



Key figures on young carers in the Netherlands (aged 16 through 24)

In light of the changing welfare state and demographic trends, the Dutch government is focusing on informal care (Kooiker et al. 2019; Van Campen and Olsthoorn 2022). Care tasks also fall on young people. There are few national figures on young people who provide such help. In this key figures report, we fill that gap with data from a large-scale survey in 2019 which included over 1,400 participants aged 16 to 24. In the Netherlands, around half a million young people aged 16 through 24 provide help to a loved one with health problems: this amounts to one in four young people overall. Providing informal care often goes well. However, a third of young people who help their ill loved one feel moderately or seriously burdened. We are publishing these figures during the national Young Carers Week to inform young people, professionals and policymakers about the most recent data.

Informal care is the help that people provide to a loved one with a health problem.¹ This can be a partner, parent, child, other relative, friend or neighbour who needs help due to physical, psychological or intellectual impairments or old age. Examples of help include assistance with making appointments, transport, companionship, administrative help, help with household tasks, bathing and dressing. This help goes beyond the so-called standard help, which is the help that can reasonably be expected of household members according to generally accepted views. The Netherlands Institute for Social Research (SCP) previously published a report on schoolchildren aged 12-16 with an ill family member living at home (De Roos et al. 2020). The report revealed that these schoolchildren are at risk of lower well-being. We also see concerns about this group and young adult helpers in the media. See, for example: 'De patiënt van de toekomst' (*The patient of the future*), 'Er zitten best grote vragen vast aan onze keuzes voor Wouter' (*There are some big questions tied to our choices for Wouter*)², 'Geef de jonge mantelzorger dezelfde kansen als een topsporter' (*Give the young informal carer the same opportunities as an elite athlete*).

Summary and conclusions

This key figures report examines the helpers aged 16 through 24 who took part in the 2019 Informal Care survey (De Boer et al. 2020).³ Little is known about young adults who provide help, also known as young carers.

Approximately one of four people aged 16 through 24 provide help to an ill loved one. This amounts to roughly 500,000 young people. Nearly one-third of these young carers provide intensive help (i.e. at least four hours per week). Young women are more likely to provide intensive informal care than young men. Young people mainly provide help to a first- or second-degree relative (85%); 15% help a friend or neighbour. Two-thirds say they can handle the care tasks. One-third (33%) feels moderately burdened and 3% feel seriously burdened. Nearly four in ten young informal carers report positive experiences. Intensive helpers report both positive and negative consequences more often than non-intensive helpers. They are also more likely to care for a household member, feel obligated to help and indicate

that they lack the skills to provide the help that is needed. It is interesting to note that only a small portion of the young people who provide help to an ill loved one (9%), including the intensive helpers within this group (16%), see themselves as a ‘carer’ (in Dutch ‘mantelzorger’). The majority say they do not need help. But if they did wish for something, understanding and appreciation would be most helpful.

At the time of the survey, a majority of the young people who provide informal care (72%) combined these tasks with attending school or study. One in five tell someone at school about it (e.g. their mentor). Most won’t find this necessary, since they think helping is normal and/or they offer mild forms of help.

One in four of these task-combiners say they don’t spend enough time on education (doing homework, preparing for lessons or completing assignments) at least once a month, with intensive helpers reporting this more often.

Another three-quarters of young people with care responsibilities have a paid job (one or more hours per week). One-quarter of them inform their manager about their care responsibilities. More than one in ten say they are sometimes less focused at work due to their care responsibilities; we also see an over-representation of intensive helpers in this regard.

The fact that a minority of young informal carers tell their school or work about the care situation does not mean that young people do not share their care responsibilities with others at all. International research indicates, for instance, that young people tell their friends about their care responsibilities even more than those at school or work (Hanson et al., 2022).

These results show that many young people who care for an ill loved one are doing well, but more attention could be paid to their situation. This is especially the case for intensive helpers, as they have a greater risk of becoming (seriously) burdened, and more often have less time to spend on school or are less able to focus on work. The COVID-19 pandemic has likely had a major impact on this group of carers as well. A recommendation is to make young people’s care responsibilities for loved ones a topic of discussion within schools and at work, so that professionals know what might be happening in young people’s private lives. The educational institution or employer can then show understanding and try to help. If and when these young people need help, this could make it easier for them to find a listening ear or some other type of support. Our recommendation underscores the importance of engaging in dialogue with young people about their care responsibilities, as in the media campaign #Deeljezorg (‘Share your care’).

The survey

More than one in four young people help a loved one with health problems

In 2019, more than one in four people aged 16 through 24 helped a loved one with health problems (Table 1). This amounts to roughly 500,000 young people.⁴ This concerns a broad description of help, meaning not only personal care or household tasks, but also emotional support. The phrase ‘informal care’ (in Dutch ‘mantelzorg’) does not appear in the survey and there is no lower limit for duration or intensity. If we compare these figures for people aged 16 through 24 with figures for all those over the age of 16 who provide informal care (one in three, De Boer et al. 2020), we see that the proportion of helpers among young people is lower. This lower proportion among young people is (obviously) related to the fact that primarily those who are middle-aged and older have ill parents or partners who need help; this is much less likely to be the case among young people. One in ten of all 16 to 24-year-olds provide intensive help, i.e. four or more hours per week (around 200,000 people). Among young helpers, this figure is one in three.

On average, all young helpers spend five hours per week helping an ill loved one. At the time of the survey, the young people had been providing informal care for approximately 2.5 years. Young women are more likely to provide informal care than young men (32% versus 23%, see Table 1). They also do so on a more intensive basis (5.9 hours versus 3.9 hours).

Table 1 Number of (intensive) helpers of a loved one in need in the 12 months prior to the survey, 2019 (in percentages of all people aged 16 through 24 and in numbers; 95% confidence intervals^a, n = 1432)

	(%)	number x1000	95% confidence interval	
			min. x1000	max. x1000
provide help	27	520	470	570
men	23	220	180	250
women	32	300	260	330
intensive help (4 or more hours per week)	10	200	180	220

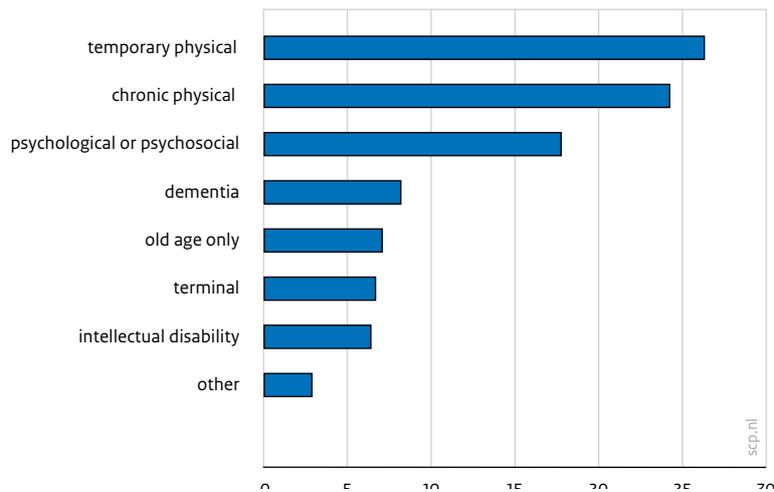
a A 95% confidence interval indicates an interval of values that contains the population value with 95% certainty.

Source: SCP/CBS (IZG’19)

Help mostly provided to people with chronic or temporary physical problems

The young helpers were asked questions about the care situation of the person whom they helped the most. The help provided to this person is the focus of this key figures report. Young people provide informal care to a mixed group: half help someone with a (chronic or temporary) physical impairment (Figure 1). Eighteen per cent help a person with psychological or psychosocial problems. The percentage of young people who help someone with an intellectual impairment is relatively small (6%). Eight per cent help a person with dementia or memory problems, such as a grandparent.

Figure 1 Types of impairments among those receiving help from 16 to 24-year-olds, 2019 (in percentages, n = 382)



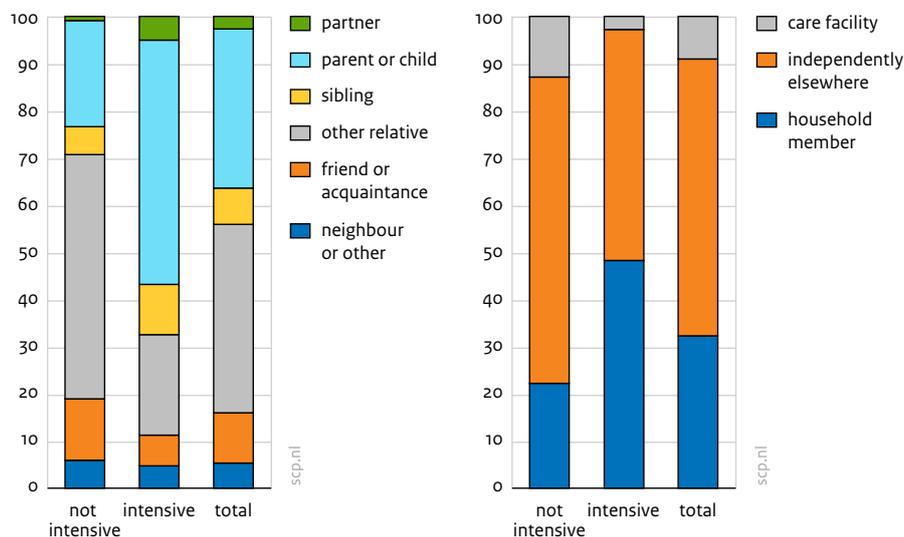
Source: SCP/CBS (IZG'19)

Care usually provided to family members, a small portion provided to friends or acquaintances

One in three young helpers provide informal care to a parent or child, and 40% help another relative, such as a grandparent, uncle or aunt (Figure 2). A small group provides care to a partner (3%). Another 8% help a brother or sister, and one in ten help a friend or acquaintance. Those who provide intensive help often care for a parent, child, partner or sibling; less intensive help is

usually provided to other relatives, friends or acquaintances. One-third of the young carers live with the person they help; 60% help a person who lives on their own elsewhere; one in ten help a person who lives in a care facility.⁵ Nearly half of the young people who provide intensive help do so for a household member; the other half provide informal care to someone who lives on their own (not in a care facility).

Figure 2 Social relationship between helper and help recipient (left) and living situation of the help recipient (right) according to intensity of the help provided, 16 to 24-year-olds, 2019 (in percentages, n = 381)



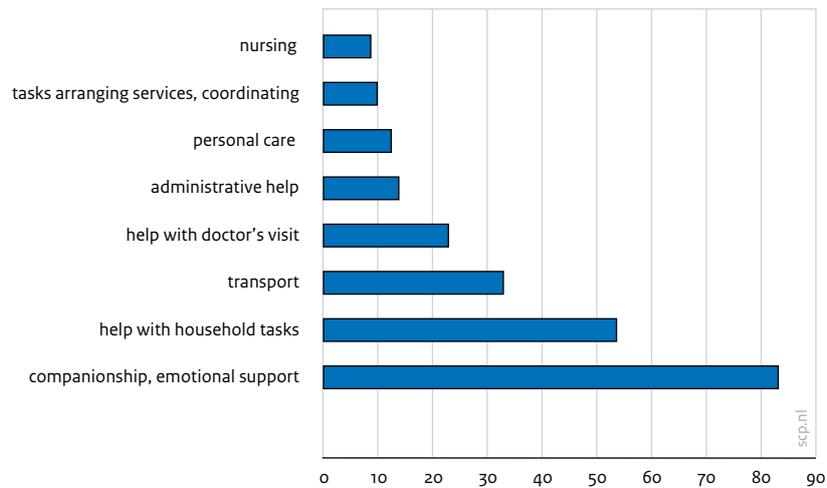
Source: SCP/CBS (IZG'19)

Companionship, emotional support and help with household tasks are the most common types of help

The present study shows that over 80% of the young people provide companionship or emotional support (Figure 3), often in combination with other types of help. Sixteen per cent only provide emotional support or companionship. Over half of young carers provide help with household tasks. Young people help with doctor's visits, transport and administration less frequently.

Some help with personal care (13%, showering or helping to the toilet), arranging or coordinating care (10%) and nursing tasks (9%, giving medications, wound care). Young carers coordinate the care in relatively few cases because only one in three young carers are the main helper. They mostly provide help along with someone else. In such cases, these types of tasks are done by another informal carer or by the help recipient themselves.

Figure 3 Nature of help provided by 16 to 24-year-olds, 2019 (n = 381, in percentages)



Source: SCP/CBS (IZG'19)

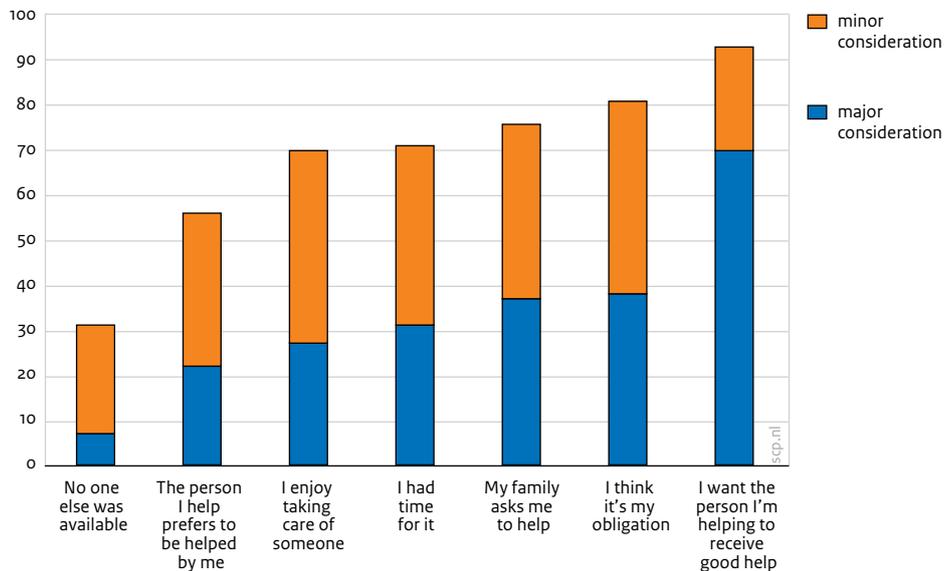
Young people want to take good care of the help recipient, one in four experience 'care dilemma'

In our survey, various statements were used to enquire about the motives for helping (Figure 4). Most young people who provide informal care report that the motive 'I want the person I'm helping to get the best help possible' is a major consideration (70%).

Other reasons also play a role. Young people provide informal care because they feel a sense of obligation, the family has

asked them to do it, they have time to do it or because they enjoy taking care of someone. Some of the young people who took part in this survey feel that they have to help: 7% say they help because no one else is available, and another 22% say that the person receiving the help prefers to be helped by them. In total, at least one of the latter two reasons is a major consideration for one in four young people. We call that a 'care dilemma'. This percentage is higher among intensive helpers compared to non-intensive helpers (37% versus 17%).

Figure 4 Motives for helping (major or minor consideration) among 16 to 24-year-olds, 2019 (multiple answers possible, in percentages, n = 307-375)



Source: SCP/CBS (IZG'19)

Broad range of experiences; relatively low percentage seriously burdened

Providing informal care can be accompanied by a variety of feelings. A significant portion of young informal carers report numerous positive experiences (37%, Figure 5), and this percentage is higher among intensive helpers (46%). Young people enjoy fun times with the person they help, feel thankful for the little things, grow closer to the person and learn new things.

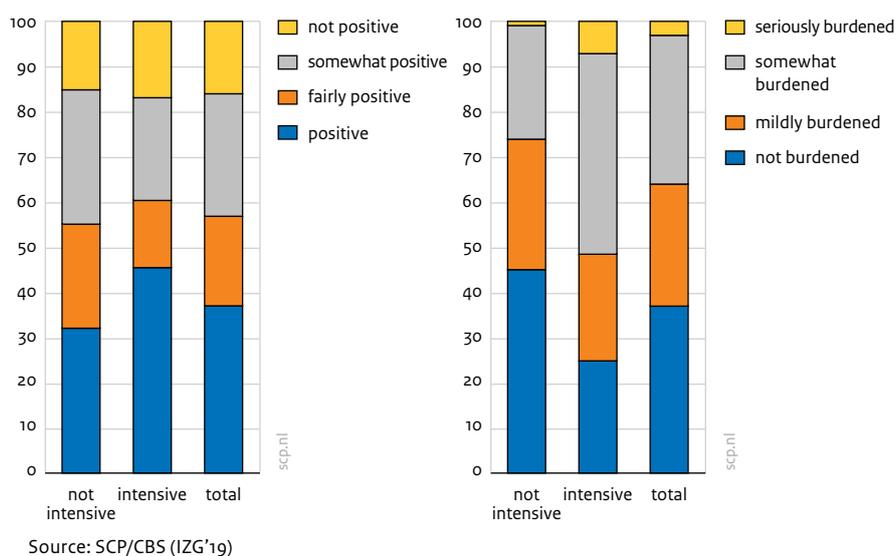
One-third of the young people feel moderately burdened by providing informal care, and this percentage is higher among the intensive helpers (45%). A small minority (3%) feel seriously burdened by providing informal care. Those who are seriously burdened feel that they are constantly tied down by situation of the person they care for, that they have a harder time managing their household or that their health has deteriorated as a result of their care responsibilities.

Intensive helpers are more likely to be seriously burdened and also more likely to report more positive experiences. However, this does not mean that positive experiences can prevent overload. The fact remains that an intensive care burden increases the risk of overload.

Additional analyses show that young people who care for someone with psychological or psychosocial problems are at a greater risk for excessive strain. Research by Van der Werf and colleagues (2019) supports this finding. Their study revealed that young people who care for a parent with mental issues experience the most problems.

Notably, the percentage of young people who feel seriously burdened (3%) is lower compared to informal carers who are older (9%, De Boer et al. 2020). A possible explanation for this is that young people provide less intensive help (five hours per week on average, versus seven hours per week among all those over the age of 16, De Boer et al. 2020) and are more likely to share the care responsibilities with others.

Figure 5 Positive experiences (left) and perceived burden (right) among 16 to 24-year-old informal carers according to intensity of help provided, 2019 (in percentages, n = 381)



Over one-quarter use municipal care support

Around one in four young carers (27%) say that they themselves or the person they care for receive some type of informal care support from the municipality. This usually includes information and advice (13%). Others report using respite care (14%), such as day care or daytime activities, a volunteer or babysitter who takes over the care for a while, overnight care or a lodging facility. A few take part in courses or training programmes, or get in touch with others in the same situation.

Some lack knowledge or skills

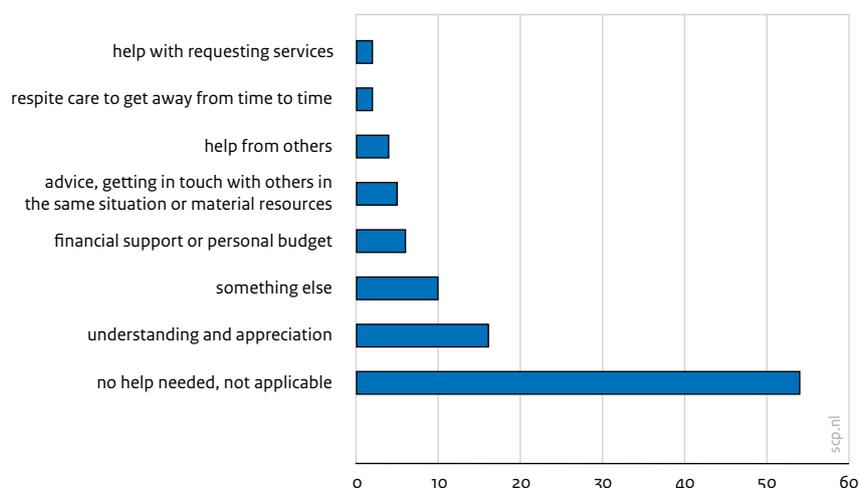
Over one in five young carers (22%) feel they lack the knowledge to provide the help that is needed. This includes knowledge about the condition, how to deal with the person they are helping and how to use medications or devices. One in eight (13%), and an even higher percentage of intensive helpers, think they lack certain skills. These include the ability to provide

personal care, apply compression stockings or interact with the person they are helping.

Half do not need support, one in six would like understanding and appreciation

The young carers were also asked what kind of support would help them the most (Figure 6). Around half (54%) say they do not need any (extra) help. Sixteen per cent cite understanding and appreciation as the form of support that would be most helpful to them. While these findings indicate that there is still room for improvement in this area, this does not necessarily mean that such appreciation should come from the municipality alone. Understanding and appreciation can also be offered by schools, employers and others. A small group (6%) would like to receive financial support or an allowance from a personal budget (in Dutch: PGB, or 'persoonsgebonden budget'). Another 10% say they want 'something else' (and therefore could not choose from the options on the list).

Figure 6 The (municipal) support which would help 16 to 24-year-old young carers the most, 2019 (in percentages, n = 341)

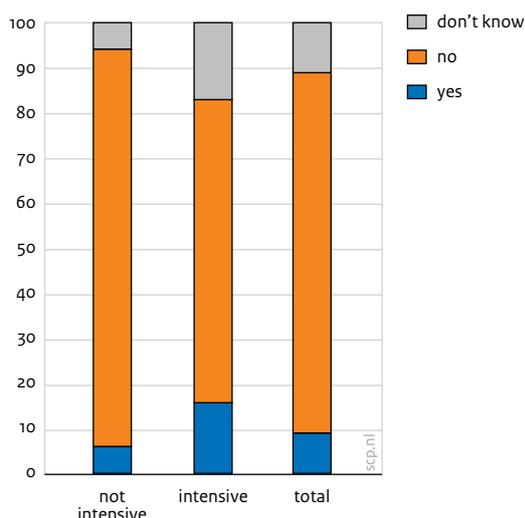


Source: SCP/CBS (IZG'19)

Majority of young people who provide care do not see themselves as informal carers

Only 9% of young people who provide care consider themselves to be an informal carer (in Dutch: 'mantelzorger') (Figure 7). Around 80% do not identify with that term and 10% don't know. Young people who provide intensive help (i.e. four or more hours per week) are more likely to see themselves as an informal carer (16%) compared to young people who do not provide intensive help (6%). The finding that many young people – including the intensive helpers – do not consider themselves to be informal carers could indicate that they think it's normal to provide help and do not see this as care. They might also perceive this term as stigmatising. The fact that young helpers tend not to see themselves as informal carers could mean that they will be less likely to seek out assistance labelled as 'informal care support' when they need help themselves. Experts also report that society has relatively little awareness of the fact that young people can also provide care (Nap et al. 2020).

Figure 7 Degree to which 16 to 24-year-olds who provide help consider themselves to be informal carers, according to intensity of the help provided (in percentages, n = 382)



Source: SCP/CBS (IZG'19)

Young people who provide informal care often combine this with school and/or work

In the study, those who reported providing help in the 12 months prior to the survey were asked whether they still do so now as well (17% of 16 to 24-year-olds). Participants were also asked questions about education and paid work at the time of the survey. Around 75% of the young people who currently provide informal care are attending school (230,000 people).⁶ Three-quarters of the young people who currently provide informal care are combining that with paid work (250,000 people, Table 2). Paid work includes working one or more hours per week, working for a short period, working for their own company or a family business, or doing freelance work. Half (52%) of the 16 to 24-year-old helpers combine their care responsibilities with both school and paid work (175,000 people).

Table 2 Number of helpers at the time of the survey who combined care responsibilities with education or a paid job, 2019 (in percentages of 16 to 24-year-old informal carers and numbers with 95% confidence intervals, n = 1432)^a

	(%)	number x1000	95% confidence interval	
			min. x1000	max. x1000
informal care at time of survey	17	330	290	370
of which also attend school	72	230	200	270
of which also work	75	250	210	280
of which work and attend school	52	175	150	200

a A 95% confidence interval indicates an interval of values that contains the population value with 95% certainty.

Source: SCP/CBS (IZG'19)

For one in five young people, the educational institution knows about their care responsibilities

One in five young people in our study say they have told someone at school or study (e.g. their mentor) about their care responsibilities. Three-quarters have not shared this information, and 5% don't know. No questions were asked regarding the underlying reasons for this. It could be that informing the school was not necessary, or that they found it difficult to discuss the care situation. The combination of attending school or study and providing care can cause scheduling conflicts and energy problems. We asked how often young people did not spend enough time doing homework, preparing for lessons or completing assignments because of their care responsibilities. One in four report that this was the case at least once a month, with intensive helpers reporting this more often. In addition, one in ten of these task-combiners say they miss some or all of their classes at least once a month. The other respondents

state that this is rarely or never the case. Research among university students has shown that, compared to those without care responsibilities, students who provide informal care report poorer academic results (Van Tienen et al. 2018). The present study did not ask about this.

One-quarter tell their manager about informal care responsibilities

One on four of the young people who combine work and informal care have told their manager about their care responsibilities. Over half have not. A small portion do not have a manager (9%) or do not know if they have told their manager (10%). The majority (86%) report not being less focused at work due to their care responsibilities. Eleven per cent say 'Yes, somewhat', with the intensive helpers among them reporting this more often (19%). The remaining respondents did not answer this question (3%).

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Notes

- 1 Worrying about an ill loved one can also fall under informal care. However, this is not included in this report.
- 2 <https://www.volwaardigleven.nl/actueel/artikelen/2019/07/23/portretmarjetkarssenbergh>.
- 3 Among other things, we examine whether there are significant differences ($p < 0.05$) between young people who provide intensive or non-intensive help. We only mention significant differences in the text.
- 4 The majority of young people (69%) help one person, 22% help two people and the remaining 9% help two or more people.
- 5 This could be a nursing home, an institution for the mentally disabled or another type of care facility.
- 6 The survey asked whether participants attended school, not which type of education they attended.

For more information, see: www.scp.nl.

Colophon

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You may also wish to get in touch with our Communications Department via email at communicatie@scp.nl.