



The Netherlands Institute  
for Social Research

# Informal carers in focus

Policy report on informal care  
in the Netherlands



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Policy report on informal care in the Netherlands

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The Netherlands Institute for Social Research (SCP) is a government scientific institute that carries out socio-scientific research both on request and on its own initiative. SCP reports to the Dutch government, both Houses of Parliament, government ministries and civil-society and public authority organisations. SCP falls under the formal responsibility of the Dutch Minister of Health, Welfare and Sport. The Institute was founded by Royal Decree on 30 March 1973.

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## Summary and conclusions

Informal care (regarded here as all help provided to a sick, disabled or frail person by someone in their immediate social setting) is indispensable. In this publication we discuss a number of important policy themes that are relevant for informal care, based on the knowledge gathered on this topic by the Netherlands Institute for Social Research (SCP). Those themes are the willingness and ability to provide informal care, informal caregiver burden and support for informal carers – three themes which are directly linked to the ability of informal carers to provide care and the conditions to enable them to do so.

The willingness of many people to help each other is evident among other things from the fact that around one in three Dutch citizens provide informal care, a figure that has not changed in recent years. Although there is a great willingness to provide help, especially to close family members, there are also limits beyond which informal carers cannot provide (more) help. These are issues with which informal carers themselves also wrestle, such as lack of time, subjective burden, lack of competence or a care recipient who is unwilling to receive informal care. How much more informal care is possible is therefore a moot point. Many informal carers are doing well, and derive great satisfaction from the help they provide. Around one in ten experience a high ‘caregiver burden’; this manifests itself in a variety of ways, such as health problems, high time pressure, absenteeism from work or faltering study results. This can also have consequences for those receiving the help; informal carers who face excessive demands are at risk of losing their patience if the care recipient exhibits difficult behaviour. People often associate caregiver burden with helping someone with dementia or memory problems. Dementia does indeed make informal caregiving very stressful, but informal carers of people with mental health problems, those helping someone with a terminal illness, those caring for a partner and those providing intensive informal care are also at risk of caregiver overburden.

There are several ways of reducing this burden, for example sharing the help with other informal or professional carers. This collaboration often works well, but there is also room for improvement, especially as regards recognising the importance of informal carers or sharing information. Home care workers, as well as general practitioners, could fulfil a signalling function here, advising informal carers who are (in danger of becoming) heavily burdened to organise (more) help and informing them about available support. One in five informal carers is not able to share the help they provide with others. This group of ‘sole carers’ often includes people caring for a partner or child, partly because the person receiving the help is unwilling to accept it from anyone else, or because no one else is available. Dutch local authorities have a duty to support informal carers. This support may include measures to reduce the caregiver burden (e.g. respite care and financial or material help) and measures to increase caregiver resilience (e.g. courses, information and advice, contact with other caregivers). The take-up of support is low, partly because of the difficulty in

finding the available support: a quarter of informal carers who are not receiving support but would like to, do not know how or where to access it.

Employers can also play a role in supporting informal carers; there are facilities for care leave and there is legislation which allows for flexible working. However, little use is made of leave arrangements, and not every employment situation lends itself to flexible working hours. Moreover, not every informal carer needs this kind of support. Contact with and understanding from line managers is found to be an important form of support. A key aspect of this is the ability to discuss the informal care openly, for example in progress interviews at work or mentor meetings at school, so that the informal carer is not afraid to go to their manager if they have questions about it. Young informal carers who are still in education also value being able to discuss their situation and being treated with understanding. It is thus necessary to continue investing in 'informal carer-friendly' employment organisations and education establishments, where people who are providing help to loved ones can engage in dialogue in a bid to find a solution for their situation when necessary. This helps both working and studying informal carers to continue functioning adequately, both at work and at home.

### Reflection

The situation described above illustrates that many people are providing help to sick, frail or disabled loved ones, and that this often does not create any problems. This study found that there are also people who are not currently providing help, but who might be prepared to do so. In 2016, a quarter of these 'non-helpers' said they would be prepared and able to help: they are willing, have the time and have no health problems. It is worth noting here that this is what respondents say; it is not easy to gauge whether they would actually provide help in practice. People may be inclined to provide help, but of course need to know someone who needs help or recognise a need for help. Impediments to providing help can be caused by uncertainty and indecisiveness: suppose someone took offence at being offered help? And do people know what kind of help they could provide? People could be made more aware of the importance of informal care, and inaccurate perceptions about informal caregiving could be removed, for example the idea that informal caregiving is mandatory and that what it comes down to in practice is 'washing the neighbour's backside'. The fact that some people are not willing or able to help or do not see the need for help is not a problem if other people from the recipient's network step in or if paid help is an option. Technology and home adaptations can sometimes also offer a solution. If there are no other options, (publicly funded) professional home care services can be used as a last resort. However, it is also possible that the recipient receives less help than they would like.

To persuade people to begin providing help, it is important to take into account their limitations, such as their time and health, but also the things they are and are not willing to do and for whom, and what knowledge and skills are needed for this. We can learn a great deal in this regard from people who are currently providing help and some of whom run up

against their own limitations on a daily basis, for example as regards the conditions enabling them to provide help in a responsible way.

The pressure on informal care is expected to increase in the coming years, and consequently also the burden associated with it. This view is supported in projections by the Netherlands Institute for Social Research (SCP) and the Netherlands Environmental Assessment Agency (PBL), which predict that there will be fewer caregivers per care recipient in the future (Kooiker et al. 2019). The growing pressure will manifest itself among others in older people who will increasingly begin caring for their partner or peers. The shrinking pool of potential informal carers also means they will more often be the sole helper, increasing the risk that no one is looking out for their well-being. The pressure will be felt most acutely in regions with a contracting population, where the relative share of older persons will increase more than elsewhere. This in turn raises another issue, concerning the regional differences in informal care and informal carer support, and what alternatives are available if there is not enough informal care available. Can people who need help then turn to professional care (in their home setting or in an institution)? And how much scope is there for volunteers and local community initiatives?

It is in fact uncertain whether the solution to the problems associated with (potential) informal carers always lies in formal forms of support. Informal carers themselves also have a responsibility (knowing where their limitations lie), as do the people they are caring for (who will sometimes have to accept care from others). But it is not always easy to set these boundaries, and some people feel trapped: 'if I don't do it, there's no one else'. When it comes to combining work and informal caregiving, the opportunities for care leave and more flexible working hours were recently expanded. It is however known that work can also be a resource, providing a distraction, social contacts and of course an income. Accordingly, informal carers do not always want to adapt their work to enable them to provide care. The question of how informal carers can continue working appears to attract less interest than the question of how those in work can 'bolt on' informal caregiving. To be able to continue working, therefore, flexible working hours and leave appear not to be the only important factors in easing the care burden, especially if the leave is unpaid. More home care or respite care are also important, as are strengthening caregiver competences, giving them recognition and clarity about the tasks and the sharing of information, for example allowing them sight of the care recipient's Personal Health Environment. These are solutions which are beyond the control of employers and which demand a broader discussion encompassing both work and care solutions.

### Gaps in knowledge

We have learned a great deal in recent years about informal carers and the help they provide, but there are also gaps in our knowledge. For example, we still know little about specific groups of informal carers who are potentially vulnerable, such as those with a migration background and older carers. If we knew whether they feel they have sufficient access

to support, whether that support meets their needs and to what extent it prevents informal care from being an obstacle to other forms of participation (e.g. work, study, social contacts, sport), we would be able to make a useful differentiation in support. We also need a greater understanding of the effectiveness of interventions such as informal carer support.

A further area for attention is the prevention of caregiver overburden. SCP has been monitoring trends for some years in areas such as the subjective informal caregiver burden, but research on how this burden develops over the longer term and the factors associated with it is not available. Longitudinal research is important in view of the fact that people often provide care over a period of several years. This type of research could also make clear whether support provided by the network, employer, school or care professionals at certain points in the caregiving process is needed or useful, and thus how best to prevent overburden.

All this makes clear that, 25 years after the establishment of the Dutch National Organisation of Home Carers (Stichting LOT), attention is still needed for informal carers and their support. The pressure on informal carers is expected to increase in the coming years due to older people with complex health problems and more chronic diseases living at home for longer, the reducing number of caregivers per care recipient, professional care staff shortages and the rising costs of care. All this means it is important to keep informal carers in focus.



## 1 Pressure on informal carers

On 10 November each year, the Netherlands marks ‘Informal Care Day’. Against the backdrop of this commemoration, the Netherlands Institute for Social Research (SCP) focuses attention on informal carers in this publication, which is based on knowledge garnered on this topic over recent years. Another reason for this is to highlight the progress made over the last 25 years in the emancipation of informal carers. The National Organisation of Home Carers (Stichting LOT) was established in 1994 by a small group of relatives of people who needed support. They were the first in the Netherlands to put the focus on the informal carer as an individual rather than as an extension of the care recipient. Stichting LOT was the forerunner of what later became Mezzo, and what is today referred to as MantelzorgNL, a national association for informal and volunteer carers which is funded by the Dutch Ministry of Health, Welfare and Sport. They are advocates for the recognition of and support for informal carers in all kinds of ways. Not everyone appreciates the term ‘informal care’, seeing it as policy jargon which people who are caring for their loved ones do not feel pertains to them), but it is in such common usage that SCP also uses the term.<sup>1</sup>

The number of older people in the population will increase in the coming years. Moreover, older people are living independently for longer, even if they have complex health problems such as several chronic diseases. There are concerns as to whether there will be enough people to help them in the future (Kooiker et al. 2019). In the Speech from the Throne in 2018, the Dutch King wondered aloud whether people in the Netherlands are living *with* each other sufficiently or are rather living too much *alongside* each other. It is clear that in the near future there will be fewer informal carers to perform the care tasks collectively, whereas they will often have to combine these tasks with other activities such as paid work, education or looking after a family. In the case of partners helping each other, they themselves will be older and perhaps less physically or mentally fit. The growing staff shortages in the care sector show that information on the contribution made by informal carers is becoming ever more important (Daalhuizen et al. 2019). Placing too many demands on informal carers could lead to overburden. The government recognises this and has developed policy to support informal carers, as set out in the Social Support Act 2015 (Wmo 2015). It is up to local authorities to implement this policy: they are responsible for advising and supporting informal carers. The Dutch government has also developed regulation to make it easier to combine informal caregiving with paid work, for example care leave and the Flexible Employment Act (Wet flexibel werken).

Developments are also taking place in the field, as a few examples will illustrate. The Work & Informal Care Foundation (Stichting Werk & Mantelzorg), which is jointly financed by the Ministry of Health, Welfare and Sport and the Ministry of Social Affairs and Employment, encourages employers to make efforts to earn the label ‘informal care-friendly’, so that employees are better able to combine their work with informal care tasks. Helped by a

grant from the Netherlands Organisation for Health Research and Development (ZonMw), and in collaboration with the Dutch nurses' and carers' association (v&vn), a guideline on setting quality standards for informal caregiver burden is currently being developed for nurses and caregivers ('Richtlijn overbelaste mantelzorg'). In January 2019 the National Student Welfare Network (Landelijk Netwerk Studentenwelzijn) called for attention for students who are helping a sick loved one and recommended that this group be offered extra support. In April 2019, MantelzorgNL launched an awareness-raising campaign aimed at breaking the taboo on talking about informal care (Van Vliet 2019). In the programme 'Up for informal care at home' ('In voor mantelzorg-thuis') Movisie, the national knowledge institute on social issues, and the National Centre of Expertise for Long-term Care in the Netherlands (Vilans) support local collaboration between professionals and informal carers and between the care and welfare sectors and the local authority.

These activities show that informal care has acquired an indispensable place in the care for older people and people with disabilities. Although this was always the case, over the last 25 years informal care has developed from an 'invisible, spontaneous and automatic help for loved ones' into 'acknowledged, necessary and unpaid help which is intended to make care more affordable'. Placing heavy demands on the unpaid contribution of informal carers is a way of 'cashing in' on the willingness of citizens to help. Without this help, the costs of caring for those in need would be much higher. People who are willing to help their loved ones are therefore very valuable.

Targets have been formulated in relation to informal help in the reforms of long-term care in the Netherlands. The government expects people to do more for each other. What do we know about people's willingness to help each other and about the factors that influence this? At the same time, the legislator wishes to protect informal carers against becoming overburdened. What is known about this overburden and its causes? The government is also focusing on support for informal carers and on improving the link between formal and informal support and care. What information do we have about the take-up of support and possible explanations for non-take-up?

In this publication we attempt to use the knowledge garnered by SCP about informal carers to answer these three questions. We take the situation in 2016 as a starting point for this, the most recent year for which we have relevant data available.<sup>2</sup> Based on the answers, we formulate a number of focus areas for policy and list the most important themes where (more) knowledge is needed going forward.

## Notes

- 1 It should be noted that SCP does not use the term 'informal care' in its survey questionnaires, instead using the formulation 'helping sick loved ones' (see chapter 2).
- 2 In the autumn of 2019, SCP and Statistics Netherlands (CBS) are collecting new material on informal caregiving; SCP will report on this at the end of 2020.

## 2 Willingness to provide informal care

We interpret informal care as help given to a person who needs help by someone from their immediate setting. It incorporates intensive and less intensive, short-term and long-term help and help provided either to someone in the same household or to more distant relatives, neighbours or friends, to people living independently and to residents of care institutions (De Klerk et al. 2017). The help can encompass many different activities, such as keeping someone company, helping with administration, providing transport, help with showering or taking medicines. Informal care goes beyond what in the Netherlands is called ‘usual help’ – help which can reasonably be expected to be given by a partner, parents, children living at home or other household members.

In this chapter we look at informal carers today and changes in the help they provide. We then explore people’s willingness to provide (more) informal care.

### Roughly one in three people in the Netherlands is an informal carer

In 2016, around one third of Dutch citizens aged over 16 were informal carers, and that proportion has not changed compared with two years previously.<sup>1</sup> This means that there are around 4.4 million informal carers in the Netherlands in any one year. If we look at the time of the survey, the total is around 3 million people. Approximately 750,000 (17% of informal carers) were providing long-term (more than three months) and intensive help (more than eight hours per week). Informal carers provide help for an average of seven hours per week, for an average of five years.

Roughly a quarter of those providing help regard themselves as ‘informal carers’; three out of four do not. The proportion of people who see themselves as informal carers is slightly higher among those providing intensive help or helping very close relatives (De Klerk et al. 2017).

### 45-64 year-olds and women relatively often provide help

People in the 45-64 age group, in particular, relatively often provide informal care, often in response to health problems affecting their parents/parents-in-law. However, very elderly people also provide informal care, as do young people: around 20 of schoolchildren grow up with a sick loved one and approximately 3% of young people provide intensive help to a sick loved one (De Roos et al. forthcoming).

Women help more often than men, but around 45% of all informal carers are men. Men are overrepresented among those helping partners, while women are overrepresented in the other groups (De Klerk et al. 2017). One reason that women help more often may be that they are quicker to recognise that help is needed. Women more often have a proactive attitude here: men help mainly in response to a request to do so (Matthews 2002; De Klerk et al. 2015). Men also more often report that they do not enjoy providing the help and think more often than women that they are not good at it (De Klerk et al. 2015).

### Providing informal help is often seen as natural, but not compulsory

Some 80% of informal carers find it gratifying and natural to care for a loved one (De Boer & De Klerk 2015). Two-thirds say they help because it is the right thing to do; this is slightly more the case among those helping family members than those helping friends or neighbours.

Although informal care can never be compulsory, some informal carers do experience it as such, and feel caught in an ‘informal care trap’ (Knipscheer 2010). This is the case, for example, if the recipient only wants to receive help from one specific informal carer, if no one else is available or if by providing his or her help, the informal carer is seeking to avoid or stave off the deployment of professional caregivers. Those providing help to children and partners, in particular, relatively often cite motives such as these.

### Share of informal carers stable, but opinions changing

A key motive for the reforms of long-term care in the Netherlands which came into effect on 1 January 2015 was to increase the degree of engagement within society: the idea was that people should look after each other more and be less dependent on professional care (Kromhout et al. 2018). The share of adults providing informal care remained unchanged between 2014 and 2016, as did the intensity of help provided (De Klerk et al. 2017). If we look at the last ten years, we also find that the number of informal helpers is reasonably constant. Opinions are however changing, with growing support for the notion of people looking after each other. However, people do not believe that the social network should be the main source of help, but that it should instead be primarily a supplement to professional help. Around two-thirds think that caring for parents who need help is mainly a task for the government, not the family. This view was generally slightly less widespread in 2016 than in 2014 and 2010 (De Klerk 2010). Opinions depend on which tasks are involved.

### More pressure on informal care in the future

The number of older people in society (and therefore the number of people needing help) will rise in the future, but the number of people in the potential labour force (and therefore the number of people available to provide help) will decline (De Jong & Kooiker 2018; Kooiker et al. 2019). Where in 2015 there were more than five informal caregivers for every person needing help, the most recent estimates suggest that by 2040 this will have fallen to around one in three. This means the pressure on informal care will increase, as there will be fewer people available with whom this care can be shared. This pressure will be felt particularly in regions where the population is contracting, on the periphery of the Netherlands, where the relative share of older people will increase even more than elsewhere.

### Professionals see that the network has in many cases reached its limits

Placing more demands on informal carers can be difficult. Assessment officers, the gatekeepers to publicly funded social care provision, often do not seek a contribution from the recipient’s social network because it is already providing a great deal of help and is either unable or unsuitable to provide (more) care. In some cases, clients do not have a social

network at all. Where they do, they sometimes indicate that they find it embarrassing to have certain intimate activities carried out by close relatives (Bredewold et al. 2016). Care institutions also find that it can be difficult to involve the social network more in the provision of care. This can require a major change on the part of informal carers of people who have lived in an institution for a long time. Family members may also be elderly and in need of care themselves, may be overburdened, have little time or live a long way away (Gijzel et al. 2017). Mental health care clients, in particular, often have a limited social network due to poor family contacts (Lemmens et al. 2017) In qualitative research, care professionals observe that, as people with impairments continue to live independently more often and for longer, the burden increases, especially when it involves caring for older people (Lemmens et al. 2017, Gijzel et al. 2017).

### Giving more help depends among other things on available time

Informal carers were asked in 2016 whether they would be able to provide more help if necessary. A quarter responded that they would (definitely) not be able to provide more help, while around three in ten said they (definitely) would be able to do so. Half said it would depend on the situation, by which they mainly meant whether it could be combined with work and whether their own health would permit it. Lack of time is thus an important impediment to providing (more) help (De Boer & De Klerk 2017).

### Time also plays a key role in the willingness of non-helpers

People who are not informal carers and who do not carry out voluntary work in the care and support sector were presented with a number of statements to investigate their attitude to providing help. Around 70% said they would be willing to help someone (though some of these could be socially desirable responses), while almost 60% said they liked the idea of giving help (De Klerk 2017). However, almost half would only be prepared to provide help on an occasional basis. Some of them cited practical objections: around one in three said they had no time to help and almost one in five said they were unable to provide help because of health problems. The proportion of people not willing to help was small (De Klerk 2017). Reasons for being unwilling to provide help may be that people do not consider themselves suited to it or have a difficult relationship with the person needing the help. It may also be that the potential recipient does not want to receive any informal help: a majority of people with a disability or impairment express a preference for nursing or support provided by a professional (Putman et al. 2016).

In 2016, a quarter of 'non-helpers' said they would be willing and able to help: they are willing, have the time and have no health problems (De Klerk 2017). More than four out of ten said they would be willing to provide help but were unable to do so. There is no difference between men and women on this point. People with children and 35-64 year-olds more often express an inability or unwillingness to help than others. The same applies for people with (substantial) jobs, and other research also shows that a (long) working week can prevent people from taking on care tasks and that this is unrelated to investments in home care (Josten & De Boer 2015; Verbeek-Oudijk et al. 2019).

### Willingness to help depends on social relationship

One in six people aged over 16 are providing help to one or both parents. When asked, 40% also say they would definitely be able and willing to help their parents (for half a day a week), while 17% say this would depend and 9% would definitely not be willing and able to provide help (De Boer & De Klerk, forthcoming).<sup>2</sup> Respondents answering ‘it depends’ cite obligations (work), travel distance, their own health and the possibility that others (brothers and sisters) might provide help (Kooiker & De Klerk 2015).

In 2016, 6% were providing help to a neighbour. More than one in three of those not providing this help say they would definitely be willing and able to do so on an occasional basis, and 40% of these say they would be willing and able to do this on a weekly basis. Much depends on which neighbour is involved: people are more willing to help their neighbours if they know them and like them (De Klerk 2017). Social relationships are therefore a very important factor in determining people’s willingness to help.

### What do we know about people’s willingness and ability to provide informal help?

Whether people provide help, and what kind of help, is heavily dependent on the context:

- The probability of knowing someone who needs help rises with age. Informal care is relatively often provided by people aged 45-64 years, who frequently have elderly parents or parents-in-law.
- Women provide informal care more often than men, partly because they notice earlier that help is needed. Men say they have less affinity with providing help.
- Giving help is not compulsory, but some informal carers feel they have no alternative.
- The demands placed on informal carers are reaching the limits of what some groups are able to offer, for example in the case of elderly people and people with severe mental health problems.
- Demographic changes will increase the pressure to provide informal help, especially in the ‘peripheral’ regions of the country.
- The willingness to help depends on the ability to do so (for example having enough time), but also on the relationship with the person who needs the help: people are more often willing to help (very) close relatives than friends or neighbours.

### What do we not know?

Summarising the foregoing, we can say that we already know a great deal about people’s willingness to help and about the help they provide. Nonetheless, there are some groups of informal carers about whom relatively little is known, for example those with a migration background and older informal carers, both of which are cited in the ‘Longer at Home’ (‘Langer Thuis’) programme of the Ministry of Health, Welfare and Sport as groups which warrant extra attention (TK 2018/2019). There are for example indications that among migrants, daughters-in-law, who take on most of the care tasks, are under a heavy burden; they may also be subject to neglect and even abuse (Fokkema 2019).

Another aspect which is harder to study is the difficulty in making an accurate assessment of the informal care potential: people may well say that they would in principle be willing

and able to help and cite the factors on which this depends, but it is difficult to gauge whether they would actually do so in practice. A great deal will depend on the precise circumstances: who asks what, when and why? Since the pool of potential informal carers is set to decline in the future, it is important to continue monitoring people's willingness to actually provide help. That will enable us to maintain a close eye on the distribution of the pressure on informal carers based for example on gender, age, labour market participation and migration background, and on groups which need support.

## Notes

- 1 The proportion of informal carers is closely related to the definition chosen. For example, Statistics Netherlands (CBS) produces smaller numbers, because their survey questionnaires ask whether someone is providing informal care for eight hours per week or more or for three months or longer (CBS 2016).
- 2 Respondents were asked whether they would be able and willing to help their parents where necessary with the household, shopping, doing odd jobs or providing transport for half a day a week for six months.

### 3 Caregiving burden

While lots of people help or would be willing to help a loved one with health problems, there are limits to what is possible. In this chapter we look at what happens if informal carers run up against their limitations – overburden – and at the factors associated with this. We discuss specific groups which are at greater risk of becoming overburdened. Where we use the terms overburden(ed), high, severe or heavy burden, we mean the same in each case.

#### One in ten informal carers overburdened

In 2016, one in ten informal carers in the Netherlands felt severely burdened (approximately 380,000 people) (De Boer & De Klerk 2017). A first sign of overburden is when the informal carer feels they are never free of the help situation and of their responsibilities (De Boer et al. 2012a). A following phase is where people find it difficult to combine running the household, family and work and are too tired to undertake any activities in their free time. The most severe form of burden is where someone experiences conflicts at home or at work because of their care tasks, where their health suffers or where someone becomes sick or stressed out as a result of providing help.

By the same token, it is also true that many informal carers have positive experiences (De Boer et al. 2012b). For example, five out of six helpers say they enjoy the time spent with the recipient of the help, and 80% find being able to help gratifying.

#### Recipients of help can also become overburdened

One in three informal carers say they sometimes lose patience when providing help, and 9% admit that this can lead to shouting or rough treatment of the person they are helping (Plaisier et al. 2015). Someone who feels overburdened is at greater risk of losing their patience. Impatience on the part of the informal carer can lead to neglect, incorrect treatment or even abuse of the recipient of the help. This need not automatically mean that the informal care situation has ‘gone off the rails’, but it can lead to that (Plaisier & De Klerk 2015).

#### Providing intensive help creates a risk of overburden

Informal carers who provide intensive help (at least eight hours per week and for longer than three months) are at greater risk of becoming overburdened. The intensity of the help provided is associated with the social relationship between caregiver and care recipient. Caring for a partner (13% of informal carers) is often intensive, averaging almost 20 hours per week, and at the time of the survey was provided for an average of almost six years (De Klerk et al. 2017). Informal carers of children (6% of informal carers) often provide long-lasting and intensive care: an average of almost eleven years and approximately fourteen hours per week. Help provided to parents (42% of informal carers) is given for an average of five hours per week over four years, and is shared with professional carers from



a care institution. The greater the social distance between the caregiver and recipient, the lower the intensity of the informal care provided. Those providing help to friends or neighbours (17% of informal carers) spend approximately four hours per week doing so (De Klerk et al. 2014).

### No changes in burden overall, but changes in some subgroups

On average, the subjective burden of informal carers did not change between 2014 and 2016 (De Boer & De Klerk 2017). Research by the Netherlands Institute for Health Services Research (Nivel) does however show an increase in the percentage of heavily burdened informal carers among those providing care to people with dementia, from 10% in 2011 to 16% in 2016 (Jansen et al. 2016). Professionals warn that the burden may be increasing among specific groups of informal carers who are providing help to people with an intensive need and who continue living at home, where in the past they might have been admitted to an institution (Kromhout et al. 2018). No hard figures are available on this, however.

### Greater burden among women

Women not only provide help more often than men (see chapter 2), but also experience a higher burden. This is not because women help more; on average, women and men provide the same number of hours' help (De Klerk et al. 2015). One factor may be that women feel they have less choice when it comes to providing informal care, because those around them expect more of them (De Boer 2017). Another (partly related) explanation is that men help in a way that is focused on tasks and solutions, whereas women provide help in a more emotional and personal way, so that the (emotional) burden on them is higher than among men. For example, men more often help with administration and transport, while women help with visiting the doctor, personal care and support tasks, which are less easy to plan into a schedule (De Boer & De Klerk 2015). There are also indications that women and men approach the take-up of support differently, and this may explain some of the difference in burden (see chapter 4).

### Dementia makes informal caregiving very stressful...

One in five informal carers is helping someone (often a parent or parent-in-law) with dementia or memory problems. These informal carers experience a relatively heavily burden (De Klerk et al. 2017). These care recipients demand a great deal of attention, for example because they constantly repeat the same things and it is no longer possible to hold a proper conversation with them. The impact of caring for someone with dementia is also evident from the fact that informal carers from this group say their relationship with the person they are helping has deteriorated, that they receive little in return from the person they are helping and that they will not be able to continue helping for another year. They also often feel that they lack the necessary skills and knowledge, for example worrying whether it is responsible to leave 'their' care recipient alone at home and not knowing how best to deal with their disability.

### ... but the same applies for mental health problems...

One group of informal carers who are less visible but who are also often under a heavy burden are those providing care to people with mental health problems (De Boer & De Klerk 2017). One in eight informal carers are helping someone (relatively often a son or daughter) with a psychological problem (such as depression, anxiety or psychoses) or a psychosocial problem (such as loneliness or addiction). These informal carers often feel they are not sufficiently competent because of the often complex behavioural and other issues of the person they are helping. They also feel they have to cope alone, often reporting that there is no one who can take on their care task if they have to drop out. This is associated inter alia with the fact that people with psychological problems have difficulty maintaining a network, but issues concerning their privacy and the taboos surrounding their problem also mean it is not easy to ask others to help. Informal carers of people with psychological problems accordingly experience more impediments than average to asking others for help (Plaisier & Schyns 2015).

### ... and terminal care situations

A small group of informal carers (6%) provide help to someone who is terminally ill (De Boer & De Klerk 2017). They often provide intensive and complex help to a loved one who is dying (De Klerk et al. 2017) and in many cases report a high level of stress and a shorter period during which they are able to continue providing help, even though that help is often shared with professionals. Roughly half of these informal carers feel they lack sufficient knowledge about their loved one's illness, a gap that could be filled by providing courses or specific information.

### Partner-carers are vulnerable

People caring for a partner can be vulnerable. They often provide intensive help and relatively infrequently share the care with others, partly because the recipient often wants to receive help from them (Plaisier et al. 2015). These informal carers are in many cases elderly and may have health issues themselves.

### Combining work and informal care difficult when the care task is intensive

Two out of three informal carers have paid jobs (De Klerk et al. 2017). Around one in three working informal carers almost always provide care on (or after) a working day. Informal carers with paid jobs (for at least 12 hours per week) work an average of 33 hours per week and spend six hours providing informal care; for those providing intensive help, the figures are 31 and 21 hours, respectively (De Boer et al. 2019). Although working informal carers generally find they are well able to combine their tasks, they do experience a higher burden than non-workers with the same informal care task, and this is particularly true for those providing intensive help (De Boer et al. 2019). Working people with an intensive informal care task also experience relatively high time pressure and take a more negative view of their own health than before they began providing help (Josten & De Boer 2015).

Long-term sick leave (two weeks or more) also increased sharply when people began providing (intensive) informal care, especially if they were still providing it two years later.

### Negative impact on young people

Young informal carers (interpreted here as pupils or students with a sick loved one) report poorer health and more mental health issues, such as emotional problems, depression and anxiety (De Roos et al. 2013; De Roos et al. 2016; Van Tienen et al. 2018). This applies especially for young people growing up with a family member with mental ill-health (De Roos et al. 2013). Students providing informal care study at a slower pace, achieve lower marks and more often consider giving up their studies than their peers who are not in such a situation (Van Tienen et al. 2018).

### What do we know about overburden?

We know the following about informal carers and overburden:

- People providing intensive help, people caring for their partner and women are over-represented among overburdened informal carers.
- The burden experienced by informal carers has not increased generally in recent years, but there are indications that it has increased in some subgroups.
- Informal carers of people with dementia, mental health problems or terminal illnesses experience a high burden.
- Combining work with providing informal care can lead to a higher burden, long-term sick leave and poorer subjective health, especially for people providing intensive informal care.
- Pupils and students who grow up with a sick loved one may experience poorer health, weaker study outcomes and higher dropout rates.

### What do we not know?

Although we know a great deal about the negative impact on informal carers of providing help, and also on specific groups of helpers, there is a lack of longitudinal research which would provide greater insight into aspects such as why and when the burden and the concomitant need for support among helpers increases. Such a study could also examine the consequences of working on informal care and vice versa.

## 4 Support for informal carers

Most informal carers are doing well. They are able to maintain a balance between the help they provide to their loved one and other activities such as paid work, caring for young children, social activities and relaxation. As the previous chapter shows, however, some informal carers experience negative consequences from providing help and may for example feel overburdened. Informal carers can benefit from support. In this chapter we describe what forms of support are available for informal carers and how much use is made of them. Support may be offered by other helpers or by local authorities, but also at work or school, for example.

### Informal carers often share the help with others

The majority of informal carers (69%) share the help they provide with other informal carers, often in an 'informal help network' consisting only of informal carers, or in a 'mixed help network' comprising both different informal carers and professionals, for example home care providers (Plaisier 2017). A small proportion of informal carers are supported only by professional helpers. They are relatively often providing help to someone living in the same household (partner or child), and relatively often to someone with dementia or an intellectual disability. Those informal carers who do not receive help from others (12%) are often providing help to members of the household, such as a partner or child. In many cases they are the only person providing help because the recipient is unwilling to receive help from anyone else, or because no one else is available.

A substantial group of informal carers is afraid to ask others to help or cannot do so because no one is available. This is most often the case for people helping someone with a psychological problem; one in five of them find it difficult to ask for support (Plaisier & Schyns 2015).

Informal carers providing help to someone in a care institution share the caregiving with professionals, but often also with other informal carers. They too can feel heavily burdened and in need of support (Broese van Groenou 2010). These informal carers are often older (over 65) and are frequently providing help to someone with dementia or an intellectual disability.

### Importance of coordination with others and appreciation of the informal carer

Sharing the help with others can be a good form of support for informal carers, as long as the help can be readily discussed and coordinated between them. Most informal carers manage this successfully, but one in four sometimes have a difference of opinion with other informal carers; this is often the case for those helping neighbours or friends. One in five experience problems in coordinating the help with other informal carers; these are often people helping someone with psychological problems.

Three-quarters of informal carers who come into contact with professionals (e.g. home care professionals, a case manager or a doctor) are satisfied with their ability to discuss the

care with those professionals, and nine out of ten informal carers are able to coordinate the care with the home care services satisfactorily (Plaisier 2017). A small proportion (4%) say they often have a difference of opinion with a professional. Informal carers appear to be less satisfied with the ability to share in decision-making about the care (almost half are not able to do this) and the feeling that care professionals do not take them into account (more than half feel this).

In addition, some (one in five) informal carers helping people in a care institution say they are only occasionally able to engage in dialogue with professionals, and generally do not have the sense that their own well-being is considered (Plaisier 2017). One in five feel that thought is rarely or never given to their well-being, and 5% say they are rarely or never able to discuss the situation with professionals.

### Privacy legislation sometimes prevents sharing of information

The contact and coordination of the care between different helpers can be supported using digital resources such as CarenZorgt or Quli, also referred to as a 'personal health environment' (PHE). A PHE provides a space where those requiring help and care staff can share information, including with informal carers. With effect from 1 January 2020, every care provider in the Netherlands will be required to offer a PHE. An informal carer needs the consent of the care recipient to access privacy-sensitive information, such as medical records. Privacy legislation can also be an obstacle to informal carers, for example if they wish to share their concerns with a doctor or GP. It is not always clear which information an informal carer may access and which information he or she may share. The nature of the relationship also plays a role here (a partner has a different status from a neighbour, for example).

### A bigger role for GPs

General practitioners (GPs) and their practice nurses can play an important role in supporting informal carers, and perhaps a bigger role than is often the case at present. They can monitor the well-being of informal carers and their patients and refer them to support services, for example those offered by the local authority. Of all professionals, the GP is the most frequently cited as the person who is aware of the well-being of informal carers, though still only by 9% of informal carers (Plaisier 2017). Volunteers, local authorities and informal care support centres are mentioned least frequently. Roughly one in three informal carers who have been told about the available support by others received advice on this from their GP; they much more often received this advice from people they knew, such as relatives, acquaintances or neighbours (over 80%).

### Adequate professional help is important

Adequate (professional) help is also an important form of support for informal carers. Overall, 70% of informal carers feel that 'their' care recipient receives sufficient help (Plaisier & De Boer 2017). Approximately two out of ten feel this is not the case, while 13% do not know. Informal carers providing help to someone with dementia or a psycho-

logical problem, in particular, relatively often regard this help as inadequate. These informal carers also relatively often experience a heavy care burden (see chapter 3).

### Support for informal carers a task for local authorities

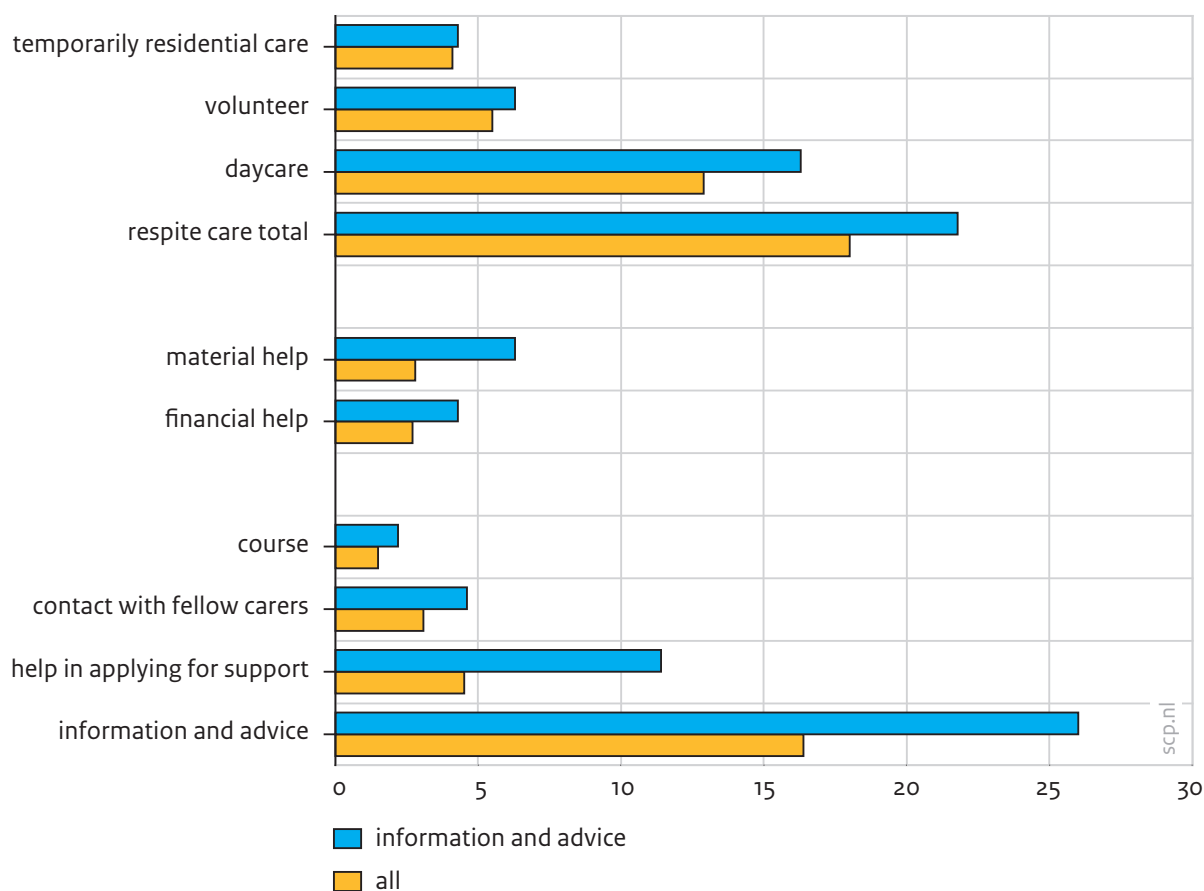
The Social Support Act (Wmo 2015) assigns responsibility to local authorities to support informal carers in order to prevent or ameliorate overburden. They can for example reduce the burden on informal carers by offering respite care (in which the care is temporarily assumed by others, for example through residential care or daycare), or can offer financial or material support (e.g. discounts or a parking permit). Other forms of support are aimed at increasing the resilience of informal carers, for example through contact with other informal carers or the provision of information and advice. Developing competences and skills, for example by following a course or training session, can also be supportive. Some forms of support are aimed at specific groups, such as those helping people with dementia (e.g. Alzheimer Cafés, case managers and the dementia app) (Vernooij-Dassen et al. 2017) or at young informal carers (such as the Roos Radeloos theatre production) (Van Tienen et al. 2019; De Roos & De Boer 2019).

### Little take-up of informal care support offered by local authorities

Virtually all Dutch local authorities offer one or more forms of informal carer support, for example through informal care support centres or welfare organisations, but the number of people making use of this support tends to be relatively small (figure 4.1). Support aimed at reducing the caregiver burden often takes the form of daycare services for the person care recipient. Intensive helpers make slightly more use of this support than those providing non-intensive help. The most widely used forms of support aimed at increasing resilience are information and advice, possibly because these are easy to access. Once again, those providing intensive help use this support more often. Once people do make use of informal carer support, they rate it highly or very highly (De Klerk et al. 2009). They feel more able to cope with providing care, take a more positive view of the help they give and feel less burdened. Informal carers also quite often say that, in retrospect, they waited too long before bringing in professional help (De Klerk et al. 2014).

Figure 4.1

Take-up of various forms of support by informal carers, total group and intensive informal carers (in percentages, n = 2430)



Source: SCP/CBS (IZG'16)

### Unmet need for support, partly through unawareness

There is also an unmet need for support: almost six out of ten informal carers of those applying for support under the Social Support Act (Wmo 2015) have a need for some form of support which they have not received (Feijten et al. 2017). This often means financial support, but also someone who could occasionally take over the care from them.

The unmet support need increases the subjective burden of informal carers (Plaisier & De Boer 2017).

The main reasons for not using informal carer support provided by the local authority are insufficient knowledge of the possibilities, inadequate or unclear information on what support is available and the bureaucracy involved in applying for support. (Feijten et al. 2017)

Three out of ten informal carers are not aware of one or more types of informal care support (Plaisier & De Boer 2017). A quarter of informal carers who need support and are not currently receiving it say they would not know how to ask for it. People who are providing help to their child or a loved one with an intellectual disability are more often aware of the available support than those helping parents/parents-in-law or loved ones with a terminal illness. It is often someone from their own circle who informs informal carers about the available support; the role of professionals such as the GP, district nurse or local authority

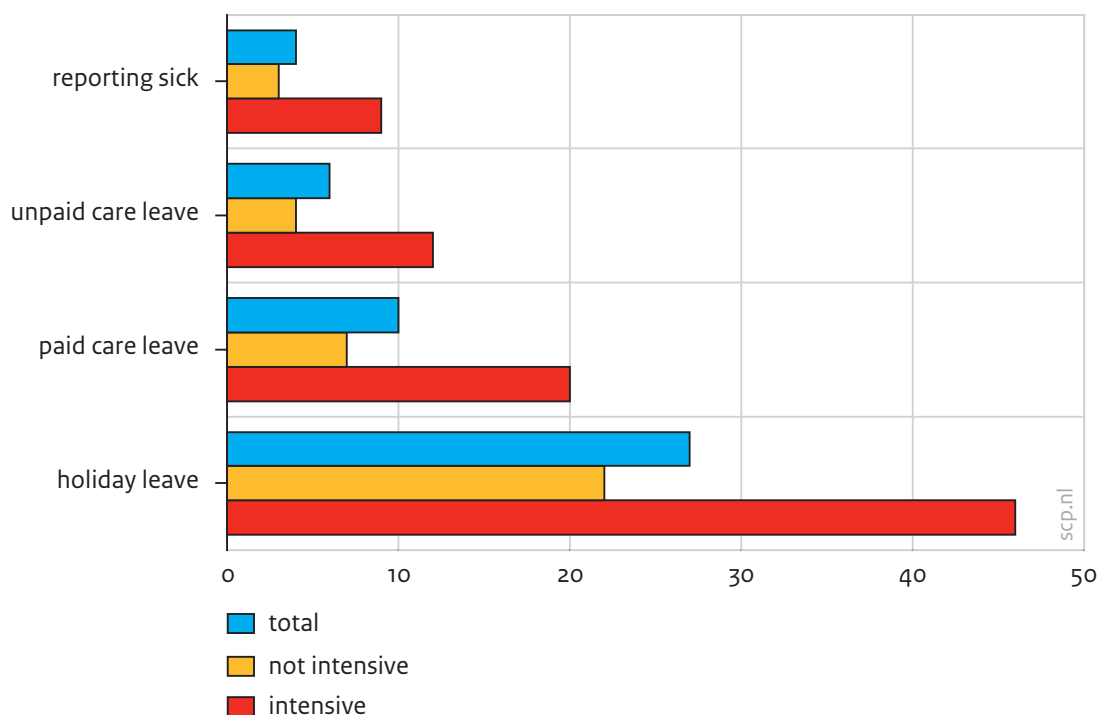
in this regard is limited. A further factor may be that people are not actually aware that they are informal carers (see also chapter 2) and that they may therefore be eligible for informal carer support.

### Working informal carers make little use of leave arrangements

In chapter 3 we discussed the relatively high burden and time pressure of working people who are also delivering intensive informal care (see also De Boer et al. 2019). In the public debate, care leave is not infrequently suggested as a ‘solution’ to enable people to combine work and informal care. Yet take-up of these formal arrangements is low: around 10% of informal carers take paid leave and even fewer take unpaid leave (Portegijs 2018; De Boer et al. 2019). The vast majority of informal carers say they have no need of such leave. Taking holidays in order to provide help is more common: roughly a quarter of employees do this (De Boer et al. 2019). This may be related to the fact that care leave is generally (partly) unpaid, and therefore impacts the employee’s income. Moreover, taking a day’s holiday is relatively easy. Those providing intensive help generally make use of care leave or holidays roughly twice as often as those providing less intensive help. If providing care eats into holidays, this could be an additional source of stress for an employee. Reporting sick also happens; 4% of informal carers have occasionally done this, intensive helpers slightly more often than those providing non-intensive help (figure 4.2).

Figure 4.2

Use of ‘leave’ in connection with informal care, by intensive/non-intensive help, employees (≥ 12 hours per week) who provide informal care, 2016 (in percentages; n = 957)



Source: SCP/CBS (IZG’16)



### Flexible working is not always possible

The Flexible Employment Act (Wet flexibel werken) was introduced in 2016 in order to offer scope to informal carers and help them combine working with providing informal care. Research among employers shows that one in five organisations allow employees to determine their own start and finish times (Van Echtelt & De Voogd-Hamelink 2017). More and more people are also working from home (Van Echtelt et al. 2016). Flexible working hours could make it easier to combine work with care tasks and thus prevent ‘combination stress’. Half of working informal carers are able to take an unplanned day off if it is necessary for the care situation, and one in five have complete freedom to arrange their own working hours (De Boer et al. 2019). Naturally, this depends on the type of occupation they have.

### Reducing working hours more popular as a solution among women

Another way of creating scope to provide informal care is to reduce the carer’s working hours. For many women, freeing up time to care for parents and other loved ones is (also) a reason for choosing to work part-time (Van Thor et al. 2018). Men who experience providing help as a heavy burden take occasional days off more often than women, or make arrangements with their line manager, and less often switch to working part-time than women (Plaisier et al. 2017).

### Working informal carers mainly need understanding

We asked employees what they felt was the best way of combining work with informal care. The most common response was understanding from managers and colleagues. Over half of the respondents discuss the care they are providing with their manager, and three-quarters of them feel they are treated with understanding. This applies particularly to those helping a relative in the first degree (a partner, parent or child) and those helping someone with a terminal illness (De Boer et al. 2019). These informal carers feel a strong need to mention their care task, and for employers these are recognisable situations for which they are willing to offer flexibility. Working informal carers helping someone who is not a close relative or who help someone with health problems that are less easily recognised as such (for example psychological or psychosocial problems) feel they receive less understanding from their employer.

Managers could invest in making it easier to discuss informal care at work and in providing information on the available leave and other arrangements. Arrangements could be made with a manager on making (temporary) adjustments to the work or the ability to telephone the care recipient or care providers during working hours. Contact with a manager on informal care tasks also helps reduce time pressure (De Boer et al. 2019).

### ... but also flexibility at work

Flexible working hours are also frequently cited as the most desirable form of support at work, more so than days off and leave (De Boer et al. 2019). This may indicate that employ-

ees are not willing to 'give up' their work in order to provide care. It is also known that work can serve as a diversion from a stressful care situation (Greenhaus & Powell 2006). A proportion of informal carers, for example self-employed workers, do not have a manager or immediate colleagues. There are indications that some of them became self-employed because of their care tasks (ZZP 2017). However, this does mean that they have no access to the various arrangements and facilities that are open to employees.

### Sub-optimal support for school students

Students who are providing care report in qualitative research that awareness and understanding from their education establishment could help them, as could greater flexibility in their education programme (Van Tienen et al. 2019). The importance of increasing the visibility of young informal carers at school is underlined by experts in this field (Hoefman & Van Zoest 2019a,b). Mentors and care coordinators feel they could be more alert when students are involved in a care situation at home, and that they could engage in dialogue with them about this at an early stage (De Roos et al. 2017; Van Tienen et al. 2019). A recent report by the Dutch Ombudsman for Children (Kinderombudsvrouw) (2019) reveals that children and adolescents who grow up with a parent with problems would welcome more rapid intervention when things are not going well at home. They would also like there to be a joint process to look at their needs so that, like their parents, they receive help, information and support. Students with a sick family member make more use than students who are not in that position of professional help such as a psychologist or youth mental health worker, Youth and Family Support Centre, and educational or school social worker or a specialist tutor (De Roos et al. 2016). They also more often need increased support. Finally, there are indications that students make different choices in relation to the provision of informal care, for example choosing not to move into student accommodation or to follow a course in a different city (Van der Eijnde 2019).

### What do we know about support for informal carers?

People providing informal care need the space to be able to do that and can benefit from support. This support can come from other helpers, from local authorities, employers and education establishments, but the GP can also play a role. We know the following about informal carers and their support:

- Most informal carers share the help with others, but some are doing it alone, especially if they are providing help to other household members.
- Dialogue and coordination with professionals about who does what and when often works well, but informal carers are less satisfied when it comes to sharing in decision-making with professionals.
- Over half of informal carers feel that professionals take too little account of them.
- Relatively little use is made of support for informal carers offered by local authorities. Reasons for this include inadequate or inaccessible information and reticence on the part of informal carers about asking for support.

- Formal leave arrangements can be used as a means of support at work, but little use is made of them. Informal carers more often take holidays in order to provide the help.
- Flexible working is not possible for every employee. Half of all working informal carers are able to take an unplanned day off work when necessary, and one in five are able to determine their own working hours.
- Contact with the manager is important. Half of all working informal carers discuss their care task with their manager, and three-quarters of them are treated with understanding. This can help reduce the time pressure on working informal carers. Self-employed workers do not have managers or immediate colleagues and in this sense have to deal with the situation on their own.
- Students who grow up with a sick loved one often have an unmet need for support. Among other things, students who are providing care need more flexibility and understanding from their education establishment.

### What do we not know?

We assume that informal carers benefit from support, yet we still know little about the effects of different forms of support. For example, is it always useful to share the help with others? To what extent does promoting knowledge and skills and offering respite care ease the burden that informal carers feel? How much of a role does the region in which someone lives play in the support available for informal carers? Only a few of the interventions for informal carers contained in the Movisie database ‘Effective social interventions’ (‘Effectieve sociale interventies’) are assessed as ‘good’. More knowledge about the effects of different forms of support could help in developing a support offer that is a better fit for informal carers’ needs.

We also know relatively little about the interaction between professionals and informal carers. We know nothing about the support received by young informal carers from local authorities, such as respite care or information and advice. Several experts in the field of young informal carers do suggest that these carers have different needs from adult informal carers, but as of yet there is little (quantitative) information on precisely what those differences entail (Hoefman & Van Zoest 2019a,b).

There are also unanswered questions about the needs of working informal carers.

For example, we do not have a clear picture of the reasons why relatively little use is made of existing leave arrangements. It may be that employees need some other form of support. There are indications that men and women choose different solutions to help them combine work with being an informal carer, but we have only limited hard information on this.

We also know little about the role played by diversity in the need for informal carer support, for example whether the forms of support offered are a good fit for informal carers with a migration background, or whether they have different needs. It is also unclear to what extent being an informal carer poses an obstacle to the emancipation and labour market participation of women, young informal carers and, in particular, women with a migration background. Answers to questions such as these could help in creating a more

effective support structure. This underlines the importance of the Movisie programme 'What works' (*Wat werkt*), which describes effective interventions for informal carers, including young informal carers (Movisie 2017).

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