Symptoms of Patients With Alzheimer Disease and Caregivers' Depression on Caregiver Burden. https://doi.org/101177/0891988719874123 [Internet]. 2019 Sep 16 [cited 2024 Apr 9];33(5):243–9. Available from: https://journals.sagepub.com/doi/zfull/10.1177/0891988719874123?casa_token=x-MCQKVZNeKMAAAAA%3AQa7BWi7CUkrHel9yqzNoM1Inqjy0PmlhG-gThEKokVhaMgKR8J82tYaS6SJ0cvNfRSzbN5QsiaETI



ANNEXES

Survey – Living with Dementia

This survey is intended for caregivers of people with some form of Dementia. If you received this survey by mistake, please do not complete it so as not to compromise the data, and kindly inform us of the situation.

Your responses are extremely important. We therefore ask you to be as accurate as possible when recording your answers and opinions. We guarantee complete anonymity and emphasise that there are no right or wrong answers. There are only essential testimonies with the potential to improve our understanding of the reality lived by caregivers of PwD.

The institutions promoting this study are the NOVA-IMS Center for Global Health at NOVA University Lisbon and the Alzheimer Portugal Association.

The estimated completion time for this survey is approximately 20 minutes.

You may save the survey by clicking the “Save as project” button located on the right side of the survey page and resume completion later from where you left off.

Informed Consent

Dear caregiver of a PwD, you are being invited to participate in a research study on Dementia from the perspective of those who deal with it outside the professional context. The study therefore falls within the field of humanised health and social care.

The main objective of the study is to quantify the main problems faced by families who are responsible for caring for a PwD.

The results will allow us to better understand the issue of Dementia in Portugal and provide representatives of PwD with evidence-based arguments, as well as give health and social care entities information that may help improve support services.

The platform hosting this survey belongs to the European Union and guarantees absolute confidentiality regarding participant data. Once the survey is completed, the database is delivered to us in fully encrypted form.

While completing the survey, you must not provide any information that could lead to the identification of the participant. If this condition is not met, the survey will be immediately deleted in full.

We invite you to authorise the collection of documentary data and participate in this anonymous survey. All personal and clinical-related data will always be collected with full respect for your confidentiality.

After giving consent in the checkbox below, you may withdraw your participation at any time and leave the study without providing a justification.

☐ I have read, understood and agree to participate in this scientific research study, contributing through the data I provide so that the study findings may help improve the conditions of caregivers and People with Dementia in Portugal.

Instructions

If you do not know how to answer a question, or if the question does not apply to you, please select the option “Don’t Know (DK)”. If you do not wish to answer, select “Prefer Not to Answer (PNA)”.

A – Respondent Profile

We will begin by collecting some information that characterises you.

A1. What is your sex?
☐ Male
☐ Female
☐ Prefer Not to Answer (PNA)

A2. How old are you?

____

A3. What is your highest completed level of education?
☐ Up to 9th grade
☐ 12th grade
☐ Higher education degree
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

A4. In which district / Autonomous Region do you live?
☐ Aveiro
☐ Beja
☐ Braga
☐ Bragança
☐ Castelo Branco
☐ Coimbra
☐ Évora
☐ Faro
☐ Guarda
☐ Leiria
☐ Lisboa
☐ Portalegre

☐ Porto
☐ Santarém
☐ Setúbal
☐ Viana do Castelo
☐ Vila Real
☐ Viseu
☐ Açores
☐ Madeira
☐ Não Sei (NS)
☐ Não Quero Responder (NR)

A5. What is your relationship with Dementia?
☐ I am/was a family member and caregiver of a PwD
☐ I am/was a professional caregiver responsible for a PwD (skip to A6)
☐ Other: Which? __________
☐ Prefer Not to Answer (PNA)

A5.1. What is your degree of kinship with the person you care(d) for?
☐ Son/Daughter / Son-in-law / Daughter-in-law
☐ Husband / Wife / Partner
☐ Brother / Sister / Brother-in-law / Sister-in-law
☐ Other: Which? __________
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

A6. Is the PwD about whom this survey is being completed still alive?
☐ Yes
☐ No

If “No” in A6:
A6.1. How many years ago did they pass away??

____

A7. Are you a member of Alzheimer Portugal Association
☐ Yes
☐ No
☐ Don’t Know (DK)

☐ Prefer Not to Answer (PNA)

1. Diagnosis History

We will now look back at the period leading up to the confirmed Dementia diagnosis of the person you care or cared for.

P1.1. Do you know the type of Dementia the person you care for has?

☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” in P1.1.:

P1.1.1. Please select the applicable option:

☐ Alzheimer’s
☐ Vascular Dementia
☐ Frontotemporal Dementia
☐ Lewy Body Dementia
☐ Other. Which? _______
☐ Prefer Not to Answer (PNA)

P1.2. Is the person you care for aware of their Dementia diagnosis?

☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” in P1.2:

P1.2.1. Does the person you care for know the specific type of Dementia they have?

☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P1.3. How long ago was the person you care for diagnosed with Dementia?
☐ Less than one year ago. How many months? ______
☐ One year or more. How many years? ______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P1.4. At the time of diagnosis, the person was:
☐ In an early stage of the disease and aware of what Dementia is
☐ In an advanced stage that prevented awareness of what Dementia is
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P1.5. From the moment you first noticed signs and symptoms of Dementia in the person you care for, how long did it take to receive a diagnosis?
☐ Less than one year. How many months passed? ______
☐ One year or more. How many years passed? ______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P1.6. During that period, how many doctors did you have to consult?

____

P1.6.1.Indicate the specialty(ies) of those doctors:
Please select all that apply::
☐ General and Family Medicine (Family Doctor)
☐ Neurology
☐ Psychiatry
☐ Other: Which? ________
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P1.7. What diagnoses were received during that period?
☐ Depression or other mental health conditions
☐ Normal ageing process
☐ Other neurological problems. Which? ________
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P1.8. Is the person you care for currently, or has ever been, placed in a Nursing Home, Day Centre, Long-Term Care Unit or similar?
Please select only one of the following options:
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” in P1.8.:
P1.8.1 The social care service (Nursing Home, Day Centre, etc.) where the person is/was placed is:
☐ Specific for PwD
☐ Not specific, but has specialised competencies in Dementia
☐ A non-specialised nursing home or similar
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA))

2. How the Diagnosis was Communicated

Tell us about how the definitive Dementia diagnosis was given.

P2.1. To whom was the diagnosis delivered first-hand?
☐ To the person being diagnosed
☐ To the caregiver / companion present at the medical appointment
☐ Both the person and the caregiver were present
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P2.2. How was the diagnosis disclosed?
Please select all that apply:
☐ In a direct and impersonal manner
☐ In a direct and informative manner about Dementias
☐ It was given without mentioning the words Dementia, Alzheimer’s, or similar
☐ A description of the expected progression of the disease was presented
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P2.3. Do you consider that the diagnosis was communicated appropriately?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P2.4. What type of information do you consider important at the moment the Diagnosis is communicated?
Please select all you consider appropriate:
☐ Factual information about Dementias
☐ Intervention Plan (which medication or therapies are suitable)
☐ Strategies for managing day-to-day situations
☐ Information about support networks and community services
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P2.5. Do you believe that knowing the Diagnosis is a Right of PwD?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P2.6. What do you consider was the **most positive** aspect and the **most negative** aspect of how the diagnosis was delivered?
Please write your answer here::

3. Training to Deal with the Disease

Tell us now about the training received to deal with Dementia.

P3.1. After the diagnosis, was any type of training provided to the person, the main caregiver, the remaining family, supervisors and/or colleagues in the workplace?

☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” in P3.1.:

P3.1.1. To whom was the training provided?

Please select all that apply:

☐ To the person’s main caregiver
☐ To members of the person’s family
☐ To the person’s friends
☐ To the person’s supervisors and/or colleagues in the workplace, if still working
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

(If you selected “To the person’s main caregiver” in P3.1.1, skip other options and continue to P3.2.):

P3.1.2. Since you, as a caregiver, received training to deal with Dementia, indicate the type of support provided.

Please select all that apply:

☐ Videos and digital media (Internet, webinars, recorded courses, etc.)
☐ Written material (PwD guide, caregiver guide, or others)
☐ In-person training (practical training and similar)
☐ Other: Which? ________
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P3.1.3. Regarding the content covered in this information on Dementias, which topics were addressed?
Please select all that apply:
☐ Information on mental health issues
☐ Information on the PwD's life organisation
☐ Information about the disease
☐ Information on social support
☐ Information on the Care Process
☐ Self-care for Caregivers
☐ Other: Which? ________
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P3.2. Do you receive or have you received training to deal with the disease through a PwD Association?
☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

4. Reactions to the Diagnosis

Let us now focus on the reactions at the moment the disease was diagnosed.

P4.1. In addition to being a caregiver, are you the spouse/partner of the person you care for?
☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

If "Yes" in P4.1.:
P4.1.2. Were you already the person's spouse/partner when the diagnosis was received?
☐ Yes
☐ No

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” in P4.1.2.:
P4.2. Tell us what your reaction to the diagnosis was.

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Very negative reaction									Very positive reaction

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P4.3.Tell us what the reaction of the person’s family was.

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Very negative reaction									Very positive reaction

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P4.4. Tell us how the PwD’s spouse/partner started to deal with the Dementia.

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Copes very poorly									Copes very well

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P4.5. Tell us how the family started to deal with the Dementia

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Copes very poorly									Copes very well

☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

From this point onwards, please provide your answers based on the most recent phase of the PwD's Dementia or, if the person has already passed away, concentrate on the last stages/years of the disease. Your contribution will help us better understand the specific challenges faced during these critical moments.

5. Changes in the Life of the Person

Tell us now about the changes in the life of the PwD caused by the disease.

P5.1. Behavioural changes caused by Dementia?

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Did not show any sadness									Showed a great deal of sadness

☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P5.2. Did the PwD show any degree of apathy?

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Did not show any apathy									Showed a great deal of apathy

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P5.3. After the diagnosis, did the PwD begin to isolate themselves?

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Did not isolate at all									Fully isolated themselves

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P5.4. Did the PwD show any degree of disinterest in social and/or family activities?

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Did not isolate at all									Fully isolated themselves

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P5.5. Did the PwD show any degree of disinterest in self-care or previous individual activities?

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Continued to show interest in these activities									Showed a great deal of disinterest in these activities

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P5.6. Did the PwD show any changes in sleep or eating behaviour?

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Showed no changes									Showed many changes

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

Observed changes in work activity, if applicable:

P5.7. Is the person you care for retired or receiving a pension?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P5.8. Has the PwD you care for/worked for continued to work at any point after the diagnosis of Dementia?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” in P5.8.:
P5.8.1. What consequences did Dementia have on the PwD’s employment?
☐ There were never any problems
☐ Work performance capacity decreased
☐ The employer reassigned the PwD to a post adapted to their limitations
☐ It became necessary to stop working
☐ Other: Which? ________
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

Changes in leisure activities:

P5.9. Did the PwD’s leisure activities remain the same after the diagnosis?

☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” to P5.9.:
Please indicate what consequences the disease had in the following activities:

P5.10. Domestic activities

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Maintained fully									Stopped performing

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P5.11. Social activities
(e.g.: having coffee with friends, visiting/being visited by friends, doing voluntary work or helping someone, etc.)

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Maintained fully									Completely stopped performing

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P5.12. Cultural activities
(e.g.: going to the cinema, visiting museums, attending concerts, etc.)

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Maintained fully									Completely stopped performing

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P5.13. Physical activities
(e.g.: practising a sport, doing physical exercise adapted to age/illness, going for walks, etc.

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Maintained fully									Completely stopped performing

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P5.14. Do you consider that holidays and similar moments have become different when compared with the period prior to the diagnosis of Dementia?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” to P5.14..:
P5.14.1. Which circumstances led to changes in holidays and similar moments due to Dementia?
Please select all that apply:
☐ Mobility became more limited
☐ Having holidays became a very difficult activity for the Caregiver
☐ Tiredness negatively influences the Caregiver’s holidays and other similar moments
☐ Other: Which? ________
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA))

6. Daily life of the PwD

Tell us about the changes in the PwD's daily life resulting from the consequences of Dementia.

P6.1. According to your experience as an informal caregiver of a PwD, please indicate which changes you noticed in routines due to the disease.
Please select all that apply:
☐ No significant change
☐ It is something that dominates life
☐ Dependence on others for domestic activities
☐ Dependence on others for hygiene activities
☐ Need for supervision when going out
☐ It was necessary to adopt a specific routine
☐ Need for support with medication
☐ Learning to live with the disease
☐ Follow-up by a professional health team
☐ Exercising the mind and cognitive abilities
☐ Increased use of consultations, emergencies or health services
☐ Other: Which? _______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

7. Daily life of the caregiver

Tell us about the changes in your daily life, as a caregiver, resulting from the consequences of Dementia in the person you care for.

In your role as a caregiver, do you feel.

P7.1. At a physical level

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
Just as tired as before becoming a caregiver									Exhausted

☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P7.2. At an emotional level

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼ Just as tired as before becoming a caregiver									▼ Exhausted

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P7.3. At a financial level

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼ No need to make a significant financial effort									▼ Need to make a significant financial effort

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

8. Relationship with Dementia

Tell us about the relationship of the PwD you care for with their disease.

P8.1. Does/did Dementia interfere with other diseases the PwD has/had?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” to P8.1.:
P8.1.1. Since you answered “Yes”, in what way does Dementia interfere with these diseases?
Please select all that apply:
☐ I felt that the PwD became more exposed to other diseases

☐ From my perspective, Dementia ends up indirectly worsening other diseases one may have
☐ Other. Which? _________
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

9. Relationship with healthcare providers

We will now talk about the relationship of the PwD you care for with healthcare providers.

P9.1. Do you feel that the PwD has/had access to the Health Services they need/needed?

☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

If "No" to P9.1.:

P9.1.1. Since you answered "No", what do you consider to be lacking for the PwD you care for to have had good support from the Health Services?

Please select all that apply::

☐ Referral for specialist consultation from primary healthcare is difficult or delayed
☐ Waiting times between specialist consultations are very long
☐ Great difficulty in accessing magnetic resonance imaging or CT scans
☐ The price of medicines, when not prescribed by neurologists, is very high
☐ There is no connection between the Health Services and Social Services
☐ It is difficult to receive home support from health service teams at the end of life or in the advanced stage of the disease
☐ They do not provide therapies to help slow disease progression (cognitive stimulation, physiotherapy, psychological support or others)
☐ Other: Which? ______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P9.2. Does/did the PwD you care for have access to physiotherapy services and similar?
☐ Yes
☐ No or insufficient
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

If "No" to P9.2.:
P9.2.1. Since you answered "No or insufficient", what are the barriers to accessing this type of services?
Please select all that apply:
☐ The number of sessions available per year is not sufficient for the PwD's needs
☐ The physiotherapy services available are very distant from the PwD's place of residence
☐ The physiotherapy services that can be accessed do not have specialisation in the area of Dementia
☐ Other: Which? _______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P9.3. In your case, as a caregiver, do/did you have access to psychology services and mental health support?
☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

If "No" to P9.3.:
P9.3.1. Since you answered "No", what are the barriers to accessing this type of services?
Please select all that apply:
☐ There are no services in the region where you live
☐ No specialised services were found that could provide valid support to caregivers of PwD
☐ Other: Which? _______

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

What is your opinion regarding the coordination between the general Health Services that the PwD you care for deals/dealt with...

P9.4. At the level of coordination between services

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
There is no coordination between services									There is good coordination between services

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P9.5. At the level of bureaucracy in health-related processes concerning the PwD

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○
▼									▼
There is no bureaucracy									There is a great deal of bureaucracy

☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P9.6. Do you live in a large city?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “No” to P9.6.:

P9.6.1. Do you feel that in smaller cities/localities the support provided to PwD is given in the same way as to PwD living in large cities?

☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA

If “No” to P9.6.1.:

P9.6.2. Since you answered “No”, what are the differences in the support given to PwD who do not live in large cities?

Please select all that apply:

☐ Long journeys are necessary, with high financial impact
☐ Journeys are required for consultations and the performance of specialised medical exams
☐ Limitations in accessing medication
☐ Reduced or non-existent offer of specialised services (Therapies) for the PwD and the Caregiver
☐ Scarce resources to obtain training about Dementia and the caregiving process
☐ Absence of community resources that bring PwD and caregivers together (Mutual Help Groups, local initiatives)
☐ There are no frequent public transport options for travelling to health or social support services
☐ Other: Which? ______
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

10. Relationship with Social Support Services

Describe your relationship with the Social Support Services for Dementia.

P10.1. Is/was the Person with Dementia you care for covered by any form of Social Support Service?

☐ Yes
☐ No
☐ Don’t Know (DK)

☐ Prefer Not to Answer (PNA)

P10.2. Does/did the Person with Dementia you care for need home support?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” to P10.2.:
P10.2.1. Since you answered “Yes”, does/did the PwD have access to this type of support?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P10.3. Does/did the Person with Dementia you care for need support to allow the caregiver to rest?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” to P10.3.:
P10.3.1. Since you answered “Yes”, does/did the PwD have access to this type of support?
☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

P10.4. Does/did the Person with Dementia you care for need home support for meal provision?
☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

If "Yes" to P10.4.:
P10.4.1. Since you answered "Yes", does/did the PwD have access to this type of support?
☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P10.5. Does/did the Person with Dementia you care for need support to pay rent?
☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

If "Yes" to P10.5.:
P10.5.1. Since you answered "Yes", does/did the PwD have access to this type of support?
☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P10.6. Does/did the Person with Dementia you care for need financial support for diapers and similar items?
☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

If "Yes" to P10.6.:

P10.6.1. Since you answered "Yes", does/did the PwD have access to this type of support?

☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P10.7. Do you know whether the Social Security services in your geographical area provide any other type of support for Dementia?

☐ Yes. Which? _____
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P10.8. In your geographical area, which other entities do you know that provide support for Dementia?

Please select all that apply:

☐ Support from associations of people with Dementia
☐ Private insurance
☐ Mutual associations
☐ IPSSs
☐ Municipal or parish councils
☐ Health subsystems (ADSE, Armed Forces social system, GNR, etc.)
☐ Other: Which? ______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

11. Costs associated with Dementia

We will now talk about the costs associated with Dementia.

P11.1. Indicate the direct costs that Dementia generates/generated, on average, per month.
Note: Direct costs refer to medication, diapers, nursing homes, day centres, etc.

Please write your answer here in Euros:

____

P11.2. Indicate the indirect costs that Dementia generates, on average, per month.
Note: Indirect costs refer, for example, to: loss of salary by the caregiver; unpaid absences from work by the caregiver; family expenses resulting from the disease; changes in food purchases; increase in health insurance premiums.

Please write your answer here in Euros:

____

12. Future

P12.1. In your view, what changes could be made to improve the life of the PwD?
Please select all that apply:
☐ Valuing caregivers through legislation
☐ Improving support for PwD through PwD Associations
☐ Improvement and accessibility of Health Services
☐ Campaigns to raise Society's awareness of the Rights of these People, in order to reduce discrimination and social exclusion
☐ Improving the quality of care provided to PwD in social institutions such as nursing homes or day centres
☐ New social responses or adaptation of existing ones, such as Home Support Services, to support the lives of these people while keeping them in their homes

☐ Facilitating the acquisition of new technologies that allow better care in terms of safety, therapies within Institutions and in the PwD's home/residence
☐ Specialised training in Dementia for professional teams
☐ Environmental improvements in the PwD's home and in community accessibility
☐ Other: Which? _______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

13. PwD network

P13.1. Does/did the PwD you care for belong to any PwD community?
☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P13.2. Describe how you think your experience may be useful in helping other caregivers of PwD.
Please select all that apply:
☐ Through sharing my experience as a caregiver
☐ Through my active participation in the PwD Association
☐ Through raising society's awareness of the reality of the disease
☐ Other: Which? _______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

14. Intimate life

Important notes:

This question should be answered only by caregivers who are, or have been, spouses/partners of the PwD.

If you are a caregiver and wish to provide a statement, a box will be available for comments on this topic. To do so, please select “As a caregiver, I wish to leave my testimony on this topic”.

As is natural in this area, these questions may be considered sensitive for some people. If you feel uncomfortable with the topic, you may click the button “I do not agree to participate in this part of the survey”.

If you believe it is important for the survey to reflect this dimension of life, click the button “I agree to participate in this part of the survey”.

☐ I agree to participate in this part of the survey, as a spouse/partner
☐ As a caregiver, I wish to leave my testimony on this topic
☐ I do not agree to participate in this part of the survey

(If you chose “I agree to participate in this part of the survey, as a spouse/partner”):

P14.1. Were there negative changes in the PwD’s intimate life?

☐ Yes
☐ No
☐ Don’t Know (DK)
☐ Prefer Not to Answer (PNA)

If “Yes” to P14.1.:

P14.1.1. Which changes did you observe in the PwD’s sexual life?

Please select all that apply:

☐ Decrease or absence of emotional connection with the partner, affecting the couple's intimacy (reduced need for closeness, to give and receive affection)
☐ Decrease or absence of sexual interest or loss of libido
☐ Decrease or absence of sexual acts/relations
☐ Expression of sexual needs in socially inappropriate contexts
☐ Expression of sexual needs through disinhibited and socially unacceptable behaviours
☐ Initiating sexual acts/relations without the partner's consent
☐ Decrease in the PwD's ability to have a satisfying sexual life with their partner as a result of changes caused by Dementia (memory loss, disorientation, etc.)
☐ Frequently confusing their spouse/partner with other people whom they perceive as sexual partners
☐ Other: Which? _______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P14.2. As a spouse/partner of a PwD, what impact do you consider exists at the level of the experience of intimacy and sexuality?

Please select all that apply:

☐ Loss of sexual desire for the PwD
☐ Feeling guilty for not meeting the sexual and affection needs of your partner
☐ Feeling betrayed when the PwD expresses manifestations or engages in sexual behaviour with another person
☐ Maintaining sexual desire for the PwD despite the disease
☐ Sexual desire for the PwD being affected by the stress of daily caregiving
☐ Desiring other people or maintaining affective and/or sexual relationships with persons outside your relationship with the PwD
☐ No longer sharing experiences, feelings, desires, or discussing intimate matters with the PwD, affecting the couple's intimacy
☐ Other: Which? _______
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P14.3. Do you consider that the sexuality and intimacy of a PwD is affected:
Please select all that apply:

☐ At the time preceding the diagnosis, when changes or signs of Dementia were already present
☐ After the diagnosis of Dementia
☐ In an early stage of Dementia
☐ In a later stage of Dementia
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

P14.4. Do you consider that PwD living in Nursing Homes/ERPI can experience their sexual needs or express them in that context?

☐ Yes
☐ No
☐ Don't Know (DK)
☐ Prefer Not to Answer (PNA)

If "Yes" to P14.4.:
P14.4.1. What are the reasons? And do you agree with them?
(If you selected "As a caregiver, I wish to leave my testimony on this topic"):
Please provide your answers based on the most recent stage of the PwD's Dementia or, if the person has already passed away, focus on the final stages/years of the disease. Your contribution will help us better understand the specific challenges faced during these critical moments.

P14.5. Please write below any comments you wish to make regarding this topic as a caregiver of the PwD:

15. Final considerations

To conclude the survey, we know that many other dimensions of the life of a caregiver of a PwD have not yet been addressed and are important. If there is something particularly relevant to you that has not been explored and that you would like to share for the purposes of this study, please write your comment in the field below.

Note: All contributions provided here will be carefully analysed and, if possible, used in service of PwD and their families and caregivers. However, you must not write anything that could lead to your identification.

We therefore ask that, at the end, you re-read your text to ensure and confirm that there is no way to establish a link between what is written and the author. The privacy and confidentiality of what is shared here must be guaranteed, and if there is any possibility of these being compromised, the survey will have to be annulled in its entirety.

✓ Contribution successfully submitted

Thank you for the time dedicated to sharing your experience!

NOVA IMS
INFORMATION MANAGEMENT SCHOOL

NOVA center for global health LAB
powered by NOVA IMS

Being an informal caregiver of someone with Dementia is an act of personal courage and a necessary response that the family, as a whole, places upon a person or a small group of family members.

This study is an in-depth portrayal of the perceptions, challenges and hopes of informal caregivers in Portugal. By exploring 14 areas of caregivers' daily life, it offers a comprehensive perspective on the reality of caregiving, with the aim of identifying solutions and helping to develop responses that meet their needs and those of People with Dementia.