In the spotlight: informal care in the Netherlands
What is informal care?

Informal care is care that is provided by someone who is close to the care-receiver. It may include:

- care given by members of the care-receiver’s household, relatives, friends, acquaintances, colleagues or neighbours which stems from a relationship between the care-giver and care-receiver; it thus excludes care and help provided by professionals or through organised voluntary services;
- support given by people because of health problems or disabilities, up to and including the terminal phase;
- support ranging from domestic help to personal care and support.

This report is based on research in which people were asked whether they provide help to relatives or friends. We do not distinguish between help provided to fellow household members as a matter of course, referred to in Dutch policy circles as ‘usual care’, and other forms of help.

How many informal carers are there?

It is not a simple matter to say how many informal carers there are in the Netherlands. The number depends on the definition chosen and the precise scope of that definition. Some restrict informal care exclusively to the giving of intensive care, while others also include voluntary work (Timmermans et al. 2004). This report is based on questions from a survey conducted by Statistics Netherlands (CBS) in 2008, which asked adults in the Netherlands whether they had offered to care for someone with a chronic disease or disability, someone with a temporary illness, someone who had received nursing care and had died at home, or someone in a different situation to whom they had given care. A survey in 2001 asked the same questions about informal care.

The report Informal care. An overview of the support given by and to informal carers in 2007 (Mantelzorg; een overzicht van de steun van en aan mantelzorgers in 2007) (De Boer et al. 2009) describes a group of informal carers who were providing intensive forms of care. The figures presented in this report cannot be compared with those from that report.
The number of informal carers in 2008

In 2008 there were 3.5 million Dutch people aged 18 years and older providing informal care (table 1). More than 2.3 million people had been providing care for more than three months, while 1.4 million were giving care for more than eight hours per week.

A good deal of government policy on informal care is targeted at people who are providing care long-term and/or intensively. In 2008, 2.6 million people were providing informal care for more than eight hours per week and/or had been giving care for longer than three months; that is around 20% of the adult population. Some 1.1 million informal carers were providing both intensive and long-term care.

What do these numbers mean for a municipality?

A municipality of 100,000 inhabitants contains an average of 80,000 adults, of whom 16,000 on average are informal carers who have been providing care for more than three months and/or for more than eight hours per week (20% of 80,000). Around 7,000 of these informal carers (42%) provide both long-term and intensive care.

Comparison with 2001

The number of informal carers was virtually identical in 2001 and 2008 (3.7 million in 2001, 3.5 million in 2008), though a shift did take place in the duration and intensity of the care. In 2001, 65% (2.4 million) of all informal carers were giving care for more than eight hours a week and/or for longer than three months; in 2008 this had risen to 74% (2.6 million informal carers). The percentage of informal carers providing both long-term and intensive care increased over the same period from 20% (750,000 carers) to 31% (1,100,000 carers).

Table 1  Number of informal carers in the Netherlands aged 18 years or older, by duration and intensity of care, 2001 and 2008 (in absolute numbers x 1,000)

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>total</td>
<td>3,700</td>
<td>3,500</td>
</tr>
<tr>
<td>more than 8 hours per week</td>
<td>1,050</td>
<td>1,400</td>
</tr>
<tr>
<td>more than 3 months</td>
<td>2,050</td>
<td>2,300</td>
</tr>
<tr>
<td>more than 8 hours per week and/or more than 3 months</td>
<td>2,400</td>
<td>2,600</td>
</tr>
<tr>
<td>more than 8 hours per week and more than 3 months</td>
<td>750</td>
<td>1,100</td>
</tr>
</tbody>
</table>

Source: scp (Mantelzorg 2001); CBS (IH’08) scp treatment
Number of informal carers in 2008 by care situation

Of the 3.5 million informal carers in 2008:
• 2.7 million were giving care to people who were chronically ill, temporarily ill or dying. The remaining 760,000 were giving care for other health reasons, such as problems relating to old age.
• almost 1 million were giving care exclusively to a person with a chronic illness or disability;
• almost 600,000 were giving care exclusively to someone who required help for a minimum of two weeks because of a temporary illness, accident or hospital admission;
• approximately 70,000 were giving care exclusively to a person who died at home and had also been nursed at home.

Number of heavily burdened informal carers in 2008

It is known that care-giving can over time impose a heavy physical, psychological or time burden on informal carers. In 2008, more than 450,000 informal carers in the Netherlands aged 18 years and older said that the burden of providing care weighed heavily on them. They felt that too much responsibility for providing care was placed on their shoulders, that their independence was suffering and that the care-giving was affecting their health and producing conflicts at work or at home.
A comparison between 2001 and 2008

The number of heavily burdened or overburdened carers increased from around 300,000 to 450,000 between 2001 and 2008 (figure 1). This is a striking increase. We know from the literature that intensive care-giving places a heavy burden on informal carers (De Boer et al. 2009). This type of care has increased in recent years (see table 1), and there has therefore been a concomitant increase in the number of heavily burdened care-givers. This increase is related to the growing emphasis placed by government policy on citizens’ own responsibility. As an example, in 2003 the Dutch government introduced the ‘Usual care protocol’ (Protocol gebruikelijke zorg), which requires fellow household members to provide long-term support and help in the household, as well as short-term help with personal care, unless they are unable to do so because of their own health problems. Moreover, there has been a shift from institutionalised to community-based care, as a result of which more and more people are receiving more intensive care at home (Van Tillaart 2010).

The rest of this report is concerned with (adult) informal carers who are providing long-term and/or intensive care. The reason for this focus is that this group are often taken as a starting point for the development of policy on support for informal carers.
Sex and age of informal carers providing long-term and/or intensive care

In 2008, 60% of informal carers in the Netherlands were women. This figure was unchanged from 2001. Almost half of all informal carers are aged between 45 and 65 years (figure 2). Here again, there was virtually no change between 2001 and 2008, though a shift has taken place within this group: in 2001, informal care was provided most often by carers in the 45-54 year age category (32%), while in 2008 they shared top place with 55-64 year-olds. The proportion of older informal carers has increased in recent years: where 13% of care-givers were aged 65 years or older in 2001, this had risen to 20% in 2008; this trend has also been described elsewhere (Sadiraj et al. 2009). The proportion of informal carers aged between 18 and 34 years fell from 16% in 2001 to 14% in 2008. This is related among other things to the fact that the share of this age category in the population also fell over this period.

Figure 2  Age distribution of informal carers providing long-term and/or intensive care, 2001 and 2008 (in percentages)

Source: scp (Mantelzorg 2001); cbs (iH’08), scp treatment
Ethnicity of informal carers providing long-term and/or intensive care

Contrary to what is often assumed, the percentage of non-Western migrants and their descendants who provide informal care is smaller (7%) than the percentage of non-Western migrants in the population as a whole (11%; table 2). Similar results have also been published by Schellingerhout (2008). This may be connected to the fact that there are few elderly members of the non-Western migrant population, and therefore less need for informal care. A difference in interpretation of the concept of informal care may also play a role.

<table>
<thead>
<tr>
<th></th>
<th>informal carers</th>
<th>total population</th>
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</thead>
<tbody>
<tr>
<td>indigenous Dutch</td>
<td>84</td>
<td>81</td>
</tr>
<tr>
<td>Western migrant</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>non-Western migrant (^a)</td>
<td>7</td>
<td>11</td>
</tr>
</tbody>
</table>

\(^{a}\) The category ‘non-Western migrants’ comprises people of Turkish, Moroccan and Surinamese origin and people from other non-Western countries, and also includes their children/descendants.

Source: CBS (IH’08), SCP treatment
Employment rate of informal carers providing long-term and/or intensive care

77% of all 18-65 year-olds in the Netherlands have a paid job for at least one hour per week; among informal carers the proportion is 71%. This difference is due to the fact that many informal carers are aged between 55 and 65 years (see figure 1), a proportion of whom do not work (any longer). Male informal carers are more often in paid employment (80%) than female carers (66%). Both groups work slightly less often than the population at large. Working women who provide informal care slightly less often have a job for at least 28 hours per week (45%) than working women in general (50%).

Social relationship between care-receivers and informal carers providing long-term and/or intensive care

In 2008, 40% of informal carers were providing care to a parent or parent-in-law (more than 1 million informal carers; figure 3). In addition, 18% were caring for a partner, 11% for a child/stepchild/foster child and 15% for another relative. One in six were providing care to friends, acquaintances, colleagues or neighbours.
In 2008, one in four male informal carers were caring for their partner (24%), compared with 13% of female informal carers. Women give care more often than men to parents/parents-in-law, children/stepchildren/foster children and other relatives.
References


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