YOUNGCARE

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



COMPENDIUM

YOUNGCARE GUIDANCE: ORIENTATIONS FOR YOUNGER PEOPLE IN NEED OF CARE AND THEIR INFORMAL CARERS

Co-funded by the European Union

ABOUT THIS PUBLICATION

This compendium is based on national reports elaborated in the partner countries. The reports are grounded in desk research and interviews produced within the Erasmus+ project **YoungCare – Relief for Younger People in Need of Care and their Informal Carers** (Cooperation partnerships in adult education, project number: 2022-1-DE02-KA220-ADU-000086558).
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Introduction

Younger people in need of care in the context of the YoungCare project are defined as people between the ages of 18 and 65 who have experienced a drastic event such as an accident or a serious illness and can no longer manage their daily lives without assistance. For this group of people, there is a big challenge in finding suitable care services and support. Their relatives are also under particular pressure due to the situation. Often, they need to perform informal care, helping them through their everyday lives. Care can be defined as the provision of what is necessary for the health, welfare, maintenance and protection of someone or something.

Perhaps you as a reader already know about these struggles and difficulties, as you are an informal carer yourself. This compendium aims to present examples of good practices, solutions and strategies to strengthen your position. To prepare these materials, we've conducted interviews and researched the circumstances of young adults in need of care (aged 18-65) and their informal carers in our partner countries, i.e., Portugal, the Netherlands, Lithuania, Italy and Germany. This Compendium will give you some insights into our findings. If you are interested in further information for each country, you can find it in the national reports here:
https://youngcare.eu/resources/

Our suggestions and help are the results of conversations we have had with informal carers and experts. Consequently, we have identified a number of topics that we have used to structure this Compendium. These are not guidelines but information from experiences that other informal carers have had that may be able to support you in your role.



Why Young Care?

The need for care can be a far-reaching event in all age groups and in every life situation. It often represents a serious break with the previous life. Severe medical or psychological conditions as well as accidents can have serious consequences. Such events can lead a person to become dependent on other people helping them and caring for them. Daily tasks and challenges may be hard or impossible to accomplish. Living independently isn't possible anymore without the help of others. With the beginning of care dependence, people in need of care are deprived of many possibilities to organise their lives on their own, and caring relatives (or other close people) are suddenly confronted with a multitude of new tasks. In addition to organisational and practical tasks, this is above all an enormous emotional challenge for everyone involved.

Those in need of care in the 18-65 age group face particular challenges. On the one hand, this is due to their living circumstances. They are at an employable age, so a condition that limits them in their jobs or even stops them from working can have a huge impact on their financial situation as well as the structure of their everyday life. On the other hand, their challenges stem from the structural conditions of healthcare systems: care-support systems are strongly oriented towards older people and children but hardly offer any suitable service for younger adults in need of care. The combination of living circumstances, which are often still characterised by employment and perhaps also children to look after, and the lack of suitable care services present particular hurdles.

Structural solutions are needed for many problems in connection with services for younger people in need of care. The YoungCare project aims to expand knowledge on the topic of care for younger recipients and make it more visible to the public and expert discussions. The YoungCare Project tries to close the existing gap with information and learning materials and to pass on the experiences of other people.



Who needs care?

The target groups of the project YoungCare are young adults in need of care and their informal carers. However, it is helpful to differentiate within the group of younger care recipients, i.e., people aged between 18-65. Some of them, in fact, have been in **need for care since birth or childhood**. Others have had an **accident** or an **illness** that has resulted in new care needs. While most cases are chronic and irreversible, there are also some conditions that **require short-term care**. These illnesses or accidents cause disabilities leaving young adults in need of care. There is no universally accepted definition of disability. Nonetheless, the World Health Organization (WHO) has come up with the following distinctions:

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

With regard to YoungCare, the age range of the group is very large and the causes and courses of care-dependence are also very different. Accordingly, the group is very heterogenous, its 'members' find themselves in disparate life situations and are confronted with different challenges. However, the common problem for this group is that there is a lack of age-appropriate care services.

The number of people in need of care varies in the partner countries but ranges from 5 to 10% of their total population. The exact number of younger people in need of care between the ages of 18-65 could not be established in each country due to the lack of accurate data. For more information on the national level, you can find the national reports on our website.



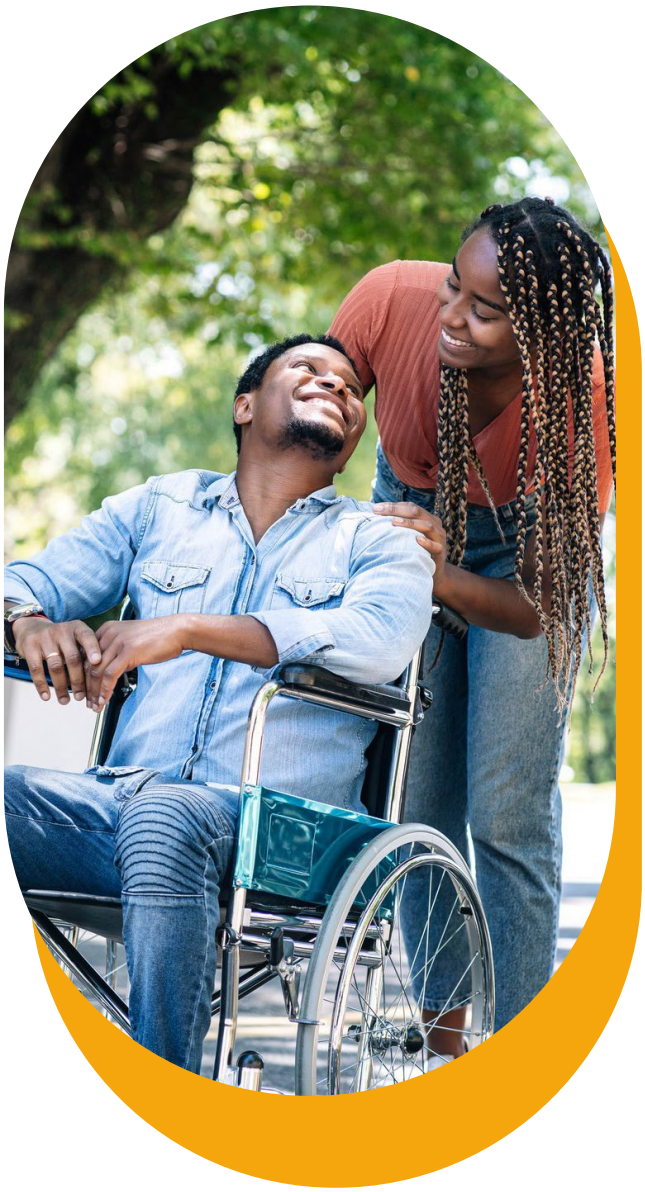
Being an informal caregiver

For the YoungCare project, interviews were conducted with informal caregivers and experts in all partner countries (Italy, Germany, Lithuania, Portugal and the Netherlands). Country-specific peculiarities are recognisable, including different structures of their care systems and social services. However, the interviews showed that many people face similar challenges and problems.

Informal caregiving for younger adults in need of care often causes a great amount of stress. Research findings in all partner countries have shown that informal caregiving has various effects on caregivers. Caregiving is a time-consuming task. Personal freedom, leisure time or even time to pursue one's work may be affected. This also means that financial difficulties and inadequacies are often a side-effect. Caregivers who have a vulnerable socio-economical background have more difficulties in finding time for leisure and work than those who are not financially vulnerable.

Caring for a close relative is often described in the interviews as a major emotional burden that can affect the relationship between carer and relative. The time spent caring for a younger adult impairs a caregiver' social life as it often leaves little or no time for leisure activities.

In the following pages, informal carers and their stories are introduced. They will talk about their challenges, but also about their wishes and suggestions for improvement. In the context of these portraits, we also go into greater detail about the situation in the country where they live. Our aim is to provide helpful information to you as an informal carer or as a person in need of care. Of course, every care situation is very personal and there is no universal solution, and you are the best person to know what helps you and what doesn't. Nonetheless, you may find it helpful to read about the experiences of other informal carers, their personal stories as well as information about organisations that can support you.



The term ‘informal carers’ describes a large group of people who take on care tasks for relatives, friends, neighbours, etc. Every country has its own rules about who is entitled to apply for official support or has the right to take a break from work because they have to care for someone. In Portugal, for example, regulations on informal carers only allow relatives to be informal carers (Decreto-Lei no. 85-A/2022, of 22 December). On the other hand, employees of a mobile care service, for example, are defined as professional carers. The group of informal carers is large and has a relevant share in care activities that are often provided at home: In Germany, for example, 73% of those in need of care are cared for at home. Looking at the YoungCare target group, this percentage is even higher (95%) (bifg, 2023, p. 8). In Portugal, 80% of care is estimated to be provided by informal carers (Teixeira et al., 2017). In the Netherlands, 40% of informal carers look after their parents, 15% a partner and 6% a child (SCP & CBS 2020: IZG2019).

How can this brochure be useful for you?

Are you taking care of someone, or do you want to support someone who cares for others? If you are looking for more information, go to the YoungCare learning platform where you can also find practical and, country-specific support.



Initial diagnosis & understanding the situation

A family member or close relative becoming dependent can be a very shocking experience as it changes both the life of the person in need of care from one day to another and that of those who suddenly have to turn into informal carers. On the other hand, a diagnosis can also confirm existing signs and symptoms and give the disease a concrete name. Accepting the situation may be challenging.

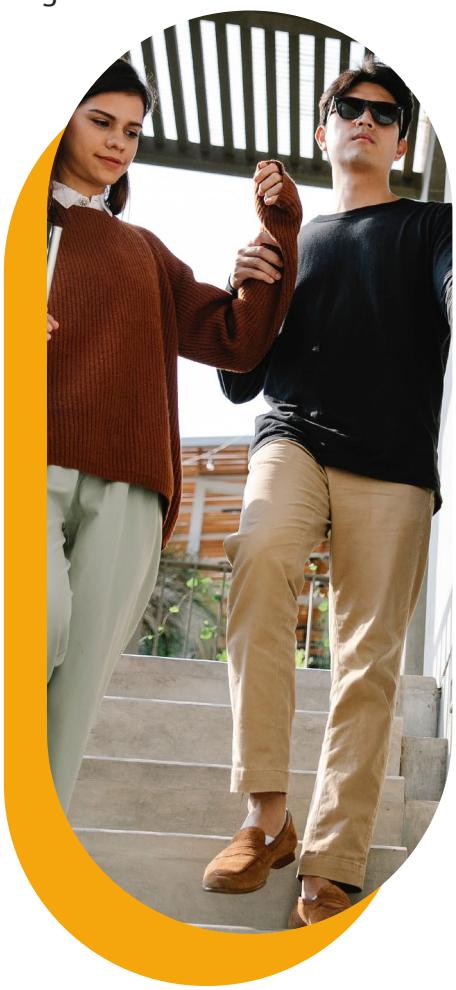
Many of our interviewees described the diagnosis as the beginning of a process during which many things had to be renegotiated, in the relationship as well as in the organisation of everyday life. Understanding the diagnosis is an important step in taking action in this new situation.

Namia (Germany)

Several respondents said that they were overwhelmed by the news and found it difficult to take the first steps. The example of Namia (54) illustrates this. She is the mother of a severely mentally disabled son (33) who she cares for. She found it very difficult to accept his mental disability. However, only after accepting his disability was she able to start looking for help. The care system (social and medical specialist services) was completely unknown to the family until then. She also criticises the expectation of counselling centres whereby clients have prior knowledge of the support services. Finding out about the system was also difficult for her because of her limited language skills due to her migration background. Providing care was a learning process for her.

What are the first steps to take?

There are quite a few challenging things. At first it is hard to accept that a close person has a life-changing medical condition. Understanding and accepting the situation is helpful in order to plan your next steps and reach out for help. This, of course, is easier said than done. Support and help aren't only dependent on your ability to respond fast or not. As shown in the above example, getting to know the healthcare system and available support services can be quite difficult. As discouraging as this may sound, it shows how important it is to accept the situation and inform yourself and reach out for help as soon as possible. Of course, the situation differs from country to country. Bureaucratic hurdles, difficulties in obtaining an official recognition of the need for care, and claiming financial support are often stressful and time consuming.



Info

In many regions there are self-help groups and counselling services, where informal caregivers can get in touch with others in the same situation. Informal caregivers can find these groups and services useful because the situation described above applies to many people who have to deal with care systems and regulations. These groups can help with open questions and provide emotional support. You can find what is on offer here:

LITHUANIA:

- The **website of the Ministry of Social Security and Labour** provides information on the provision of social services to various groups of people, including persons with disabilities and their relatives:
- As far as the provision of **social services** is concerned, a person can apply directly orally, in writing, by mail or e-mail to the municipality of the person's (family's) place of residence or to a social service institution that provides and/or organises social services.

GERMANY:

- **"wir pflegen! e. V. – Die Stimme der pflegenden Angehörigen in Deutschland"** - "Wir-Pflegen! e.V" is an organisation representing the interests of family caregivers throughout Germany as well as self-help organisations. You can find details about it **here**. Among other forms of support, they provide an app called **in.kontakt** to helps caregivers connect with each other online.

- **NAKOS („Nationale Kontakt- und Informationsstelle zur Anregung und Unterstützung von Selbsthilfegruppen")** - NAKOS has been the nationwide information and mediation body in the field of self-help in Germany since 1984. It works on fundamental issues of self-help work, self-help support and promotion. Among others, they offer a database to find self--help groups.

THE NETHERLANDS:

- **MantelzorgNL** is the Dutch national informal care association. Its website features information on various topics, articles, tips and advice.
- **Mantelzorgelijk** is a foundation promoting the interests of informal carers. It provides a platform where caregivers can share their knowledge, experiences, and feelings.
- **Mantelzorg centraal** is a regional centre of expertise for informal carers. This centre works with several informal care organisations. Its platform includes news, information, personal stories, and helpful links to support services.

ITALY:

- **Thematic 'social' area of the Emilia-Romagna region**.
- **ReportER:** Health and Social Policies Information System - Emilia-Romagna Region
- **Georeferenced map** to find your way around local centres and units in Emilia-Romagna
- **Social Co-operation Database**
- **Tax breaks and contributions** for people with disabilities

PORTUGAL:

- "**A Cuidadores**" offers self-help and sharing groups for caregivers in an online face-to-face or telephone format. You can explore these resources **here**.
- Another option is to reach out to **associations** specialising in the diagnosis your care recipient is dealing with or the one you are facing. These associations often provide opportunities to join self-help groups. You can discover relevant associations by visiting the **website**.

Dealing with the diagnosis

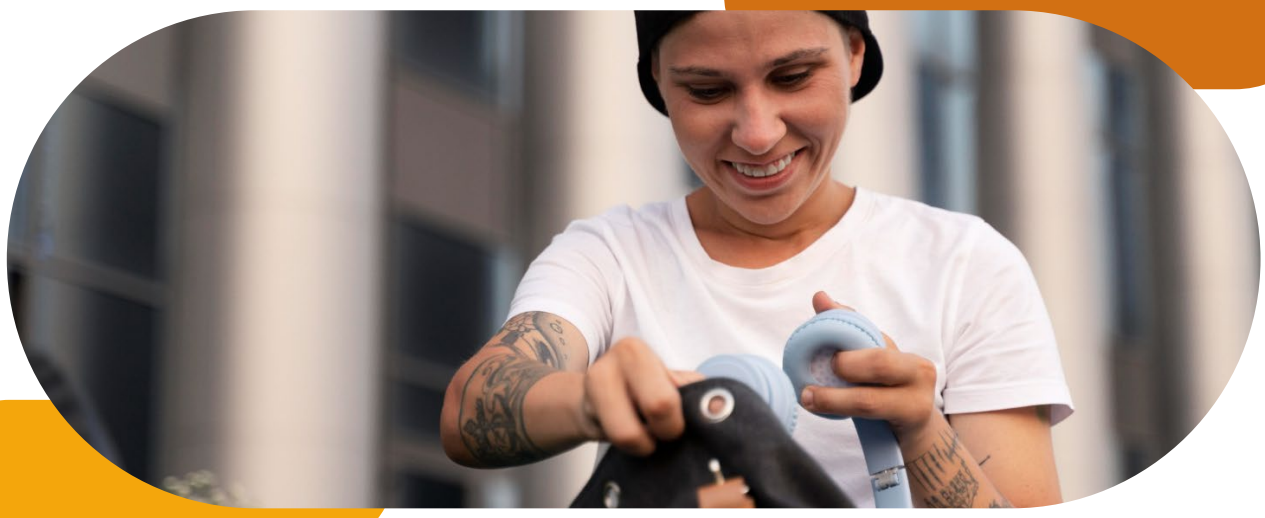
Some of the interviewees reported that it was difficult for them to understand and interpret the medical aspects of the diagnosis. This includes the fact that what the 'course of care-dependency' would be was often unclear to them. They were also not very clear about the challenges this could pose them as informal carers. Some interviewees reported that they were advised to look for professional support based on the medical condition of their close relative. One interviewee from Portugal said: *"This diagnosis is very strong. It affects the body, but it also affects the whole household."*

This interviewee stated that the entire household was affected by the serious diagnosis of a family member, even if he was not initially expecting this. It is useful to ask doctors and other professionals about possible developments of a particular diagnosis. Direct exchange with other informal carers in self-help groups also offers great help as it makes it possible to adopt good strategies and understand the situation better.

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What can you do after the diagnosis?

If you don't know what to do after a diagnosis, an online search is a good way to find potential support. But you should also always consider consulting professionals. An interviewee from the Netherlands said that it is important to ask for and accept help: *"And I notice that many people don't do that. They seem to think: 'I'm doing this for my husband or my child. Why should I ask for help?' But that help is truly necessary because there are moments when you can go and do something else for a while."*



Getting into the system

A proper diagnosis is not only important for you and your family to understand what is happening and what might happen in the future. A diagnosis is also the door opener to obtain official support from the health system. This means that you will be able to enjoy support services or have the right to other measures. However, this does not happen automatically. You will have to fill in applications and understand what your rights are; there will also be many questions and assessments during this process.

This is what a mother from the Netherlands said about the struggles of getting a new wheelchair for her son: *"In terms of healthcare, a lot is possible in the Netherlands. But by the time you receive it, your hair is grey"*.

Contacting people who are already informal carers through support groups can be a good starting point to find out about the support available through the health system. However, for some people this can be more difficult than for others: *"Little by little it's like a treasure hunt, we go from one spot to another and pick something. But it would be so much easier if neurologists or doctors or specialists could recommend an association. Because I have the possibility to go online, to go on the internet. If the same diagnosis had been given to my parents, none of this would have been done."* (Portuguese respondent)

Depending on the condition of the person in need of care, you may also have some support from the very beginning. One Italian family reported that after their 27-year-old child had an accident that left him in need of care for the rest of his life, they received help from the hospital to gain initial access to services and support.



Eva, 76 years old (Lithuania)

Until five years from now Eva cared for her daughter (52) at home for 16 years. Her daughter has psychosocial behaviour problems and, after an accident, has a short-term memory impairment, is partially paralyzed and cannot walk and also has problems orientating herself.

Although it was very difficult for the mother to accept her daughter's sudden disability, after losing her husband and another daughter, she could not give her daughter institutional care, so she took her home and cared for her.

It was very difficult for her to accept the severe disability or her daughter, but she always sought to support her in every way possible. Daily life is always a struggle. She lives on the 4th floor of a block of flats, there is no hoist in the staircase, no lift for people with disabilities, and the flat does not have an accessible bathroom. Her daughter has no opportunity to go outside, even though she wants to.

Five years ago, Eva suffered a broken leg, which made her unable to care for her daughter. Her own medical condition opened the door for her to receive help from a local organisation that provides home-based social daycare for people with disabilities. They help Eva with work in the house and also care for her daughter. Thanks to a social worker from the organization, she received a specialized bed for her daughter, where she can be bathed and given exercise by a physiotherapist.

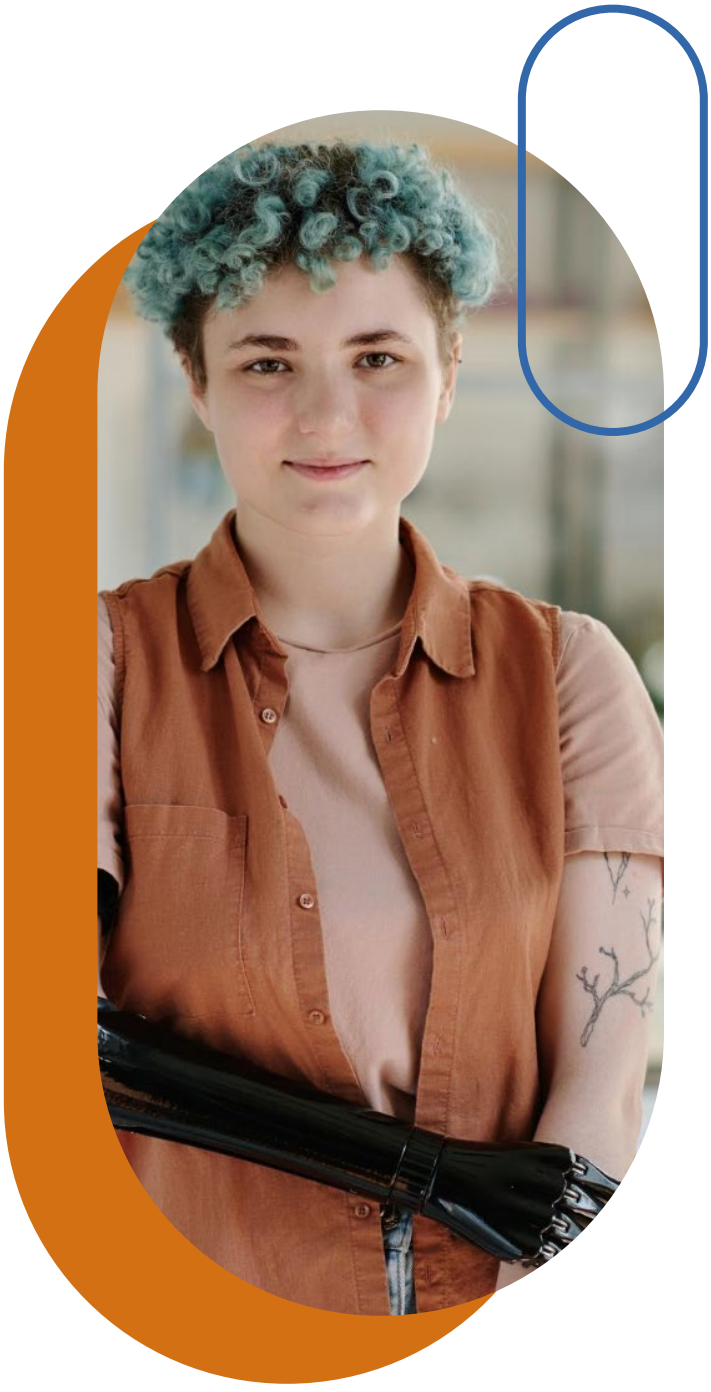
Current situation for younger people in need of care

The type and nature of the support measures depend on the national context but also on the regional offer. This means that younger persons in need of care are not in a worse legal position than others.

However, two aspects in particular pose a challenge for this group of people:

1. The care sector is essentially oriented towards caring for older people. This group is larger in number, and offers are therefore economically more cost-efficient. Therefore, for younger people there is a significant lack of suitable day care, short-term care places, outpatient care measures, etc.. Appropriate care is therefore harder to find. This is why younger people are often cared for with older people. Many people in need of care and their relatives describe this way of caring for younger people inappropriate and stressful.

2. Younger people in need of care and their relatives have a different life from that of older people in need of care. For them it is primarily characterised by participating in the labour market, raising children and often having an active life with many appointments and activities.



Lieke, 56 years old (The Netherlands)

The interviewee was caring for both her now-deceased husband with dementia and her son suffering from Multiple sclerosis (MS).

She only became involved in her son's care at a later stage. He was in a wheelchair but could still do quite a lot. Home care helped him where necessary and together they had a good time. In 2020, he stayed with her for about six months because he was bedridden and needed more care. In October 2022, he needed a new wheelchair. This was because he had an open wound that was probably caused by the wheelchair. However, getting a new wheelchair is not easy.

Thanks to the neurologist, she was assigned a case manager for her husband. However, no case manager was assigned for her son because case managers are for older people. Young people are on their own. Even a general practitioner (GP) could not provide that. Only if you live in an institution you can get something similar in terms of support.

According to her, you have to dare to ask for help and dare to accept help. She noticed that many people don't do that. They seem to think 'I'm doing this for my husband or child, why should I ask for help with that?'

Stigmas and discrimination

People with disabilities are often stigmatised in society. This stigmatisation can also extend to the people who are close to that person (Stewart et.al. 2018). Informal care for a disabled person is thus accompanied by various stigmas and discriminations. This can be very hurtful and stressful and can have an impact on daily life. You too may have experienced these situations as an informal carer. Social awareness is necessary to accept people with disabilities in society. People with disabilities should be accepted and included in society and not stigmatised as described by a German interviewee with care needs:

"Many people also react alienatingly. [...] With negative comments. [...] We were doing some exercises to boost our respiratory systems and had to rest (leaning against a lantern to get better air) when a woman said to her child "They must have been drinking" and pulled her child away."

Situations like this can be damaging or even traumatising, causing people to avoid social interactions and certain situations. The example of an Italian woman who informally cares for her daughter illustrates this dilemma. She describes her caregiving role as quite tiring and lonely, not least because of the feeling of guilt that has always accompanied her. In fact, she has always felt responsible for her daughter's disability and has been afraid of exposing her to social stigma because of personal and family experiences related to shame. Perhaps you have also felt this way in similar circumstances.

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How can you address stigma and discrimination against people in need of care?

First of all, it should not be your task or responsibility to break down prejudices against people in need of care. However, because of your role as an informal caregiver, you are also an expert, at least for the specific situation that concerns you and the person you care for. Nevertheless, you can try to counter some preconceptions about the impairment of the individual in need of care by talking about your everyday life as an informal caregiver in your family or your closer social environment. Although this can reduce some prejudices, a lot depends on how open people are to the subject. It can also help to avoid isolating yourself or the person facing the social stigma. Of course, this is easier said than done and does not mean that harmful or negative experiences will no longer occur.

Communication

A care situation brings with it great responsibility and makes it necessary to make decisions for oneself and, if necessary, also for the care recipient. Of course, this is strongly dependent on the type of impairment and, above all, on the communicative and cognitive abilities of the person in need of care. Therefore, it is important to talk to care recipients and find out what their needs are. What kind of help do they need? What would they like to do themselves?

In some cases, verbal communication is affected by the condition of the care receiver. If this is the case, it can be a great challenge to adapt communication with each other so that the boundaries, wishes and needs of the person in need of care can be understood. As with the other aspects of caring for young adults, it is difficult to find information and help. Finding the right balance between serious communication/interaction and consistent care is certainly not easy.

> *"[...] the person in a wheelchair is just as important as the person behind them. And if, for example, you are pushing someone in a wheelchair and have to go up a pavement, tell them what you are going to do. After all, it's convenient for the person to drive backwards down the pavement but say that first. And the care receiver should remain in control, especially if they can mentally handle it."* (Interviewee from the Netherlands).





What could good communication look like?

Communication with a relative that has become care dependent can be challenging. In some cases, the familiar way of dealing with each other cannot be maintained. Adapting communication is not easy, as it is also a very emotional process, especially if the person in question is very close to you. The following advice can be helpful if you have problems communicating with the care recipient:

- Accessible communication. Ensure your communication relates to the individual's specific disability. For example, use sign language with people who are deaf or use written communication with those with oral impairment.
- Ask about preferences. Ask individuals about their preferred communication methods and support needs. This helps tailor your approach to their specific requirements.
- Use plain Language. Avoid using jargon, complex language, or abstract concepts. Use plain and straightforward language to ensure clarity.
- Visual supports. Visual aids like picture boards or communication cards can assist those with cognitive disabilities as they can help convey information or choices.
- Non-verbal communication. Pay attention to non-verbal cues, such as facial expressions and body language, as these can be significant for individuals who have problems with verbal communication.
- Active listening. Be an active listener, showing that you are genuinely interested in what the person is saying. This helps build trust.
- Patience. Individuals with disabilities may require more time to process and respond to information. Be patient and give them the necessary time to communicate.

Conflicts

Autonomy and the ability to make independent decisions are essential values that we associate with adult life and, in our perception, distinguish this stage of life from other stages. A care situation changes these values for everyone involved. While the person in need of care becomes dependent on support, the carer, at least in part, becomes responsible for this support. This is an area of conflict highlighted by many interviewees.

A Dutch couple (with the wife caring for her husband) mentioned that they had to adapt the way they communicated and interacted after his diagnosis of Multiple Sclerosis (MS). They also spoke about meeting other couples who had problems during their new situation, really hurting or even ending their relationships. The partners needed to learn again how to deal with each other, what their needs were, what they could and couldn't do, and where they needed help. They even recommended a communication training. The interaction between the informal carer and the care recipient is thus very important for the relationship and the care itself. Taking the diagnosis and situation seriously also implies finding a form of interaction that suits the situation.

Thomas Sanders (The Netherlands)

Thomas describes that it was difficult for him to ask for help. After being diagnosed with MS, he wanted to be in control of his life and felt the urge to develop initiatives to fight the disease. He describes how he went from surprise to denial and then to anger and frustration. It took him several years to accept that he needed a wheelchair. Because MS is a degenerative disease, he still struggles with his growing dependence. He also wrote a book about his struggles ("Achteruit lopen").

His story is a good example when it comes to asking for and receiving help from family, friends or neighbours. The same problem is expressed by several other respondents who state that they want to retain as much control over their lives as possible. A study on people in need of care in the Netherlands also showed that Dutch people value their independence very much. They are embarrassed to ask their relatives for help because they want to protect the nature of their relationship and are afraid of overburdening them.

How to avoid conflicts

We also collected some advice that could help avoid conflicts with the person you care for:

Open communication
- Encourage open and honest communication.
- Create a safe space where both parties feel comfortable expressing their thoughts and feelings.
- Regularly check in with each other to discuss concerns, expectations, and any change in the caregiving arrangement.

Set clear expectations
- Establish clear expectations and boundaries from the beginning. Discuss roles, responsibilities, and the level of care needed to avoid misunderstandings.

Respect and Empathy
- Foster empathy and understanding.
- Recognise that both the caregiver and care recipient may be facing challenges, and approach situations with patience and compassion.

Involve Care Recipients
- Include care recipients in decision-making whenever possible. Allowing them to voice their preferences and concerns can help prevent conflicts and empower them in their care.

Support for caregivers
- Ensure that caregivers have access to support, resources, and respite care and self-care. Avoiding burnout is crucial for maintaining a positive caregiving relationship.

Flexible approach
- Recognise that caregiving needs may change over time. Remain flexible and adapt the caregiving plan as necessary to accommodate the evolving needs of the recipient.

Promote Independence
- Encourage care recipients to maintain as much independence as possible. This can help reduce feelings of frustration and dependency, contributing to a more positive relationship.

Seek professional advice
- If conflicts arise, consider seeking the advice of a professional, such as a counsellor or social worker. They can provide guidance and strategies for managing difficult situations.

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Do you also experience similar situations as described in the examples above?

Especially in relation to younger care recipients and their relatives, there seem to be particular hurdles. The children, employment, career, perhaps loans and various other aspects can further exacerbate a care situation.

Self-care

In many ways informal care for young adults is both physically and mentally exhausting, time-consuming and financially difficult. Maybe you too have experienced these problems. Perhaps you feel alone and burnt out. These conditions can affect your own health and well-being in the long run. Without neglecting the importance of caring for a close relative, your own health as an informal carer should not be underestimated.



In an interview, a caregiving wife emphasises how important her own free time and independence are to her, even though she has to care for her husband: *"In my case, because of the domestic situation, the glass is always half full and therefore overflows more quickly than, for example, in the case of colleagues who are not carers."* As a caregiver, she finds that almost everyone focuses on the person in need of care all the time and how they are doing. Almost no one asks her how she is doing. She emphasises that carers too are very important and says that she has learned to say "no" sometimes and to do more at work again.

"Does it make me happy? If the answer is yes, then I do it." She has had coaching to help balance her own needs with caring for her husband. This is partly because her husband is still quite independent and public transport is close to where they live. Not everyone can provide care in these circumstances. It can be helpful to find out when help is needed.

Where can you find psychological care?

Caring for people who need your help for a lot of aspects of their lives, if not day and night, is very demanding, both physically and psychologically. Many interviewees have reported that they ignored the impacts of being an informal carer on themselves. An interviewee from Italy for example told us that she had never thought of being psychologically supported. She has now realised that it would definitely have been useful, also because her husband never supported her when looking after their child. She was the only one managing the life of her child alongside her own life. This type of stressful situation should not be taken lightly. You can find offers for psychologically support here:

LITHUANIA:

- Psychological and emotional help provided by phone: **Emocinė ir psichologinė pagalba telefonu | Bendrasis pagalbos centras (lrv.lt)**
- **This support is also available in primary health care centres**

GERMANY:

- **Pflegen-und-leben.de** is a non-profit psychological counselling service for carers and families. People with statutory health insurance who care for loved ones receive personalised help from specially trained psychologists. You can find them **here**.
- **116 117** is the telephone number of the nationwide medical on-call service that helps you to find a doctor and psychologist. There is also an **online database**. As a member of the statutory health insurance, you can also book an appointment at a doctor or psychologist **here**.

THE NETHERLANDS:

- Informal carers in the Netherlands are entitled **to professional psychological support.** This is covered by **basic insurance** up to 10 hours per year. Informal carers can visit their GPs and discuss their needs for support. GPs can then refer them to a psychologist or coach.
- **Kompassie** offers informal care support through family coaches who can provide guidance, advice, and information as well as a listening ear. Using a family coach is entirely cost-free and there is no waiting list.
- **MantelzorgNL** has a national informal care helpline for all questions and problems: **030 – 760 60 55** (phone calls), 06 **27 23 68 54** (WhatsApp), **mantelzorglijn@mantelzorg.nl.**

ITALY:

- **Thematic area 'social' of the Emilia-Romagna region.**
- **ReportER:** Health and Social Policies Information System - Emilia-Romagna Region
- **Georeferenced map** to find your way around the territorial branches in Emilia-Romagna.
- **Social Co-operation Database.**
- **Tax breaks and contributions for people with disabilities**.

PORTUGAL:

- The **National Association of Informal Caregivers** has established partnerships (check **here**) to offer psychological support for free or at a reduced price to informal caregivers.
- "**A Cuidadores**" also provide emotional support services to informal caregivers, in person, online, or over the phone.
- A more general option for informal caregivers, which can be helpful in crisis situations, is to contact the **Linha de Saúde 24** from Sistema Nacional de Saúde at **808 24 24 24**. This helpline is free. These healthcare professionals specialise in providing psychological intervention in challenging situations.

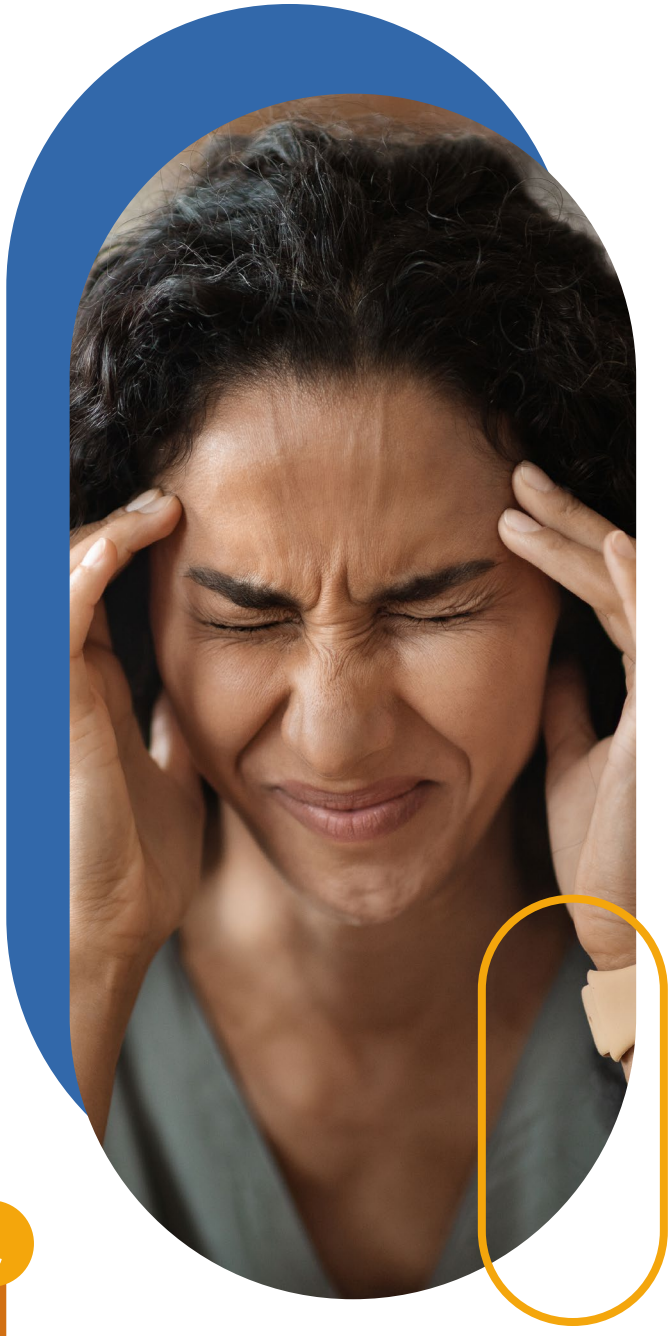


Respect your own health!

Caregiving tasks and particularly stressful circumstances such as lack of free time or money worries can be serious health risks. Many different experiences were reported in the interviews. Burnouts and depression were reported by our partners. Some carers also mentioned the fact that they should have reached out for help earlier.

A mother who takes care of her children spoke about her burnout. The treatment in an inpatient clinic helped her a lot. Do not be ashamed to be treated for an illness while caring for someone, because your own health is important too. The following is an example:

A caregiver caring for her husband recalled that her own health had become a secondary factor. She suffered injuries in a car accident and later developed breast cancer. She returned to work far too early and her role as an informal carer also had an additional impact on her health. During this time, she learned that, as a caregiver, you have to take care of yourself before you can help another person: “Listen to your body.”



Statistics show that many caregivers are female. In all countries participating in the study, women are much more involved in looking after relatives in need of care, especially when it comes to their own children (Eurostat, 2022).

Maria (Germany)

Maria (56) looks after her two adult sons (28 and 23), who have been both diagnosed with autism spectrum disorder. Her husband lives in the same household, but she is practically the only one to care for them. Although the disability is congenital, the older son's diagnosis was not confirmed until he was an adult. Both sons live at home and have difficulties maintaining social relationships and dealing with multiple stimuli.

Maria is under a lot of stress (burn-out) because of her sons' disabilities and all the caring she is doing. Besides, she is deeply concerned about the future of her children. In order to prepare their sons for a more independent life, she has sought the help of a supervisor. The older son has already acquired some skills (cooking, ironing, cleaning). The same thing is planned for the younger son in the near future. After her burn-out, she also looked for external help and was offered treatment in a rehabilitation clinic that has helped her a lot. She is currently looking for shared accommodation for caring parents and their children in Germany, but hasn't been successful yet.

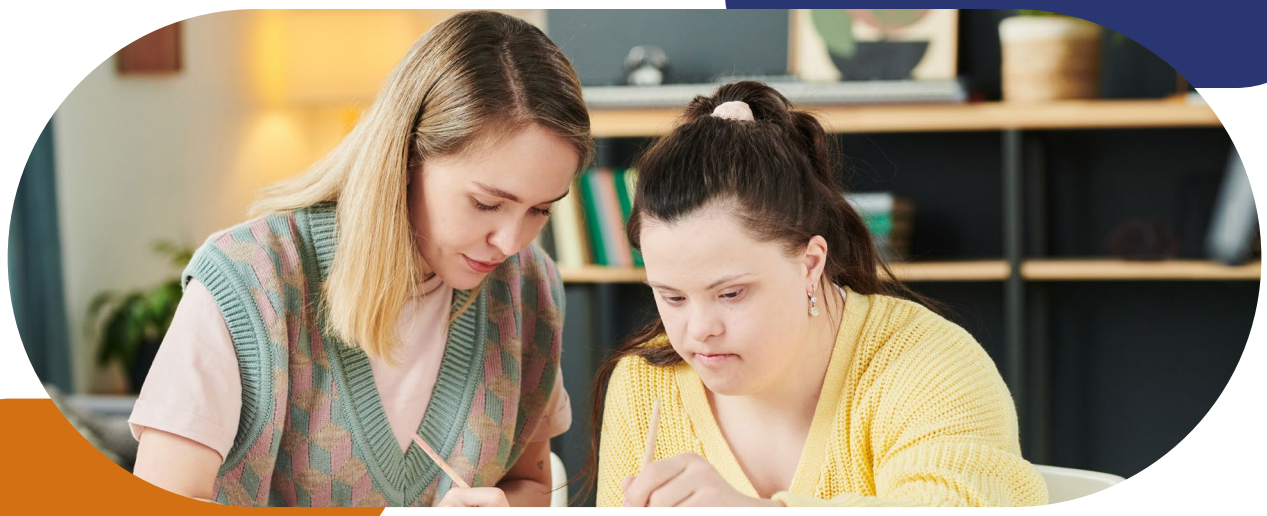
Considering external help

As a carer, it is important for you to know when the person in need of care is able to be independent without needing or even wanting assistance. Clarifying this can help to relieve you of certain tasks thus gaining some time for yourself. Another option that many carers who have been interviewed resort to is getting help from family members. For example, one carer mentioned that he has asked her mother-in-law to take care of her daughter one week a month. Asking family members, friends or other social contacts should not make you feel ashamed or uncomfortable. Talking to other people about the condition of a family member in need of care is not easy. However, if there are people among your contacts who are open-minded and helpful, talking about your situation may make them truly aware of what is going on and might be able to support you.

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Is it possible for you to take a break?

It is important that, from time to time, you take a break from caring. Of course any such break has to suit your personal situation and the care needs that need to be met. Do not be afraid to ask for professional services that can reduce your burden a little. Some interviewees have stated that they use short-term care services to look after family members. A huge relief can be a mobile service or day care centre that takes over home tasks (as mentioned in page 17 for example).



Have you already used these services and do you know about the legal framework?

You can find information here:

LITHUANIA

- Relatives of children with disabilities, adults with disabilities or elderly people who are receiving care or need constant supervision can apply to municipalities for a **respite service**. The service can be provided at home, in a day centre or in a social care institution:

GERMANY

- **ZQP („Zentrum für Qualität in der Pflege“)** - Das ZQP provides a lot of information, which can also be sent free of charge, on all aspects of caring at home. The ZQP is a nationwide, non-profit foundation whose **website.**
- **Pflegestützpunkte** - Members of the statutory health insurance are entitled to free and independent counselling on all topics of social care insurance through their local “Pflegestützpunkt” (care support centre). You can find your local “Pflegestützpunkt” among other counselling centres in this **database**.
- Members of private health insurance can find information on the care insurance **here**.

THE NETHERLANDS

- Information on respite care, such as help at home, day care, or homestay, can be found on the **regelhulp page of the VWS (Ministry of Public Health, Welfare and Sport)**.
- On the **website of MantelzorgNL** you can consult a guide to help you find the right support services.

ITALY

- **Thematic area ‘social’ of the Emilia-Romagna region**.
- **ReportER:** Health and Social Policies Information System - Emilia-Romagna Region
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PORTUGAL

- You can find information on accessing the “**Descanso do Cuidador Informal**” (Informal Caregiver’s Rest) at the following **link**.
- For more details on specific conditions, refer to pages 13, 14, and 37 of the **“Guia Prático – Estatuto do Cuidador Informal: cuidador informal principal e cuidador informal não principal”** (Practical Guide - Statute of the Informal Caregiver: main and secondary informal caregiver). Please click **here**.

Life and work balance

As we already mentioned and as you possibly already know, performing informal care is very time consuming. Caregivers commonly alter or reduce their work schedules, decline promotions, assume less-demanding jobs, retire early or quit their jobs entirely to fulfil caregiving commitments (Žmonių turinčių negalią, 2022, p.77). Especially when care is performed more than once a week, the numbers of hours of paid work is drastically reduced. Sometimes there isn't even time to work at all. The effects of intensive caregiving on employment status and work hours are stronger for women than for men (Ciccarelli & van Soest, 2023, p. 365).

Almost all caregivers from Germany were women and had either given up their paid work or dealt with the double burden of working and caring, sometimes at the same time: *"I then called him from work several times a day to prevent food from being forgotten on the cooker or avert some other incident because it had been burnt. Luckily nothing serious ever happened."* (Wife caring for her husband who had a stroke).

In most European countries, there are opportunities to receive help in these circumstances. You can find examples from our partner countries below. However, although those offers can be helpful to a certain degree, they often cannot fully compensate for the lack of paid work and can cause problems afterwards:



LITHUANIA

Lithuania is one of the countries with an innovative approach to labour market policy. On request of an employee taking care of a sick family member, part-time work may be granted once a healthcare institution has given its favourable opinion (Labour Code, Article 146). Part-time work, in other words reducing the number of working days per week or shortening the typical working day (shift), may also be agreed between employers and employees. Unpaid leave for up to 30 days a year can be granted to an employee taking care of a sick family member (Article 184). The period of care is taken into account when the annual leave an employee is entitled to is calculated (Article 170). Employees who take care of sick or disabled family members have greater flexibility in choosing when to take their annual leave (Article 169) (Daugėlienė et al., 2023, p. 13).



GERMANY

"Familienpflegezeit"

With the Act to Improve the Compatibility of Family, Care and Work, which came into force on 1 January 2015, the existing regulations in the Caregiver Leave Act (PflegeZG) and the Family Caregiver Leave Act (FPfZG) were further developed and better dovetailed. Not only can employees take six months' full or partial leave from work to care for a close relative at home (care leave), but they are also legally entitled to partial leave of up to 24 months with a minimum working week of 15 hours (family care leave).
Employees can apply for an interest-free

loan from the Federal Office of Family Affairs and Civil Society Functions (BAFzA) for the period of time during which they take time off work to provide care. It is paid out in monthly instalments and is intended to help cushion the loss of earnings. The interest-free loan must also be repaid in instalments at the end of the leave of absence (Bundesamt für Familie und zivilgesellschaftliche Aufgaben, 2023).



NETHERLANDS

Informal caregivers have the right to take care leave from work. Each year they are entitled to twice the number of hours they work per week at 70% of their salary. Long-term care leave can be taken for six times the number of hours someone works per week every year, but payment is not required (Rijksoverheid, last access January 2024).



PORTUGAL

According to the Statute of the Informal Caregiver (Estatuto do Cuidador Informal), informal caregivers are entitled to rest periods to promote their well-being and emotional balance. Under the "descanso do cuidador" within the framework of the National Network of Integrated Continuous Care (Rede Nacional de Cuidados Continuados Integrados or RNCCI), a set of interventions is provided to offer caregivers relief or effective rest, temporarily releasing them from caregiving duties. The objective is to reduce caregiver overload, or the quantity of care provided, allowing them to recharge their batteries, attend to personal and/or health matters, etc. In Long-Term Care Units, caregiver rest is facilitated through the temporary hospitalisation of the dependent person, with a maximum period of 90 days per year.

In Mental Health typologies there is also provision to admit care recipients to give a break to caregivers for up to 45 days per year.



ITALY

Law No. 104 of 5 February 1992 sanctions the rights for several categories of persons with disability. In relation to caregivers, Law No. 104 grants the right to take paid leave from work for three full days per month or the equivalent in hourly periods of time by submitting an application to the employers in the form of self-certification documenting the condition of the person for whom care is to be provided.

In addition to paid leave, cohabiting family members of the person with a certificate of serious disability (Law 104/1992) are entitled to paid leave for up to two consecutive or non-consecutive years (Legislative Decree 151/2001, Article 42).

Moreover, early retirement is a financial benefit for certain categories of workers until they reach retirement age. The categories that can apply for it include caregivers who have been assisting for at least six months a spouse or first-degree cohabiting relatives with a severe disability.

Adaptation of Housing

The severity of the medical condition of the person you care for can vary. Very often, though, life is no longer what it used to be. Structurally, there is a lack of suitable housing for young adults in need of care. This applies both to young adults who want to become independent, but also to adults in need of care who want to maintain their independence as long as possible. Therefore, most of the time, caring takes place at home where obstacles and barriers 'materialise' after a disabling event. The place where the person with an acquired disability lives can become a major obstacle for restoring acceptable living conditions. Redesigning the living space to be barrier-free and introducing some adaptations may become necessary to ease the daily struggle for the person in need of care as well as for yourself as an informal carer. It is necessary for people to start arranging their homes at an early stage. This is due to long waiting lists for adapted housing that are the reality in the most European countries.

Further information on this topic can be found on our website: https://youngcare.eu/



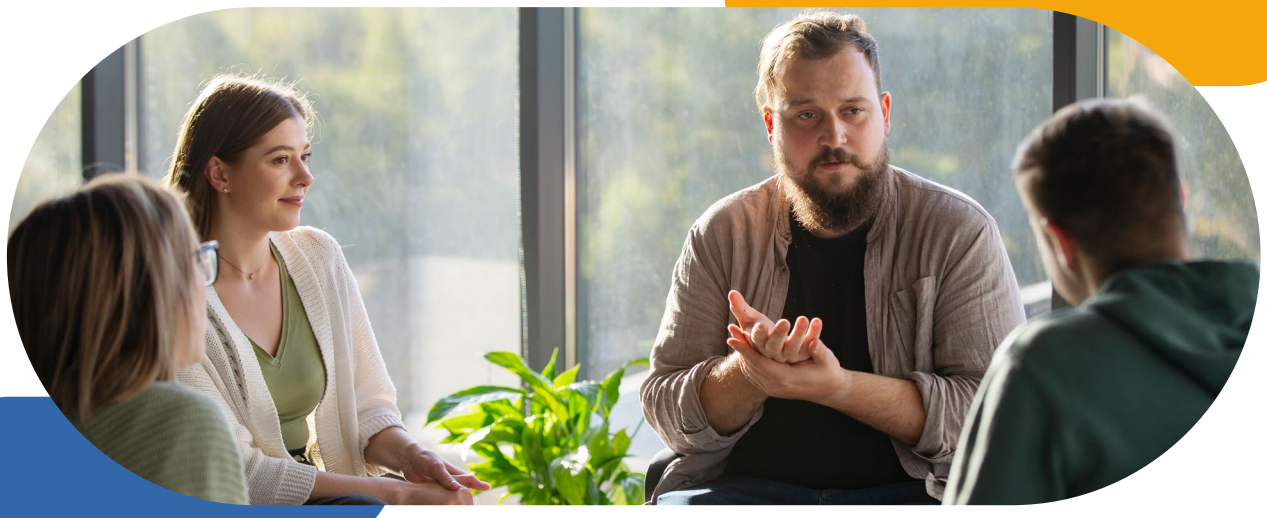
Self-help groups

One of the major takeaways of the interviews with other informal carers was the need for support from and the exchange with others. Connecting with other people in similar situations is one possible way to better cope with your own situation.

> *"It is wonderful to meet people with the same illness, the same disease, some in more advanced stages than others, but sometimes accompanied... This community is fundamental."* (Interviewee from Portugal)

As difficult as the situation may be, connecting with other people in the same circumstances can be very helpful. Sharing experiences can be very useful. Other people may have found solutions to similar problems and can help others with their experiences. They may know where to go for professional help you were not aware of before. Simply listening and talking to each other among people who know how you feel can be a great help.

Many interviewees regretted that they never reached out for professional help or connected with others sharing the same struggle. Exchanges with other informal carers can be very valuable in many different ways. Whether you have just received the diagnosis or have performed informal care for a longer time, it is good to talk to people who know how you feel and what you are struggling with.



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