



YOUNGCARE

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

National report:

An Overview of the Situation of Informal Caregivers and Younger Adults in Need of Care in Germany



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ABOUT THIS PUBLICATION

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

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Abbreviations and Acronyms

ADS	Autism spektrum disorder
COPD	Chronic obstruct-tive pulmo-nary disease
MS	Multiple sclerosis



1. Aims of the national report

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

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

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

2. Methodology

Before describing the methods applied to achieve the above-mentioned aims, it is important to specify the target groups summarized as "younger adults in need of care". The main criterion for the differentiation is the question if need for care has already existed since birth or was acquired in the course of life (between 18 and 65 years of age).



We intentionally use the term "younger adults" for the project to describe the age group that can neither be described as children and young people, nor as senior citizens. This is done with the knowledge that this age group encompasses a large age variation.

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

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

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

2.1 Desk Research

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

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

2.2 Interviews

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

In Germany the interviews included six caregivers, two younger adults in need of care and one expert. Most of the caregivers were female. Only one person declared his son to be the main care giver. Four of the caregivers and care dependent person were under the age of 50, three 50 years or older. Based on one of these interviews, there will be a short portrait of one person in need of care, which can be found in chapter 3.5.



3. Results

3.1 Overview of the national situation

3.1.1 The current situation of the target group

Figures about the number of persons in need of care in Germany cannot be totally accurate. One common way of measuring is to see, how many people achieve benefits from the national social care insurance (see 3.1.3). Looking at this, all persons with an officially accepted degree of care (“Pflegegrad”) are counted. Numbers based on that “legal definition” are very helpful to terminate the need of care. Thus, not every person with disability is in need for care and vice versa. But it excludes those who haven’t applied for benefits from the social care insurance and/or are not examined and officially accepted yet, no matter if they are dependent on support or not. That is why, numbers on people in need of care can be estimated higher (Bäcker et al., 2020, p. 764). On the other hand, persons with very few limitations of their self-reliance can achieve the lowest degree of care (“Pflegegrad 1”) and are counted in the overall statistic as well (Rothgang; Müller, 2022, p. 46). All in all, there have officially been **4.546.814 persons in need of care** in Germany in 2021, corresponding to around 5 percent of the German population (bifg, 2023a).¹ In general, numbers of people in need of care have increased since the founding of the social care insurance in the 1990s and especially since its reform and inclusion of more kind of disabilities in 2017 (Rothgang; Müller, 2022, p. 47, 57).

Most of the people in need of care belong to the oldest group of the population, being 60 years and older (see figure 1). Around **15 percent of the people in need of care** (679.753) are neither children nor older people and **belong to the target group** of this research: younger adults.²

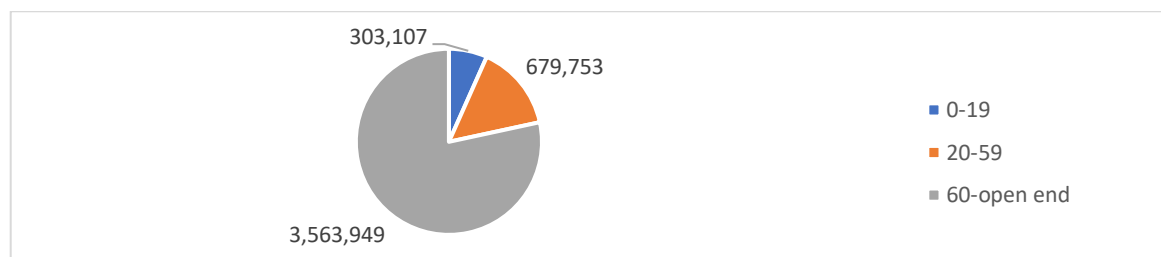


Figure 1: People achieving benefits of the social care insurance in Germany (2021) related to their age (own figure based on bifg, 2023b)

¹ Around 623.734 of them belong to the lowest degree of care which means that they mainly live at home and achieve support for services like cleaning or shopping. Most of the persons in need of care achieve benefits in the second degree of care (“Pflegegrad 2”) (1.804.906). In comparison to the lowest degree of care people with this and higher degrees of care have to cope with substantial to severe limitations in handling their own lives anymore. From this degree of care onwards people in need of care can apply for financial support for their informal carers (“Pflegegeld”) as well as professional ambulant care services. Beside these financial and in-kind transfers, people with the need of stationary support can achieve financial support for housing in residential care homes as well (Althammer et al., 2021, p. 232 f).

² Due to the tenner measurements in the available data on people in need of care, statements about the number of those who are among 18-65 years old, have to be adapted to the age group of 20-59 years.



Almost one million people (917.608) are supported temporarily or fulltime in residential care homes. 748.968 of them receive fulltime care in a residential care home and live there for 24 hours a day. All the other persons in need of care – around 80% of all persons in need of care – are mainly living at home (bfig, 2023a). Looking at the target group, the number of persons living at home is even higher: **95% (645.765) of the people in need of care between 20-59 years** are not living in a residential care home fulltime, thus they are **living at home** and depend on informal care and/or ambulant care services (bfig, 2023a).³ In general, there are enough places existing. The occupancy rate was about 80% lately. But the majority of people living in a nursing home is older than 80 years. Hence studies show differences between the current and desired form of housing while suitable places for younger people are missing (Rothgang et al., 2017, p. 237 f.).

As mentioned, one of the key elements of the research on younger care recipients in Germany and their conditions is the distinction between those already in need of care since their childhood and those entering care as adults. Young adults in need of care since their childhood mostly suffer from paralysis, intellectual disabilities, epilepsy, incontinence, developmental disorders, and down's syndrome (Rothgang et al., 2017, p. 185). Individuals who enter care in young adulthood often have very different medical conditions. A disturbed fluid and electrolyte balance, cancer, a tendency to fall, and mental illnesses such as depression or addictive disorders are most often the reason (Rothgang et al., 2017, p. 184). According to an older study of the medical service for the social care insurance the most common diagnosis in the age group of 20-65 years are mental and behavioral disorders, cancer as well as diseases of the circulatory and nervous systems (Brucker; Seidel 2012: p.15).

Numbers on the people who provide care at home are more difficult to define. In general, the percentage of people in need of care who live at home is decreasing with their age (bfig, 2023a). Taking the number of people in need into account, there must be **at least around 346.145 informal carers**, because those are the people who officially receive financial support for caring ("Pflegegeld") from the social care insurance. Looking at the figures of around 646.000 people in need of care living at home, the number of carers can be assumed to be much higher.⁴ There are many different studies about the amount of time and financial efforts informal carers need to care, but a standardization is not existing yet. In general, studies show that the amount of time for caring is usually increasing when people are living in the same household. With increasing time for care the percentage of

³ The number of people not living in a residential care home fulltime includes people in need of care who are temporary or fulltime living and/or working in facilities for disabled persons (125.853) (bfig, 2023a). Thus, a part of this group might not be living at home, which could lead to a non-specified decrease of people in need of care living at home.

⁴ The low number of carers achieving a care allowance by the social care insurance can be explained by the fact that not every informal carer (respectively the person in need of care) is applying for own financial support. Instead of that she/he might decide to receive professional (ambulant) support only or temporarily live in residential or disability care homes.



female carers seems to increase as well (Hielscher et al., 2017, p. 1 ff.). Studies show as well that the matter of caring at home and the question of achieving benefits from the public social care insurance is a matter of **social inequality**. Mainly people with higher income and status choose stationary or ambulant care facilities for their family members. These people are better informed and have more financial means. Since the care allowance is no income replacement, their opportunity costs rise with their own income if they would do home care. On the opposite, people with lower income rather decide to care at home because they do not tend to lose as much income if they are staying at home or they cannot not afford residential care homes by their own means either (Blinkert; Klie, 2008, p. 27f.).

Further discussions about the general situation of carers and young people in need of care are shown in chapter 3.2. Before, the role of the German welfare state in general as well as the German health care system including the social care insurance in particular are considered respecting the target groups.

3.1.2 The German welfare state in general

The German health care system is part of one of the oldest welfare states of the world. Founded at the end of the 19th century it was supposed to secure the working class from life risks like illnesses (health insurance, named “Krankenversicherung”, 1883), accidents and invalidity (accident insurance, “Unfallversicherung”, 1884) as well as ageing (pension schemes, “Rentenversicherung”, 1889). The implementation of these **social insurances** is the origin of the German welfare state. In opposition to mainly tax-financed systems dominating in Northern Europe, the German social insurances are equally financed by contributions of the employees on the one side and the employers on the other side. During the following century the social security system was opened to a broader group of people. Besides the extension of the people who are covered by the social insurance system, life risks like unemployment have been supplemented to the welfare system as well. As last resort basic a **social assistance system** was introduced in 1924. Many years later, in the 1990s the topic of care, especially of older people was included in the national welfare system too. It led to the foundation of the youngest German social insurance named social care insurance (“Pflegeversicherung”) in 1995 (Althammer et al., 2021, p. 59 ff). Based on the background that 75% of those who lived in residential care homes for the elderly were dependent on social benefits, the aim of the social care insurance has been to secure people from their own financial risk of long-term care (Parnack; Kempkens, 2022, p. 19).

Despite the highly developed German welfare state the individual responsibility increased since the 1980s again. Especially at the beginning of the 21st century a process of economic **liberalisation of the welfare system** took place. Based on the idea of a third way the German government introduced the so called “Agenda 2020” which was supposed to give the populace more responsibility in their own social protection (Boeckh et al., 2017, p. 112). Amongst others several cutbacks in the health care system were introduced to make the German health system more cost-effective. The reforms had



impacts for everybody in Germany.⁵ Nevertheless, regarding the **expenditure on social protection** (including social benefits, administration costs and other expenditure) Germany is with 33% of the GDP still at the 4th place of all European member states, behind France, Italy and Austria (Eurostat, 2023).

3.1.3 The German health system in particular

A German feature especially in the health care system is the coexistence of public and private insurances. All social insurances are compulsory for the broad public. But as a member of the public service, as a self-employed person or a person with a high income you can choose to be insured by a private social insurance in case of illness and care. This development is often criticised as a **“two-class-system”** in public, science and even within the health ministry (Butterwegge, 2011, p. 393 f.). Because services for people who are a member of a private health insurance are rewarded at a higher level (Walendzik, 2008), there is a high risk that it leads to a preferred treatment of privately insured people (Bäcker et al., 2020, p. 697 f.).

Regarding the issue of care the youngest German social insurance – the **social care insurance** – is the most important part of the health system. Besides its principle of prevention and rehabilitation to avoid the need of care, the care insurance is delivering monetary and in-kind transfers for those who are already in the need of care. To obtain access to these social benefits a person in the need of care has to be examined and evaluated by the medical service of the health insurance. There are five degrees of care depending on the degree of severity. Since a reform in 2017 all physical as well as psychological and cognitive health impairments are covered by the insurance. Before, the need of care because of illnesses like dementia wasn't sufficiently covered by the social care insurance (Althammer et al., 2021, p. 233).

Another principle of the social care insurance is the focus on private **support at home**. Residential-care homes are only financially supported if medically necessary. Otherwise, a person is only allowed to receive appropriate in-kind transfers. Thus, as shown before, most of the people in need of care are living at home (bfig, 2023a). Those who care can at least receive a financial benefit for caring (so-called: care allowance) from the social care insurance and entitlements for the public pension schemes. The fear of a hospitalisation of people in need of care because of the introduction of a care insurance didn't come true (Althammer et al., 2021, p. 239). Instead, a lot of different ambulant care services were founded, providing services for people in need of care at home.

The high percentage on informal and ambulant care at home (see 3.1.1) can also be seen as a matter of financial boundaries of those who care. Despite the social care insurance high costs especially for stationary care evolve because the social care insurance is supposed to be only a **partially comprehensive insurance** (Althammer et al., 2021, p. 234). It is covering only a fixed proportion of the emerging costs of care. Relating to the principle

⁵ For example, prescriptions are now free of charge only for minors (exceptions included). Large parts of the population have to pay a fixed basic contribution.

of subsidiarity the remainder must be paid from the income of those in need and that of their core family. Should neither the care recipient nor her/ his family be able to pay, costs can be covered by social assistance as a last resort. Compared to the health insurance, the social care insurance is constructed the other way round. Using the health insurance patients are (only) paying a fixed rate (e. g. for prescriptions). The health insurance will cover the rest, no matter how much. However, for those in need of the care the social care insurance will only pay a fixed rate. The rest of it has to be paid by those in need of care no matter how much it is. As long as contributions for the insurance aren't increased, any cost increases in the system have to be paid for by those in need of care in the end. That is why a discussion about a **change in the structure of the social care insurance** is taking place in public. The same financial system of contributions as in the health system is demanded to finally secure financial stability of those in need of care (Parnack; Kempkens, 2022, p. 19).

Example:

When the social care insurance was founded, the aim was to avoid a social decline of the people in need and to relieve the social assistance scheme at the same time, because people are insuring themselves (Rothgang; Müller, 2022, p. 108). Nevertheless, even with the highest degree of care the costs of a professional non-informal care in a residential care home are too high to be paid for by the benefits of the social care insurance. Including benefits of the social care insurance the individual costs for stationary care vary from 1600€ per month in an East-German federal state (Sachsen-Anhalt) to 2500€ in a federal state in West-Germany (Nordrhein-Westfalen). Altogether it is around 2179€ a person has to contribute in Germany (Rothgang; Müller, 2022, p. 96). In comparison, the average pension for older people in Germany is less than 1000 € with a strong difference between men (1306€) and women (832€) (DRV, 2022, p. 174 ff.). That is why even with the help of the social care insurance there is a high risk of not being able to finance residential care by own income. In 2019 31,5% of the people living in residential care homes have been dependent on social assistance schemes again (Rothgang; Müller, 2022, p: 108).

3.1.4 Further support measures

People at an employable age who are not able to work because of physical as well as psychological and cognitive health impairments can receive money from the public pension schemes if they have been contributing to the pension system for at least five years (so-called “waiting-time”, including times of care or parental leave). This **disability pension** benefit (“Erwerbsminderungsrente“) is often not as high as the old age pension, because the amount of money which was saved in the qualifying period (while the person was contributing to the pension scheme) is reduced up to 50 percent if the person is still able to work on the regular labour market between 3-6 hours per day (Althammer et al., 2021, p. 243). The average disability pension for upcoming pensioners is 932€ for men and 923€ for women (IAQ, 2023). Appropriate to the old age pension scheme it is criticized that especially for upcoming pensioners who don't have other private insurances, wealth

or income within the family, the pensions itself are too low to make ends meet and lead to social assistance schemes as a supplement for living (Köhler-Rama, 2020, p. 99).

If a person becomes dependent on care because of an accident at work or at its commute to or from work, the **accident insurance** will cover. The public accident insurance is compulsory for every employee as well as students or informal carers (DGUV, 2022). In contrast to all other social insurances in Germany it is generally paid for by the companies only. One purpose of the insurance is to cover the employers from claims for damages if there is any work-related accident or occupational disease. The benefits of the insurance are comprehensive and range from rehabilitation and reintegration to a substitution of labor income if the person isn't able to work temporarily to a disability pension if the person is permanently unable to work based on the potential annual earnings (DGUV; DHM, 2010, p. 40 f.).

All in all, it can be seen that most of the health expenditures in Germany are paid for by the public health insurance, as well as the social care insurance, private households and private health insurances (see figure 2). Although the public accident insurance plays an important role in the establishment of safety at work, its role for health (including care) expenditures seems to be negligible on the whole. The same can be said of the disability pensions as part of the public pension schemes.

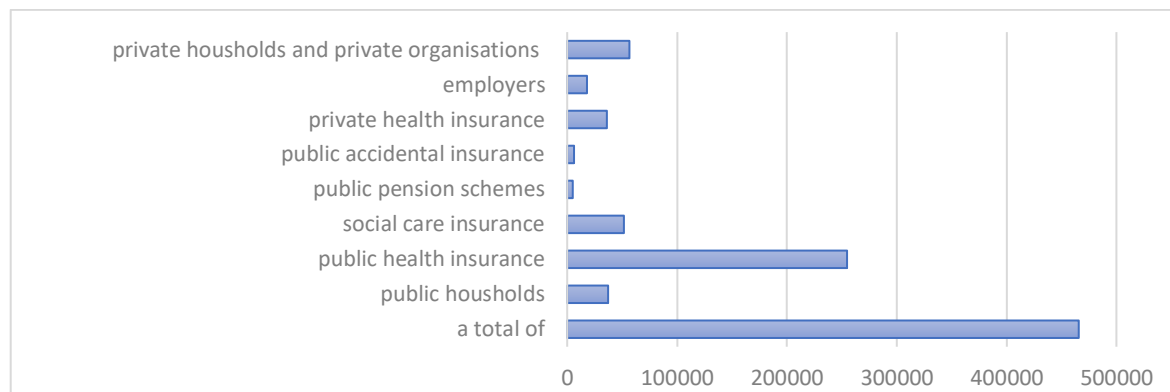


Figure 2: health expenditure in Germany in million Euro, 2021 (own figure based on Destatis, 2023)

3.2 Overview of the political, public and scientific discussion regarding younger care

Especially since the Covid-19 pandemic there is a huge discussion about the state of care in Germany in general. There is a lack of staff, financial resources and time for comprehensive accompaniment. The German population is also growing older which will only increase the need for care in the future. At the same time, more and more carers in training are quitting the job early due to bad working conditions. It comes to no surprise that there are claims for better working conditions, salary und support for professional carers as well as more support for people in need of care. The government is aware of this dilemma, but political measures have fallen short. The ruling parties are in disagreement of the right steps to financially secure care – especially for older people – in the future. In



January 2023 the German Association of statutory health insurance funds (“GKV-Spitzenverband”) called for more financial support from the German state. A raise of care contributions or even taxes, in order to fund the social care insurance more effectively, is discussed (Slavik, 2023). Also, the costs for stationary care are being discussed broadly. People in need of care and their relatives are being faced with rising costs, an average of 2411€ per month. That’s a rise of almost 300€ compared to 2022 (Tagesschau, 2023). Relatives of people in need of care are therefore not only faced with the fact that they must be informal carers but also with financial problems (Gerlinger, 2022).

With the current state of care in Germany in mind the situation for young people in need of care is mostly neglected. The need for care is mostly perceived as a problem of older people. Of course, those being 60 or more years old are the main group of people in need of care. And that’s part of the problem: As the German population is estimated to grow even older in the near future, the focus of public and political debate, discussing the state of care in Germany, is primarily focussing on these older target groups. This debate is important for sure, but it is also still overlooking the situation of younger adults in need of care and their informal carers.

Public discourse about young care is triggered most commonly by scientists who share their findings and concerns in the context of the health insurance companies' health reports, like the “BARMER Pflegereport” from 2017 by Rothgang et al., that is also quoted a lot in this national report. After the publication of the BARMER report, many newspapers and other media published articles about the situation of young adults in need of care. But most of the times this topic is almost non-existent in political and public debates. The BARMER-Report being almost six years old and still one of the most recent publications regarding young care is symptomatic.

The rather small number of scientific discussions on this topic shows how underrepresented the topic is in the scientific discourse. Most papers on "young care" deal with young carers, predominantly for the care of the older adults. Does an article address the care of young people, it is often limited to a specific area (psychiatry, substance use, rare diseases). One of the few exceptions is a scientific work from Schmitt and Homfeldt from 2020. In their work they stated that there is a need for more scientific research and articles concerning young care. They also spoke with two young adults living in a nursing home. One focussed on older people and the other also dedicated to young care. Although there should be a difference according to this initial situation, both interviewees suffer with quite similar problems. Both complain about conditions that highly constrain their mobility and leave them very dependent to the carers in their respective institutions. They criticise that carers are responsible for so many people, that there is only little time for individual care. Also, bad technical equipment, a lack of cell service and internet access leaves them excluded from their former social contacts and friends. Other people in their nursing homes are much older, impeding appropriate conversation. Leisure activities and the food offered by the nursing homes are also



targeted on older people. One of the interviewees is feeling like he is living in prison (Schmitt; Homfeldt, 2020, p. 237-242).

Yet, as seen in 3.1 most of the people in need of care do not live in nursing homes. Especially for young adults this might also be a case due to the lack of accessibility to suitable nursing homes. There is a website with a search tool helping people searching for nursing homes or similar institutions providing young care (www.wohn-pflege-finder.de). But most of these offers are focussing on children and teenagers, excluding younger adults. Recent studies show lighthouse projects which implement innovative living forms for young people in need of care respecting age-appropriate activities and the greatest possible autonomy. But there are no statistics how many young people are able to use such offers (Wolf-Ostermann; Kremer-Preiß, 2022, p. 201 ff.). Furthermore, the authors point out that a more needs-based design of residential care services for young people in need of care will only succeed if all those involved in the care process, i. e. those in need of care, as well as the informal and formal carers, will have more direct influence on the design. Finally, more participation is necessary as well as whole “caring community” (Wolf-Ostermann; Kremer-Preiß, 2022, p. 203) next to the professional nursery services and the informal carers. Neighbours and civil engagement are required as well to ensure the participation of young people in need of care in their social environment.

When long-term care is mostly performed by relatives (in 2015, 73,6% of all people in need of care were treated at home (Rothgang; Müller, 2018, p. 100)), what is known about the physical and mental conditions of people providing care at home for their relatives? There aren't many studies on these aspects, except some that focus on depression. Studies do show as well that the health burden on the caregiver increases with the duration of care. This burden increases if there are children or other people in need of care in the same home (Rothgang; Müller, 2018, p. 125). More than one in three of the caregivers stated, that they don't have enough time to get some relief from stress and physical exhaustion (Rothgang; Müller, 2018, p. 128). The care of a dependent person – this includes younger adults too – is a big constraint for the caring relative often bringing a huge mental and physical burden.

3.3 Needs, challenges and solutions

To deepen the information about needs and issues of young people in need of care and their caregivers qualitative interviews were conducted between February and April in 2023. In addition to one expert interview, seven further interviews could be done with carers and people in need of care, resulting in eight cases (see table 1).

Case No.	1	2	3	4	5	6	7	8
Status in research	Care-giver	Care-giver	Care-giver	Care-giver	Care-giver	Care-giver	Person in need of care	Person in need of care
Reason(s) to be in need of care	Autism spectrum disorder (ADS)	ADS, anxiety and obsessive-compulsive disorder	ADS, mental disability, mutism	Alzheimer disease	Multiple sclerosis (MS)	stroke	Parkinson's disease	Chronic obstructive pulmonary disease (COPD), transplantation, dialyse
Age	28	23	33	Deceased	63	43	61	63
Age, when need of care was diagnosed	18	16	3	46	56	40	51	43
Caregiver	mother	mother	mother	wife	partner	wife	herself	Himself and son

Table 1: Overview over evaluated cases based on interviews with persons caring and being in need of care

3.3.1 From diagnosis to care: door opener and relief or shock and suppression?

To get access to the broad system of public support including the social care and health insurance an officially accepted diagnosis has to be done at the beginning of care. That process can hold up. Serious diseases such as the Chronic obstructive pulmonary disease (COPD) can be unacknowledged for a long time and they can last a very long time before affected people develop a need for care:

“In 2001, when I certainly already had COPD1, I was still running Ironmen.” (Man with COPD about his initial lack of knowledge and worsening of his illness, case eight)

Even to realize that there is a need for care can take time. If a disability or severe illness which requires a special need of care is inherent, it does not mean that it is realized from birth on. In the case of children or adolescents, the detection, that there is a developmental delay, that requires care which would not be the case with peers, is necessary first. But that is not as easy as it might seem. For example, congenital disorders such as autism spectrum disorder (ADS) combined with mental retardation and muteness in case 3 were only detected in the course of the initial medical examination for kindergarten. As in that case, the **awareness and acceptance** of a disability can take time. But in the end, it is the main **first requirement for getting help**. As the authors among Rothgang (2017) already pointed out, the parents of children in need of care always need to know the developmental stages of healthy children first in order to see a need for action. Thus, in the second case, this knowledge of recognising unusual development



steps helped to diagnose the second son's congenital ADS earlier than with the first son. There, ADS was assumed when he was a child but the official diagnosis and validation took place when he was a young adult (case one).

Besides proper medical and social support after a diagnosis, the validation of a need of care is necessary to achieve **benefits from the social care insurance**. The most important support measures of the care insurance mentioned in the interviews were the access to **care allowance** as well as **ambulant care services** and **stationary care homes like a day or short time care**. Especially young adults in need of care want to preserve their self-reliance as long as possible or try to retrieve it as fast and good as possible. Hence, successful **measures of social and vocational inclusion** were positively mentioned in the interviews too:

"He can cook some meals now, iron and do laundry." (Mother about the successes of the caregiver who came home and helped with the learning of daily living skills of the son suffering from ADS, case one)

"I had a handicapped parking spot out front, got to the car park with my oxygen tank, was able to fill up and was able to do an eight-hour day." (Man, suffering from COPD, who could still work fulltime due to the help of his employer, case eight)

Thus, the **diagnosis** might be a **shock** but it is also a **door opener** to the existing and suitable means of help. But first the interviewed persons mainly described the diagnosis as a situation of being lost. Despite the cases, in which the disability was already existing within the family and one case in which the carer is a nurse, all interviewed persons have not had any deep knowledge about the disability or severe illness they were suddenly confronted with.

The mother in case one remembers: "Thus I drove home with the diagnosis and thought what we are going to do with it."

The **process of caring** for somebody else or themselves is a **learning process**. The understanding of a severe long-term illness or a disability which needs care is not common for those who informally care or be in need of care at the beginning of the situation. Despite the information gained due to medical consultations, the **internet** is described as a useful instrument for learning. It is used as an open source for information of all different kinds: information about the illness or disability as well as information on treatments and social support. While those pro-active measures are necessary at the beginning, some people describe a kind of "snowball effect" as soon as relief work takes place: one information leads to another and finally a different kind of support. But at the beginning of a diagnosis and a state of care, previous knowledge cannot be presumed. In addition, especially persons with limited language skills in German, as in case three, complain that professionals expected knowledge about support measures they have not been aware of yet. Moreover, the problem of how people being in need of care but live alone are

supposed to **get access to the support system** is mentioned in the interviews for several times:

"How is a person who is alone supposed to cope?" (Mother of a son with ADS, case three)

"If you (as a mentally ill person) don't have anyone in your family or friends, then you're lost!" (Mother of two sons with ADS, case one and two)

As seen, a diagnosis can take time and is based on the awareness of an illness or disability that requires an (unusual need for care). But even an approved diagnosis does not guarantee access to all existing support measures if it is not **accepted by the people** in need of care or those who care. People in need of care might **feel too young to be helpless** as in case six and delay or deny some kind of support:

"He was only 40." (Wife about her husband's delay in applying for a severely disabled person's card after his stroke, case six)

In general, being in need of care is seen as a problem of older people. In professional surroundings care is focused on geriatric help (Rothgang, 2017, p. 238f). The expert interviewed emphasizes that point too, saying that care still is mainly about helping older people with physical limitations:

"Care? That's old, ill and bedridden." (Interview with the head of a local organisation, advising people with or threatened by disabilities and their relatives)

Thus, the **diagnosis** of a severe illness or disability can **be suppressed on the one side**. But it can also be **a relief** if it is used as an **access for suitable help on the other side**. Furthermore, some people mentioned, that it was a relief, because they finally realised why their children or partner behaved differently. If accepted, a diagnosis can help to legitimize the differentness of oneself or somebody else. Some interviewed people stated a lack of acceptance of the necessity of the care situation, especially (but not only) in the case of a developmental disability like ADS. A diagnosis can help to legitimize the need for care in the social surroundings too, but it is not necessarily the case:

"The (grandson) has to be able to bear with that." (Grandparent about his grandson knowing that he has ADS and being in need of care, case two)

Despite a diagnosis, a need for care or support can be **trivialised**. Sometimes it is also **tabooed**. In case seven, a woman suffering from Parkinson's disease is complaining that her broader family does not take her illness seriously. Nobody is offering her help. Her limitations and need of care are suppressed by her family. Living alone, she is finally caring for herself without family support (see chapter 3.5). Different perceptions of impairments and the need for care can lead to tensions among the carers too. In case one and two the mother is taking the whole care work for the two disabled sons while her husband legitimizes his behaviour by claiming that:

“It’s not really our children who are sick, it’s society that’s to blame.” (Mother quoting her husband on the ADS diagnosis of their sons, case one and two)

3.3.2 Care between and within generations: different needs and challenges

As part of this project, differences within the challenges and needs of those who care for people since their childhood and those people suddenly caring for people who became dependent in the middle of their life, are presumed. It is assumed that people caring for people who are in need of care since their childhood already know and are part of the support system (see chapter two). This can be confirmed in the interviews.⁶ Relating to that assumption, the interviews showed differences in the needs and challenges of people who care between generations (e. g. support their children) and those who care within generations (e. g. care for their partners) in particular (see table 2).

	Care between generations: when parents care for their children	Care within one generation: when one partner cares for the other one
Duration of care	Support process often starts with birth, permanent burden of long-term care, which can be lifelong	Support process starts "in the middle of life", permanent burden of long-term care possible
Role perceptions	Stable role perceptions, adult children in need of care remain in their role as children and parents remain in their role as supporters	Changed role perceptions, partner becomes dependent on the other one and may lose the role of a supporter towards the spouse and/ or potential children
Bonding	Despite permanent stress, the bond remains stable because the parent/child role does not change	Changing role perceptions might more easily lead to a loss of emotional connection
Fear about the future	Fears about the future beyond one's own death	Fears about the future are mainly limited to one's own life span

Table 2: Differences in caring between and among generations

If the need of care is inherent, the parents mostly remain the informal carers lifelong. According to German statistics, 90% of all children in need of care are living at home. This amount is decreasing to 80% for people in need of care in their twenties, but still one third of all people in need who are between 50-60 years old are living at home with their parents (Rothgang 2017, p. 214 f.). In both interviews taken with families who care for their adult children (23-36 years old) this is the case too. The responsibility for care is mainly taken over by the mother since birth. Since then, it is taken for granted that she remains responsible for the care of the (adult) children for the rest of their lives. Their **role perception** never changed and a lack of recognition of the mental load and care work within the family evolved:

"You have all the time in the world. [...] My men don't understand that." (Mother about the husband and the sons in need of care, case one and two)

⁶ Although, as seen in case one, an awareness and validation of a disability and a special need for care can endure until adolescence.



At the same time this stable role perception leads to the fact that parents might better cope with the impairments of their children they care for:

"He [son] never did anything anyway." (Mother of a son with ADS, case one)

In contrast for partners caring about another role perceptions might totally change. A partner suddenly becomes dependent in the middle of her/ his life and may lose the role of a supporter within the partnership or towards the children:

"After seven PM I don't need to give him any more information. He won't remember it." (Wife about his husband after his stroke, case five)

When role perceptions change within a partnership, a loss of emotional connection to the partner might occur. In two cases partners were separated in the course of the diseases. Especially, if the state of mind changes because of the illness, caring partners had to struggle with **bonding**:

"I felt as if I were married to ALF. But nobody wants to be married to ALF. [...] I sat next to him and cried and he made jokes and didn't even notice." (Wife about her husband who was permanently ridiculing the situation with inappropriate humour and showing no attention for the exceptional emotional situation of his wife and daughter after his stroke, case six)

Furthermore, the process of caring for an adult person is mostly unknown for informal carers if the situation of care arises as an adult for the first time. Caring for an adult tends to be taken place **between encroachment and neglect**. Conflicts between carer and cared-for person can arise easily:

"If I always offer my help, it might be too much, if I don't offer it, the other person might feel neglected. [...] Putting a jumper on a child is something completely different. [...] Every adult wants to keep and show their independence." (Woman on caring for her friend with MS, case five)

Quite the contrary, unchanging role perceptions within a family do seem to help with a live-long bonding situation no matter how exhausting live-long care of parents can be:

"When my son is happy, [...] I am doubly happy. But when he is sad, I am sad too." (Mother of a son with ADS and muteness, case three)

Finally, there is a burden which seems to affect parents who care about their grownup children more. They do have **fears about the future beyond their own death**. They are very worried about who will take care of the children in need of care when they are in need of care or died. People who care for their partner are worried too, but the interviewed parents strongly emphasized their worries beyond their own death. It might be more important for them because their grownup children are in need of care but will still most likely overlive their parents.



3.3.3 The individual costs of care: needs and challenges

Studies show a tremendous burden for informal carers (Hielscher, 2017/ Rothgang; Müller 2018). Caring for somebody at home includes, next to the possible medical caring, lots of different tasks in daily life: personal hygiene, nutrition, mobility, domestic care (Rothgang et al., 2017, 194 f.) as well as support with social and professional (re-)integration which, in particular, is important for young adult person in need of care. The results from the interviews confirm the individual costs of care for those who take over these tasks. The duration of care can last for decades to a lifelong need for care. This leads to a permanent burden on the carer. It can be seen, that care was often done at the **expense of the health of the caring person**. Some of the carers neglected own medically necessary care, others even denied operations or suffered from a stroke or burn-out:

"I worked so much, I had a stroke." (Wife and mother who cared for her husband who had Alzheimer's disease, case four)

Caring about one person is often done at the **expense of the rest of the family** too. Carers complained for example that there was not enough time left for the children (case six). One caring mother could not attend to the funeral of her own parents (case three). Care is also often done at the **expense of the own social environment** like the own circle of friends. People criticised a lack of time or missing flexibility being fulltime responsible for someone else at home (case five). Especially people in need of care complained that they completely had to change their sportive hobbies and thereby their circle of friends because they have not been able to do it physically anymore:

"My circle of friends from before, they don't exist anymore [...] There are few opportunities to do something." (Woman with Parkinson's disease, case seven)

In general care is often done at the **expense of the own leisure time, freedom and needs** of the carer:

"I'd like to cut myself off from everyone, from everyone again. [...] Learning to say no. [...] And then I'll have the dog again!" (Complains of a mother caring for her two sons and doing all the housework, case 1 and 2)

Caring is also done at the **expense of one's own job**. Almost all interviewed carers have been female and rather gave up their paid work or dealt with double burden of working and caring, partially at the same time:

"I then called him from work several times a day to prevent food from being forgotten on the cooker and something happening because it burnt several times. Luckily nothing serious ever happened." (Wife caring for her husband who had a stroke, case 6)

All persons caring (and in need of care) felt an **emotional burden** due to the fear that the physical and mental condition might worsen. Persons who know the courses of the disease suffer from knowing how their situation or that of the persons they care for can

or even inevitably worsens in the course of the disease. Thus, the wife who cared for her husband deeply struggled with her experiences she had with persons suffering from Alzheimer disease as a nurse. She was aware of all its consequences up to death (case four). Another wife could hardly deal with the unpredictability of her husband's condition after his stroke:

"We had made a phone call with video and he was eating and I saw his arm hanging in the soup, so I was already worried that it would stay like that and he would be a care case, that I would always have to feed him." (Case six)

Both interviewed persons who are mainly caring for themselves emphasized how important it is to **take precautions** if you know that your illness is inevitably worsening:

"As a person affected, you should always make sure that you get the aids in good time, e.g.: if I notice or know from the clinical picture that it will get worse, in the case of a COPD illness it was foreseeable that the air would become increasingly scarce, and then you must also organise the aids in good time." (Case eight)

In particular, when people are considered to have **been treated-out** but they **are not cured**, it is very difficult for them to accept and cope with this situation, as seen in case six. Years after his stroke a man cannot use his arm properly. Despite his medical diagnoses that this situation will not change anymore he cannot accept it. But as seen in another case, this unacceptance and a very strong personal initiative can still lead to an improvement of one's own quality of life. There, a COPD patient fought for his own lung transplantation:

"Alone, if your doctor says you are out of treatment, here's what I did, I went to support groups, I got a second opinion and then I got more involved with the disease." (COPD patient who finally managed to get a lung transplanted, case eight)

Finally, in a lot of cases there is a **burden of double and multiple care**, as caring for a family member is often not the only care situation. Carers of young adults in need of care are often at an age when they themselves still have minor children and/ or their parents become care recipients due to advanced age. In two cases people had to handle a double burden because they have been caring for their children or partner and for their own parents or parents-in-law at the same time (case one and three). In another two interviews people were caring within their partnership and have been responsibility for underage children too (case three and five). Then, the burden of care is not only carried from people who are healthy themselves. Sometimes **people care for somebody else despite their own long-term illness** (case five) or are in need for care for themselves as in case seven.

3.3.4 The structural obstacles of care: needs and challenges

As emphasized by the expert as well, care is mainly focused on limitations in old age. Studies show, that there is a desire for independent living especially of people in need of



care still living with their parents. But **appropriate living facilities** like residential groups for young adults in need of care **are missing** in Germany (Rothgang et al., 2017, p. 219 ff). Other studies show that care homes tend to focus solely on geriatric care (Schmitt; Homfeldt, 2020) and most young adults in need of care do not prefer that kind of accommodation (Rothgang et al, 2017, p. 219 ff.) (see chapter 3.2). In particular, the interviews have shown, that in two cases persons were unsuccessfully looking for inpatient facilities, such as assisted living. The man suffering from COPD was afraid because the assisted living institutions more less just offered common meals. There was no special medical supply in case of need (case eight). Thus, on the one hand the advantages of such facilities are very small compared to the high costs. On the other hand, the woman with Parkinsons disease could not even find one for herself because they were aimed exclusively at older people in need of care over 65 years of age. Now she is afraid of having to move in a care home when her physical condition worsens and she will not be able to live on her own anymore (see chapter 3.5).

But even **voluntary engagement** as self-help groups⁷ often **do not** implicitly **suit to the needs** of younger people in need. In the interviews people increased their self-initiative and founded their own groups, because the existing ones aimed more at older people:

"Young people with the disease have different problems than older people [...] Even my mother said to the older people that they are only old people, you don't go there". (Parkinson's sufferer about a self-help group, case seven)

Besides, a **shortage of staff in the care sector** prevents that there are **quickly and sufficiently available offers in professional support**, be it short-term or respite care or outpatient services and nursing homes. Informal carers who were looking for ambulant care complained, that finding a suitable service requires increased self-initiative. In one case the ambulant service was even terminated due to the lack of staff (case five). Furthermore, a lack of staff can have an impact on the application for and approval of care degrees. The **application process** itself is often **not comprehensible and controllable** for those affected. Appeals are permissible, but time-consuming. A feeling of being helplessly exposed to the authorities arises when the illness situation of the person concerned is not recognised as in case seven or the process of assessment takes a long time and cannot be influenced (case five).

"Nobody could understand that I don't have a degree of care." (Woman suffering from Parkinson's disease after her application for a degree of care was rejected twice by the same assessor, case seven)

⁷ Self-help groups are self-organised associations of people who have the same problem or concern and want to do something about it together. Their central concern is the mutual support among affected people, the exchange of information and the (political) representation of interests. Self-help groups exist in general on the topic of "disability/chronic illness/inclusion" and in particular on individual types of limitations and challenges. Self-help groups dealing with health problems are funded by statutory health insurance.



People in need of care are often require many different medical treatments by various doctors and institutions. When dealing with his disease, the man suffering from COPD for example would have liked better advice from medical professionals. Even though he has had good experiences with some doctors, he felt that he has had to obtain a lot of information himself and that he had to make sure that the various doctors treating him receive all the information about the treatment and the disease from each other. Therefore, he would like his **medical information stored digitally on his health insurance card** so that he is spared, for example, two double blood tests in one day, on the grounds that this is easier than manually entering other doctors' findings into the system.

Considering the fact that despite the existing care allowance there is no income replacement benefit similar to the German parental allowance for caregivers,⁸ it is surprising that no points of criticism can be found regarding to this in the interviews. This may be due to the fact that the (female) carers interviewed either continued to work parallel to their care work (case four-seven) or that the mothers of the adult children in need of care have not had an own income for years (case one-three). Their income was therefore not missing as part of the household income. Instead, the care allowance was even an extension of the household income. The adult children in need of care were again not (yet) expected to have their own income or it was accepted that their income was based solely on state social benefits (case one-three). Instead, it was criticised that the **disability pension** of the formerly professionally active persons in need of care is **hardly sufficient** to maintain their standard of living or is **not yet accessible** due to a lack of pension points (case seven and eight):

"You must still have in your mind as a pensioner with a disability pension, what money do I have left." (Case eight)

Especially the self-employed person complained that she would have liked to stop working as her doctor recommended, but could not do, because she had not gained enough points to receive her disability pension (for more details see chapter 3.5).

3.3.5 Possible Solutions

At the time of diagnosis, some of the interviewees would have wished for psychological support in order to be better supported in this life-changing situation. This applies both to the person being cared for and to themselves. It would be helpful to make **psychological counselling** more accessible to those affected. This could happen directly in the course of the medical diagnosis or also in the course of applying for care degrees. The carers in particular would also like **professional supervision** of their role as a caring parent or partner vis-à-vis the person being cared for and the wider family. There is often an uncertainty about the extent to which the fulfilment of one's own needs as a carer is

⁸ Up to now it is possible to make a socially insured leave from work for up to six months in order to care for somebody. But the income replacement you can get is only given as an interest free loan (BMG, 2023).

justified and how to deal with the demands and possible criticism from the person being cared for and the family.

In general, informal carers often yearn for **more moral gratitude** for and **support** in the care and household work at home. This is especially the case when it is not the partner but the child who is being cared for. Here, it could help to raise **social awareness** for the work and burden of caring at home. The classic image of mothers as solely responsible for raising children and the household should be more strongly questioned too. In the course of the need for care of adult children, this means in extreme cases that especially women may never again leave their role as full-time caring parent in their own lives.

Social awareness is also necessary for the acceptance of disabled people within the society. People with disabilities should be accepted and not stigmatised as happened in case eight:

"Many also react strangely. [...] With negative comments. [...] We were on the way to lung sports and had to rest (leaning on a lantern to get better air) when a woman said to her child "they must have been drinking" and pulled her child away."

To maintain mobile and independent as long as possible for people in need of care it could be helpful to offer **training courses for maintaining** their **mobility** before their limitations worsen. Potential contents could be how to ride a wheelchair on the bus, how to use an electric wheelchair or how to stay remain mobile with an oxygen bottle:

"The point is that I can do it! Riding a wheelchair with an electric wheelchair, that has to be learned! [...] Mobility is the be-all and end-all of the whole story." (Case eight)

In order to save patients and carers unnecessary medical treatments and to relieve them in situations where they have to deal with serious, permanent illnesses and/or disabilities, the idea of an **electronic patient record** should be further promoted, and its implementation facilitated.

Informal carers who are working at the same time complained about that exhausting situation. While paid work can be a welcome change of care work, it is not always done voluntarily. To enable an independent choice of informal carers, if they solely do care work or do paid work at the same time, the **care allowance** should be an **income replacement** rather than a subsidy for the household income like today. This could be done in the style of the existing parental allowance and not as the existing interest free loan (BMG, 2023), none of the people who were interviewed took. The possibility to temporarily leave work to care should be extended in time as well. None of the interviewed persons cared for just six months (BMG, 2023).

People in need of care are always at risk of losing their income. To maintain a living-standard like before is barely possible relying only on the public **disability pension** (see 3.1.1/ case seven and eight). There is no full income replacement, and it requires at least



five years of “waiting time” (time of gaining entitlements). Especially young people in need of care do not necessarily fulfil this requirement. Furthermore, self-employed people are not necessarily part of the public pension schemes at all. That is why they are at a much higher risk of losing their standard of living if they become in need of care. Depending on their health insurance they might also get no income replacement if they become long-term ill as most employees automatically do. Hence, **self-employed** people must be **better included** in the German **social security system**. A social civil insurance (“Bürgerversicherung”) including all privately or (in case of pensions even non-insured people) in the public health insurance and public pension schemes might be helpful.

Structurally, there is a **lack of suitable housing for young adults** in need of care. This applies both to young adults who first want to become independent, as in case two, but also to adults in need of care who want to maintain their independence as long as possible, as in case seven. While nursing homes do not play a role, the desire for **assisted living** is expressed. Here, the corresponding capacities would have to be expanded. A suitable form of housing is also sought for the care of grownup children in need of care in old age and after death. Here, carers are looking for a **home for the elderly in which their children in need of care can live with them** and remain there even after their death.

The shortage of staff in the care sector also affects the provision of ambulant care providers. In order to find a suitable care provider matched by the health insurance fund, a great deal of personal initiative is often required. At this point, the help of a local, **independent placement service** similar to the central registration and placement of kindergarten places in some German municipalities, such as Frankfurt am Main,⁹ would be desirable.

The interviewed persons emphasized the Internet as one of the main resources for information about care. In Germany there are so called “**care support points**” (“Pflegerstützpunkte”) that are set up by the health and social care insurance.¹⁰ They do offer advice and support to those seeking help. But they as well as their digital equivalent have been unknown in some cases and should be **better announced**.

3.4 Good practice examples

A lot of the support measures might not be sufficient all the time, but in some cases, they are a good practice example. Caring for somebody at home brings a lot of responsibility and takes a lot of personal time as seen in chapter 3.3.3. But there are options substituted or fully paid by the social care insurance for getting relief if the person in need of care has at least the second degree of care (see chapter 3.1.1/ 3.1.2). There is the so-called **respite care (“Verhinderungspflege”)** if the carer is not available for a short time (e. g. being ill or on holiday). Another private person or an ambulant care service can take over and receive money by the social care insurance. If a person can temporarily not be cared for at home,

⁹ For further information look at: <https://www.kindernetfrankfurt.de>.

¹⁰ For further information look at: <https://www.bundesgesundheitsministerium.de/service/begriffe-von-a-z/p/pflegestuetzpunkte.html>.

people in need of care can attend a so called **short-time care institution** (“**Kurzzeitpflege**”). This can be day care facilities during the week or during the weekend. But it is extremely important for the carer to accept such kind of help too. As in one case the informal carer tries to encourage other people who care for people with Alzheimers disease:

"That the carer dares to put the sick person, the partner with dementia, into day care." (Case four)

Families caring for (adult) children in need of care might barely use those short time care institutions as surveys reveal (Rothgang, 2017, p. 168) but there are **family relief services** which offer group activities and also holiday games and individual support to relief families and socially include and strengthen young people in need of care. Their offer is directed at children and adults with disabilities who still live with their families. Even a transport service to the group activities is organised to relieve the burden on caregivers. But as the expert says in the interview these services, which are very much in demand, are unfortunately too few due to the lack of staff.

Self-help groups can help people to connect with each other, to share information and to gain emotional and social support:

"Yes, you have to work that out for yourself, what you have to listen to - that is of course why I think that self-help groups, for example, are so important, so that you can tell people." (Case eight)

Finally, it is not just the person in need of care who needs medical or psychological help. Also **Rehabs** and psychological support have been emphasized by the informal carers as being very helpful to reduce stress and gain energy again.

3.5 Portrait

The person chosen for this portrait (case seven) shows different features a person in need of care might have to deal with. In contrast to all the other interviewed persons the woman lives alone. She is not married, has no children and has to care for herself being aware that she might not be capable of doing it anymore in her near future. Furthermore, she had been caring for somebody else despite her own physical limitations and next to her profession. Thus, she is a good example for the multiple burden of care: she was in need of care, but caring for somebody else and working at the same time. Her example is also important to point out the blind spots even a strong welfare state like Germany has. As a self-employed person she has been much more responsible for her own social security than employees are. That is why she did not stop her professional activities although it was contrary to the medical recommendations. Finally, her example shows how social support within the broader family is sometimes neglected because caring and her illness are trivialized and tabooed.



The woman in this portrait was diagnosed with Parkinson's disease in 2013 at the age of 51. She was self-employed at the time of diagnosis. The correct diagnosis took time. She initially misinterpreted her symptoms. After clarification with several doctors, including an orthopaedist, she was diagnosed with Parkinson's. She remembers the situation of her diagnosis as a shock with her doctor saying:

"You don't have anything orthopaedic you have something on your head!" (Case seven)

For eight years, she lived with her mother, whom she cared for additionally to her own illness and work. She moved with her mother - who was increasingly in need of care - into a barrier-free flat in order to save costs. In the last few years, the care of her mother intensified, so that she hardly found time to do errands for herself and to maintain social contacts. She received no help from her siblings in caring for her mother or for herself:

"I was always quite busy, from working to caring for my mother and I wasn't healthy myself. That was a difficult situation." (Case seven)

The sisters rejected her request for support, saying that her mother could move to a nursing home. Recently, the mother (94 years old) has been placed in one. The reason was that she (the caring daughter) had to stay in hospital unexpectedly. Due to this situation her mother would have had to live alone at home for a short time, but her mother's nursing service refused to take over that responsibility.

Her illness was accompanied by financial worries. Based on her complaints, the doctor looking after her brought up early retirement. However, due to her self-employment, she was not yet able to retire because she had not yet reached the period of entitlement to a reduced disability pension of her pension insurance. She continued to work but had to take on fewer clients and thus had a loss of income. She could not find any support for her situation in the form of financial compensation or other assistance. As a self-employed seriously ill person, she "always just failed" (Interview, case seven) the regulations for support. Finally, her mother's need for care gave her the opportunity to claim care allowance while she was caring for her mother at home. Because of that she could supplement her income a little and collect pension points for her own pension.¹¹ That is why she could lately claim her disability pension.

With regard to her own Parkinson's disease, she receives no support from her sisters. She has the feeling that her disease is a taboo. Recently, she was not asked to take part in family photos at family celebrations. She believes this is because she would be seen with a walking stick. With the diagnosis and also the care of her mother, the former circle of friends has been completely lost. She built up new friendships by attending a self-help group and later founding her own group. The decision to start her own group was also

¹¹ If a person is receiving the second lowest degree of care ("Pflegegrad 2") she/ he can receive a care allowance, which is mainly given to the informal carer as a benefit for caring. The informal carer is insured in the German pension system at the same time (see chapter 3.1.3).



due to the fact that there were a lot of older people in the self-help group who had to deal with other problems and a much worse state of health. Although she liked the people, she did not feel well understood on all points and did not get to hear others' experiences on all the topics relevant to her:

"The young sufferers just have different problems than older people." (Case seven)

Now she receives support in the self-help group she founded for young people with Parkinson's disease. Through its members, she received valuable tips regarding her retirement too. For her there is a gap in the provision of counselling and support for (young) people with serious illnesses who are self-employed. She sees another gap in the lack of assisted living for younger people in need of care and complains that people under 60 are often even excluded from moving into assisted living, a situation happening to her. That is why she is still living on her own, but she is very concerned about the worsening of her own illness in old age. Therefore, she is looking for places in assisted living for herself again, but she does not want to move to a nursing home. Although she has physical limitations, she is completely sane. Due to the mainly high-aged persons living in a nursing home she is very afraid of their potential mental situation:

"They are all people who are no longer right in the head. Then I imagine what it's like for me." (Case seven)

That is why she tries to be independent as long as possible. She currently needs support in the household (cleaning, shopping) and would also prefer support for her own personal hygiene and mobility. Yet, she always tries to find solutions. For example, food is ordered online and delivered to her home. For remaining mobility, she is looking for an electric scooter. Finally, she deeply hopes for a medication that could slow down her disease.

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