Informal Care

The contribution of family carers and volunteers to long-term care

Dr. Alies Struijs
RVZ

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Council for Public Health and Health Care

PO Box 19404
2500 CK Den Haag
The Netherlands
Tel +31 (0)70 340 50 60
Fax +31 (0)70 340 75 75
E-mail mail@rvz.net

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Foreword

Family carers and volunteer caregivers make an important and indispensable contribution to long-term care. It is almost impossible to set a monetary value on the care that they invest in their loved one or other person requiring care, nor could it ever be entirely replaced by professional care. They contribute time, quality and attention that professional carers often cannot provide or, at least, cannot provide to the same extent.

However, the story that family carers and volunteers have to tell is not always a happy one. They are not trained for their task, they have difficulty combining work with other obligations, and they often face their problems alone and, as a result, run the risk of becoming overstressed. Apart from the pressure of personal circumstances, there are also the heavy demands that society and politicians are making upon them. The underlying reasons for this are simple but pressing: rising care costs and the anticipated labour shortages are necessitating cost control measures and other interventions in the care system.

What is the present situation and what will things be like in the near future? Are there enough informal carers available? And if there are, are they in a position to properly perform their care task? And how do informal carers relate to formal, professional carers? This study seeks to answer these three questions. The outcome of this enquiry lays an important foundation for the future advice on care under the Exceptional Medical Expenses Compensation Act (AWBZ).

Various experts have contributed to the realisation of this study, some of whom we mention by name here. A complete list of those consulted will be found in the Appendices. The internal preliminary study (RVZ, 2004) by Wendy van der Kraan offered a good start for this present study. The ‘Signalement Mantelzorg, kostenbeheersing en eigen verantwoordelijkheid’ (Report on Family Caregiving, Cost Control and Self Responsibility), by Maartje Schermer (CEG, 2004), provided an important foundation. The pleasant and fruitful collaboration with Trudy Schreuder Goedheijt and Geraldine Visser of the Expertisecentrum Informele Zorg (EIZ/NIZW) led not only to information, advice and comments, but also to a successful expert meeting under the skilful leadership of Henk Nies (NIZW/Zorg). It is partly thanks to the contributions of the experts during and after that meeting that this background study is able to provide as complete as possible an overview and an up-to-date picture of what informal care can contribute to caring for people with a limitation.

Council for Public Health and Health Care,

Chairman of the Council for Public Health and Health Care,

F.B.M. Sanders

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Informal care: the contribution of family carers and volunteers to long-term care

Summary

It is anticipated that greater demands will be made in the years to come on informal care (that is, care provided by family carers and volunteers) as a result of developments such as the increasing ageing of the population, the socialisation of health care, and the higher thresholds for the allocation of professional care. This background study reveals the contribution that informal care can make over the next 5-10 years. Three questions occupy a central position: Are there enough informal carers available? What is the situation regarding the quality of informal care? What is the situation regarding the interrelationship of formal and informal care?

Capacity

Various national and international research studies have shown that no shortage of informal carers should be expected if present circumstances remain unchanged over the next 5-10 years. Indeed, if the present trend continues, then supply may even outstrip demand. Some observations do, however, need to be made regarding a development that may at first sight appear favourable. Of course, it is not beyond the bounds of possibility that circumstances will change (for example, due to the continuing socialisation and extramuralisation of care, budgetary restrictions and labour shortages). In addition, there are two competing policy aims that could have negative consequences; namely, an increase in the participation of women and the elderly in the labour market, and greater demands on informal carers. Family caregiving will come under pressure if more women are more highly educated and if they obtain either full-time jobs or part-time jobs requiring more than 12 hours of work a week. The conclusion that there are and will continue to be sufficient informal carers, despite the increased labour participation of women, must therefore be treated in a cautiously positive spirit.

Quality

The situation regarding the quality of informal carers, especially family carers, is less favourable due to:

- Difficulty in combining care with other tasks and lack of support, which increase the risk of excessive stress.
- Excessive stress that can degenerate into abusive care and a risk of mistreatment of persons in need of help.

- Professional carers who pay insufficient attention to the family caregiver's ability to cope and who offer insufficient supervision and support.
- The combination of work and care, which leads to a double burden.
- A lack of structural possibilities for respite care and other forms of family caregiving support.
- Extra financial expenditure and loss of income.

Relationship of formal and informal care
The relationship between formal and informal care is defective but improving. Formal care will have to pay more recognition and attention to the deployment and quality of family caregiving. Formal and informal care badly need each other and will have to accept each other as (unequal) partners in the care process. It is important that the family caregiver and the professional carer collaborate from the needs assessment stage onwards, supplemented on occasion by volunteers. Regular communication, harmonisation and task allocation (as well as a shared vision of the approach to care tasks) can improve the quality of care for the care recipients, prevent family carers from suffering excessive stress, and prevent or postpone expensive admissions. Family carers must not only be seen as co-carers. They are often also co-clients and also need supervision and support. Carers should integrate a family caregiving policy into their quality policy, as is already often the case for volunteers.

Capacity and quality of informal care:

1. Invest in different forms of supervision and support for informal carers. A greater appeal to informal care demands a higher investment in supervision and support. Investing more in informal care does not mean investing less in professional care.

2. Make it easier for people to opt for informal care (or family caregiving) by offering discounts on public transport, tax relief and vouchers for respite care.

3. Ensure that care recipients can retain their freedom of choice and (relative) independence via the Personal Care Budget, and regulate this in the WMO and the Health Care Insurance Act (ZVW). Expand the Personal Care Budget opportunities, and do not prevent people from paying for family caregiving out of the Personal Care Budget.

4. Encourage structural measures aimed at creating an employer’s policy that is positive towards family carers. If the

government wants to achieve two competing policy goals, namely greater participation in the labour force by women and the elderly and a stronger appeal to the deployment of family carers and volunteers, then this demands that bridges be built between work and care. Projects such as the family caregiving broker deserve expansion and follow-up.

5. Ensure that, via the WMO and consultation with the union of Dutch local authorities (the VNG), local authorities focus on the contribution that immigrant population makes to family caregiving and volunteer caregiving. Immigrants are more likely to provide family caregiving, but they risk their position in the labour market as a result. Attracting immigrants to voluntary work demands an extra effort but repays double, because it also has an integrating and emancipating effect.

6. Encourage local authorities and care providers to familiarise non-natives with family caregiving support in order to prevent non-native women from missing out on educational opportunities or chances in the job market.

Cooperation between informal and formal care

7. Use legislation (for example, the Health Care Establishments Licensing Act, the WTZi) or financial incentives to encourage cooperation and harmonisation between informal care and formal care. Informal carers are an indispensable but vulnerable link in the care chain. With the support and guidance of professional carers, they can stick at their task for longer and the admission of the person in need of help can be prevented or postponed.

8. Encourage professional care institutions to give volunteer caregiving and family caregiving a structural place in their quality policy. This is necessary to guarantee a sufficient quality and quantity of informal carers in long-term care.

9. Encourage frequent cooperation between professional and informale care. Professional care has a great deal to offer informal care, such as advice, guidance, skills training and the sharing of knowledge. Conversely, professional carers also benefit from good communications with the family caregiver. This can be achieved via regular exchange of information, harmonisation of views and the sharing of care tasks.

10. Encourage a situation where the client and the family caregiver are (jointly) given more say in the desired task allocation, and receive more support in this process from the needs assessment stage onwards. Involve the client and the family caregiver directly in joint consultation in the needs assessment, and work on more flexible harmonisation of vision and tasks between family carers and professional carers.

11. Discourage care professionals from working in an exclusively client-directed fashion and encourage them to adopt a family approach or to involve family carers in the care process. Family carers are not only co-helpers but often also co-clients. Supervising and supporting family carers not only benefits them, but also has a positive impact on the state of health of the care recipient.

12. Ensure that the local authorities implement structural and financial measures for respite care within the framework of the WMO by purchasing care from care providers and volunteers. This could be done, for example, via a voucher system for respite care.

13. Give informal care (family caregiving and volunteer caregiving) a structural and systematic place in the training of carers. Ensure that dealing with informal care is included as a competence in the syllabuses for professional qualifications. The professional partial qualification for social health care nurses can act as a source of inspiration for this.

1 Introduction

Informal care is an important and indispensable part of long-term care. Informal care is in this study an umbrella term that covers the types of care provided by anyone other than professional carers. Over three-quarters of all long-term care is provided by 'family carers'[1] and volunteers. The potential for informal care as an integral part of long-term care cannot be overlooked, nor can it any longer be ignored when formulating health care policy.

1.1 Study objective and topics for research

It is anticipated that increasing demands will be made in the near future on informal care as a result of developments such as the 'double ageing' of the population, the extramuralisation of care and higher thresholds for referral to professional health care. The objective of the present background study is to obtain a clear idea of the potential of informal care (family carers and volunteers) over the next 5-10 years. In particular, it will examine the contribution of carers and volunteers to long-term care.·

This study sets out to answer three questions. The first of these is whether there will be enough carers and volunteers to meet the future needs of long-term care. It is, of course, anticipated that the demand for informal care will increase and that the supply will diminish due, among other factors, to the increase in the number of women in the labour market. The second question concerns the competences of informal carers. Are carers and volunteers really in a good position to provide care? Do they have sufficient in-house expertise, and can they physically, mentally and financially sustain that level of expertise for what may be a considerable length of time? What problems are they are likely to encounter? The third and final question concerns the relationship between formal and informal care: what is the existing degree of cooperation between them and are improvements in this relationship necessary and possible?

This study, which focuses on carers and volunteers in long-term care, is primarily concerned with the situation in the Netherlands, although there are occasional glances at the situation beyond Dutch frontiers. After all, an international perspective sometimes offers valuable clues to the direction in which solutions to the problems of the Netherlands might be found. However, to prevent excessive overlap with other background studies in which the international perspective predominates (see RVZ, 2005; RVZ, 2006) this study adopts such a perspective to only a limited extent. The study is further constructed as follows: definitions of the concepts used are followed by an overview of the facts and the foremost problems in the light of the three above-formulated questions. The findings will be analysed and conclusions drawn in a 'final consideration'.

1.2 Conceptual framework for Informal Care

'Informal care' (in the Dutch context) can be understood to mean various types of care that are not provided on a professional basis. In a broader sense, the term covers such concepts as 'self-care', 'usual care', 'family caregiving' and 'volunteer caregiving.'

Self-care comprises all those actions and activities that a person consciously performs for the benefit of his or her own health (including both preventive actions and, for example, treatment via self-medication) (EIZ website, 2005).

Usual care is "care that does not involve any recourse to the Exceptional Medical Expenses Compensation Act (AWBZ). It is the normal everyday care that partners or parents and children living at home are considered to offer each other because they maintain a household together as a dwelling unit and on this basis are therefore jointly responsible for the functioning of that household." It is only correct to use the term 'usual care' in the context of a joint household (Protocol Gebruikelijke Zorg, CIZ, 2005).

The Dutch term for usual care ('gebruikelijke zorg') has only been around for a couple of years (LVIO, 2003). It is a policy term used in patient needs assessments to demarcate those circumstances under which no recourse can be made to the AWBZ. Usual care cannot, therefore, be replaced by care under the AWBZ, unless there are no other people in the dwelling unit. Usual care is primarily a classificatory term and establishes a threshold for eligibility for care under the AWBZ. Only the domestic, personal and supervisory assistance aspects of usual care fall within the scope of claims under the AWBZ. Thus, the other functions to which care under the AWBZ relates (exercise activation, nursing, treatment and residential care) play no part in usual care.

Family caregiving (Dutch:'mantelzorg' and English: 'informal care') is defined by the Netherlands Ministry of Health as "the long-term care for a person in need of help that is provided by people from that person's immediate environment and which is not provided within the framework of a caring profession, in which the care provision directly arises from the relevant social relationship" (VWS, 2001).

The original Dutch term *mantelzorg* dates from the seventies (Hattinga Verschure, 1977). The Expertise Centre for Informal Care (EIZ) distinguishes between the following aspects of family caregiving (EIZ, 2003):

- the *extra* care (that is, more than is usual in a personal relationship);
- the care that family members, friends, acquaintances or neighbours provide on a voluntary and unpaid basis;
- the care provided within a to people with quite severe physical, family, domestic situation or social network intellectual or psychological limitations.

One striking difference in this latter definition is that, in contrast to the definition used by the Ministry of Health, it explicitly states that family caregiving is *voluntary* and *unpaid*. This is striking because family caregiving is not always regarded as voluntary and because its cost is often defrayed via the care recipient's Personal Care Budget[2]. As a result some people think that caregiving that is paid for out of the Personal Care Budget is not, in the strict sense, informal or family caregiving at all. Others think that it is so important to be able to pay for some or all of the informal caregiving that this constitutes a major reason for applying for a Personal Care Budget in the first place (Ramakers & Van den Wijngaart, 2005). In some other countries, e.g. Ireland and Finland, it is quite usual for carers to receive a reimbursement or an allowance, or alternatively (as in, for example, Austria) to be paid out of the Personal Care Budget of the care recipient (RVZ, 2005; NIZW 3, 2005). The boundaries between compensation, reimbursement and payment are sometimes not entirely clear.

Carers do not always think of themselves as such. This is true, for example, of parents of handicapped children, partners who care for each other more than the average couple do and people from other ethnic or cultural backgrounds.

Volunteer care is a form of voluntary work. ‘Voluntary work’ is understood to be work that is performed in any context on a non-obligatory and unpaid basis for other people or for society in general (Van Gorp & Steenbergen, 2004). Volunteer care is therefore care provided on a non-obligatory and unpaid basis to people in need of help outside one’s own social network, whether or not as a supplement to professional care or in order to support or replace carers (EIZ website, 2005).

The tasks of volunteers can vary and are based on choices made by the organisation to which they belong. A contract is often concluded with the volunteer, who receives out-of-pocket expenses[3]. The management of the voluntary organisation will decide where it wants to deploy its volunteers. Volunteers in health care are active in sectors such as:

- buddycare: providing emotional support and practical help for people suffering from serious illnesses such as AIDS, cancer. ME or an addiction;
- maatjesprojecten ('friend projects'): initiatives in which trained volunteers undertake recreational activities and sometimes provide practical help to former and existing psychiatric patients, teenage mothers, homeless youngsters or the handicapped;
- nursing home care: almost all nursing homes have volunteers who perform tasks such as providing social contact, psychological support and practical assistance;
- caring for the handicapped: providing support for social, recreational and sporting activities, general assistance and handyman help, assistance with transport and meals-on-wheels;
- home care: care, supervision and support for people in need of care provided by volunteers in the care recipient's home environment. This is often coordinated by volunteer centres, but also by home care institutions;
- respite care: the temporary assumption by other people of all the responsibilities of carers (for example, caring for someone in their own home, day care, short-term admissions, etc) (EIZ website 2005; Scholten 2004; Van der Kraan 2004).

1.3 Similarities and differences between types of informal care

Family caregiving and volunteer caregiving are jointly known as 'informal care' (as umbrella term) and are accordingly seen as a counterpart to formal or professional care.

Similarities between family caregiving and volunteer caregiving include:

- Obligation or free choice: purely voluntary, with no possibility of compulsion by the authorities.
- Motivation: finds its roots in love, a sense of responsibility, a desire to be useful, helpfulness, the desire to receive credit for making an effort, acquisition of experience.
- Remuneration: unpaid.

Differences between family caregiving and volunteer caregiving include:

- Social relationship: family caregiving is performed within the social network of the care recipient on the basis of a family or social relationship. Voluntary care has an external origin, in that the volunteer has no previous connection with the care recipient.
- Obligation or free choice: family caregiving is seen as a moral obligation, which means that it is not easy for the family caregiver to withdraw from the care relationship. Voluntary care is a free choice to either perform a care task or not. Family carers will also become overstressed more rapidly than volunteers because of their 'feeling of obligation'.
- Degree of organisation: volunteer caregiving is distinguished from family caregiving by the organised and contractually-based nature of the relationship.
- Policy: it is particularly intramural care institutions, such as nursing homes, that often have a volunteer policy, although they do not usually have a policy on family caregiving.

Role in patient needs assessment

Usual care and family caregiving have a role to play in patient needs assessment. Whether they get the opportunity to play that role, and to what extent, depends on the circumstances. The care needs assessment is formally dependent on the degree of usual care present. All care above and beyond usual care is family caregiving and/or care subject to a needs assessment. The 'Usual Care Protocol' was drawn up to ensure accuracy in assessing whether such extra care is necessary (CIZ, 2005[4]. This is the threshold that is established for the allocation of professional care. The aim is to encourage people to shift for themselves for as long as possible and for family members themselves to provide the usual care. Differences of opinion can arise between the needs assessor and the family members as to whether the extent of the care should or should not be regarded as 'usual'. If such disputes arise, then a needs reassessment can be requested. In practice, the family caregiving that is available is playing an increasingly important part in the needs assessment and is involved in the execution of the various care tasks (Marseille, 2004).

Usual care precedes the request for formal care and determines its extent. If the carer voluntarily states during the needs assessment that she/he is willing to assume responsibility for certain tasks, then the needs assessment can be accordingly reduced. Once formal care has begun, formal and informal care (that is, family caregiving) complement each other. In certain care tasks, formal and family caregiving can actually replace one another. Family caregiving is enjoying increasing recognition in government policy, but the professional care institutions are also taking more and more notice of it in their everyday practice.

Degree of moral obligation or deliberate choice
Usual care is definitely thought of as much more of a natural obligation or personal responsibility than is family caregiving. The underlying idea is that people who form part of one and the same household are jointly responsible for its efficient functioning. Usual care cannot therefore be replaced by professional care, unless there is no one else in the dwelling unit. Usual care is based on values such as caring for your nearest and dearest, taking responsibility for each other (solidarity) and reciprocity. Family caregiving occupies an intermediate position in this conceptual framework. From a policy angle, family caregiving is based on a moral appeal to individual or joint responsibility and the sense of fellowship. At the same time, the voluntary basis of family caregiving is emphasised. Carers themselves often see it as a moral obligation or responsibility and not as a free choice. "Family caregiving takes you over", as one carer put it. Or again, "It's an obligation to your nearest and dearest" (RVZ expert meeting, 2005). Voluntary care is a deliberate choice of the individual, but it can be motivated and stimulated by appealing to values such as social responsibility, solidarity and citizenship.

Duration and intensity
It is generally assumed at policy level that usual care (that is, if it includes at least personal care) will last for a period of less than three months. Family caregiving can last for more than three months and is offered for more than eight hours a day (Protocol Gebruikelijke zorg, CIZ, 2005). Voluntary care has no time limit. The intensity of the different types of informal care also varies. Usual care is often 'light' care, but it can also sometimes be heavy, while family caregiving varies from heavy to light, and volunteers perform both heavy and light tasks.

1.4 Conclusion

Informal care is understood as an umbrella term in this study, that is, the term is used to mean family caregiving and volunteer caregiving[5]. This restriction helps explain why informal care is being studied in connection with recommendations about the future AWBZ. After all, this legislation addresses the question of how much of a contribution informal care makes to long-term care. The government sees self-care and usual care as natural or usual forms of care, which cannot in principle be replaced by professional care. Family caregiving is care that is subject to a needs assessment and which is characterised as ‘extra care’ given by someone from the care recipient's immediate environment (family and/or social network). In certain tasks, informal care (understood below as family caregiving *and* volunteer caregiving) can both supplement (complement) and replace (substitute for) professional care.

2 Facts about capacity

2.1 Introduction

Society is changing. It is becoming more individualistic and more multicultural, and is also subject to double ageing[6]. Health care is becoming more socialised, demand for health care is increasing and so are the costs. Family composition has also changed, especially during the period after the Second World War. Families have become smaller, which means that there are fewer children to care for more old people. The high divorce rate also means more broken homes and more step-families. It is partly as a result of this development that the number of people living alone has increased. Children are more often to be found living further away from their parents. Older people are living longer. Instead of three generations, there are now more likely to be four. That means not only that the care period is becoming longer, but also that the availability of carers aged 65 and over is increasing[7]. These social and demographic shifts are also affecting the availability and deployability of informal care. This chapter begins with some facts about informal carers, followed by a section that focuses on the first question that this study seeks to answer: are there enough carers and volunteers available to meet the demand for informal care? To answer this question, we first need to examine whether demand for informal care will indeed increase over the next 5 to 10 years.

2.2 Characteristics of informal carers

The composition of the supply side of informal care has changed due to changes in the make-up of the population and shifts in subgroups of carers/volunteers. To obtain a clear idea of what informal carers are like, distinctions are made by gender, age and ethnic origin (immigrant/non-immigrant), as well as according to whether care is combined with paid work.

Table 2.1 **Composition of the group of informal helpers[a] aged 18 and over, 1991 and 2003 (percentage values in vertical columns)**

	1991	2003	significance[b]
Age category			*
18-34 years	26,7	17,9	
35-44 years	22,7	19,4	
45-54 years	20,9	25,1	
55-64 years	17,2	20,5	
≥ 65 years	12,6	17,1	
workforce participation[c]			*
not working	63,0	50,3	
working part-time	12,6	25,3	
working full-time	24,5	24,4	
gender			n.s.
male	32,0	34,1	
female	68,0	65,9	

[a] People who regularly (but not professionally) provide help to the sick or handicapped.

[b] *: $p < 0.05$; n.s.: not significant ($p > 0.05$).

[c] By everyone aged 18 and over, thus including the elderly.

Source: SCP (Social and Cultural Planning Office, Amenities and Services Utilisation Survey '01 & '03)

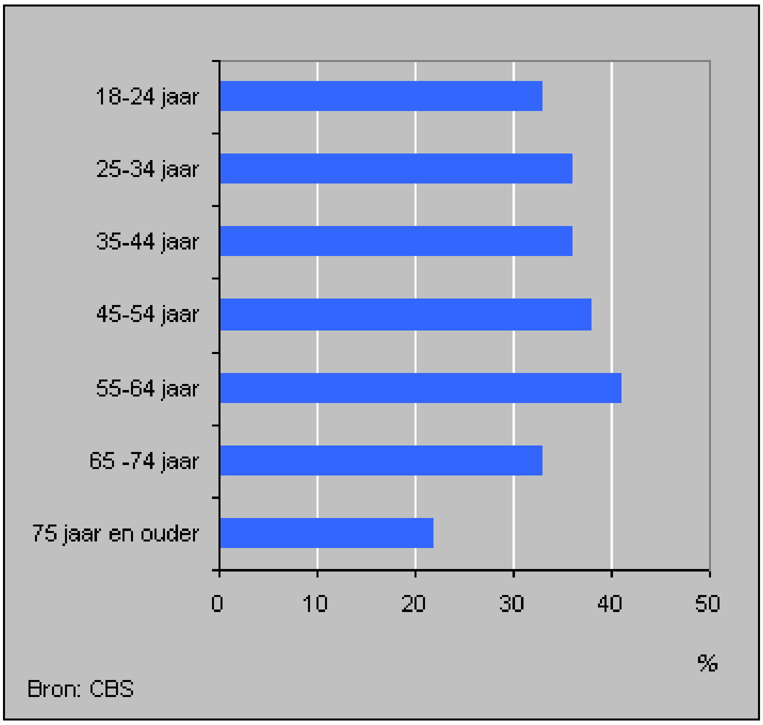
Male/female ratio

Research carried out in 2003 (Timmermans & Woittiez, 2005) revealed that informal carers are much more likely to be women (65.9%) than men (34.1%). However, the gap between the number of men and women has narrowed compared with that in 1991. In 1991 the proportion of women was 68%. The proportion of men and women becomes more equal after the age of 65.

Age
According to the SCP (Timmermans & Woittiez, 2005), there has been a decline in the amount of help provided by younger people (18-34 and 35-44 years of age) and an increase in the number of older helpers (aged over 65). Hardly any data are available on young (below the age of 18) carers. Most carers are aged between 45 and 65. The group of older carers has modestly increased compared with 1991. There was a 3.3% increase in the 55-64 age bracket and there was a 4.5% increase in those above the age of 65.

Over 30% of informal carers are aged 55 or older, while 20% of all carers are over 75. According to Statistics Netherlands, the number of people over 65 in voluntary work and in informal assistance (i.e. family caregiving) has increased [8]. The number of informal helpers has also increased among the rest of the adult population, but the number of volunteers actually fell. The percentage of people over 65 who are performing voluntary work increased from 27% in 1997 to 35% in 2004. Elderly people in the 65-74 age bracket were approximately twice as likely to be active in voluntary work as the over-75s during this period. The percentage of volunteers fell in the age brackets 25-44 and 45-64. The figures among the young fluctuated so that no clear trend was visible. An overview of the numbers of carers in each age bracket is provided below.

Figure 2.1 Informal helpers (=carers) according to age, CBS 2002



jaar = years
jaar en ouder = years and older
Source: CBS 2002

Autochthonous and immigrant population

Family caregiving is found in all population categories. People's views on family caregiving differ because of differences in their lifestyles and cultural background. Many immigrant families see it as a moral obligation to resolve care-related problems within their own circle. Family solidarity is much more strongly emphasised than it is among autochthonous Dutch population, as is also apparent from the higher percentage of carers to be found among immigrants (CEG, 2004). The other side of this particular coin is that young women, in particular, remain at home to provide care and can thus fail to complete their education or perhaps miss out on opportunities in the job market.

Although immigrants provide a relatively large amount of family caregiving, their contribution to volunteer caregiving is not quite so great. It is chiefly Turks, Moroccans, the less well educated and the young who are less involved in voluntary work in general (Klaver, 2004). Those who are active as volunteers have a better socioeconomic position, well-paid jobs, are well educated and have intensive contacts with Dutch people. The higher the educational standard, the greater the proportion of immigrants involved in voluntary work. Even so, the relative proportion of immigrants still lags behind that of the autochthonous population.

Table 2.2 For purposes of comparison, this presents the social participation percentages of immigrants and autochthonous people measured on two dimensions: Family Caregiving (FC) and Volunteer Caregiving (VC) (Klaver, 2004)

	VC and FC	FC only	No acivities
immigrants	22	58	21
autochthonous people	43	40	18

The SCP (Schellingerhout, 2004) has calculated that 54% of independently-living older Moroccans and 30% of Turkish over-55s receive informal help (i.e. family caregiving from children living at home with them). The provided help is primarily of a domestic nature. Home care is not, or is hardly, used by Moroccans, Turks, Moluccans and Antilleans. Immigrant users of home care are generally satisfied with the services offered (indeed, more so than autochthonous Dutch users). They do, however, find home care too expensive. Turkish and Moroccan women aged 65 and over seem to be the least familiar with home care. According to the SCP, immigrants make hardly any use of private paid help.

Participation in the labour market

The number of people that combine their care task with the performance of paid employment has increased. The difference between working and non-working informal carers has shrunk to virtually zero. Whereas the ratio in 1991 was two-thirds non-working to one-third working, the ratio is now 50-50. There has been a decline in the number of people available for family caregiving in the 18-34 age bracket. This is explained by the fact that participation in the workforce by women in this age bracket has risen over the past 12 years. Especially noticeable is the proportion of carers working part-time. In 1991 12.6% of carers combined their care task with a part-time job, whereas by 2003 this percentage had increased to 25.3%. One explanation for this is that more women have started working, especially in part-time jobs requiring less than 12 hours of work a week.

Summary
The picture that emerges from the above data is that there are still more women than men performing informal care tasks. However, the gap is narrowing. A shift is also discernable as regards age, in that there are an increasing number of older carers. Immigrant and autochthonous people generally provide just as much informal care, but there are some differences. Immigrants provide relatively more family caregiving, while autochthonous people provide relatively more volunteer caregiving.

It is also striking that the number of people working part-time who are combining that work with informal care has doubled over the past 12 years. The difference between the number of working and non-working carers has decreased. There are now almost as many working informal carers as non-working ones. The increase in the number of women on the labour market does not, in general, seem to have led to a decrease in informal care provision. The relative proportions could turn out differently if women start working in part-time jobs requiring more than 12 hours of work a week (which, given the rising educational standard of women, is not unlikely).

2.3 Is the demand for informal care increasing?

According to the latest data from the SCP (De Boer, 2005), the demand for informal care (=family caregiving) is expected to increase by 5% in the period up to 2020. This rate of growth is much less than anticipated. That is primarily due to the fact that many (older) people in need of help can call on private (usually domestic) help, thanks to their better financial position. The combination of family care alone supplemented with private domestic help is increasingly common. In addition, part of the demand for help can be met by the supply of professional home care. The SCP does, however, point out that in making this estimate it has assumed that the supply of professional home care is not going to be restricted by government policy and that the financial position of people in need of help is not going to worsen.

Table 2.3 Trend in the number of users of informal care aged 30 and over, by help combination, 200-2020 (index: 2000-100)

	Population	Informal care only	Informal + private help	Informal + domestic AWBZ help informal		Informal care + admission to care home	Informal care + admission to nursing home	Total informal care
2000	100	100	100	100	100	100	100	100
2005	106	103	106	102	113	109	105	104
2010	109	103	108	101	119	118	111	104
2015	112	102	112	96	132	125	114	104
2020	114	103	120	101	141	130	117	105

Source: SCP (Amenities and Services Utilisation Survey '99 & Elderly people in institutions survey '00)

The striking thing about this table from the SCP (De Boer, 2005) is that it shows that demand for informal care (= family care) will, in general, moderately rise over the next 15 years, while the combination of informal care (= family care) and a form of professional care will sharply rise. The combination with private help will increase by 20%, with home help provided under the AWBZ rising by 40%, the combination with admission and residential care by 30%, and the combination with care in a nursing home by 17%.

The elderly

The increase in the proportion of elderly people and the proportion of men in the population combined with the growth in chronic diseases is causing the demand for informal care to rise. According to the SCP, this rise is almost entirely neutralised by the better socio-economic conditions of the elderly and by, in particular, the rising standard of education. Van der Geest (RVZ, 2005) also asserted that the average income position of the elderly is considerably improving and that the standard of education is a decisive factor in determining demand for professional care. A striking feature of this is that the better-educated seek help earlier than less well educated people with similar health problems, but ultimately make less use of care paid for under the AWBZ. The trend in the Netherlands is that people will continue to live at home longer, with fewer admissions, a sharp increase in demand for 'care at home' and less recourse to care under the AWBZ by the better-off among the elderly. This is in line with the trend in almost all OECD countries (RVZ, 2005; OECD LTC, 2005).

More than one-third of people aged 55-64 have physical limitations, while the equivalent figure for those aged 75-84 is almost three-quarters and 95% of people over 85 have long-term physical limitations. Potential demand for care financed under the AWBZ will rise by half over the next 20 years. Use will increase by one quarter. This means that, in the future, the elderly will increasingly have, and will sometimes be able to and prefer, to find their own solutions to their care needs (Factsheet Vergrijzing en Informele zor*g* [Fact Sheet on Ageing and Informal Care], NIZW, 2005).

People with dementia
The Netherlands has approximately 200,000 people with dementia. By 2030 that figure will have increased by 50% to 300,000. It is estimated that 29,000 places will be available in nursing homes ten years from now. In other words, a very large number of volunteers and carers will be required to assume responsibility for providing intensive and, for the carer, stressful care for demented elderly people (ARN, 2005; *Factsheet Mantelzorg en Dementie* [Factsheet on Family Caregiving and Dementia] EIZ/NIZW 2005).

Approximately 7% of all people over 65 have dementia, while the figure for the over-80s is approximately 20%. The average age of people with dementia is 79, the majority of whom are female (71%) because women live longer. More than three-quarters of dementia patients have high-level care needs: 38% of all dementia sufferers need daily care and 39% need continuous care. Approximately 60% of those living at home are dependent on daily or continuous care. In nursing homes, 99% of people need care every day and 90% need continuous care. Care increases as dementia advances (*Factsheet Mantelzorg en Dementie*, EIZ/NIZW, 2005).

According to researchers at the three Alzheimer centres in the Netherlands, more home care will have to be provided in the future. Whether that demand can be met will be determined by the behavioural problems of the dementia sufferers and by the (perhaps excessive) stress or feelings of competence of the carers. The admission of elderly dementia sufferers to a nursing home can be postponed by one year if supportive interventions are made[9].

Psychiatric centres
Relatively little research has been done on the relationship between psychiatric centres (GGZs) and informal care. It is known that approximately 2% of the entire population suffers from a serious psychiatric disorder. It is estimated that at least half are receiving help from carers. The majority of the people being cared for do not live in the same house as the family caregiver. As a result of the socialisation

of health care, people with a psychiatric disorder are making increasing demands on their social network. Family members, partners, friends and others in their social circle are assuming a considerable share of the responsibility for providing support and supervision so as to enable many people with psychiatric complaints to live (or continue living) at home (Website and *Factsheet Mantelzorg en Dementie*, EIZ/NIZW, 2005).

Summary
The demand for informal care will, in general, not increase by very much. In the case of elderly people, this phenomenon can be explained by the fact that more and more older people have a higher standard of education and are better placed socioeconomically, and are therefore starting to combine informal help with private care. If we take the present situation as our baseline, then it is primarily combinations of informal and formal care that will increase. The combination of informal (= family) care with professional home care under the AWBZ will increase the most. Highly educated and well-off older people make relatively less use of care financed by the AWBZ. The number of people with dementia will substantially increase. Here again admissions will increasingly be postponed and the demented will be cared for at home for as long as possible. As a result of the socialisation and extramuralisation of health care, there is increasing demand for the informal care of people with a psychiatric disorder.

2.4 Is there a sufficient supply of informal care?

Carers

The Netherlands has about 3.75 million carers. Of this number, 2.4 million are long-term carers (in other words, they provide care for at least 8 hours a week or for more than 3 months at a time). The latest SCP report (De Boer, 2005) also dealt with the latter category and arrived at a figure of 2.5 million for the year 2000.[10] On the average, carers care for people 19 hours a week, but for family members and partners that figure can be as high as 45 hours per week. Eighty percent of all carers do *not* form part of the household. They are often children who are looking after their parents or in-laws. The supply of carers is currently keeping pace with trends in demand. The number of carers has not fallen. Availability has, however, decreased. Important reasons for this are recourse to paid work and the physical distance between carers and requesters of care. Family caregiving is more difficult to organise and the stress levels are increasing, but carers are not (yet) ready to throw in the towel (RVZ expert meeting 2005; Isarin, 2005; OECD, 2005)

It is anticipated that the supply of informal care will increase over the next twenty years by 15% and that this increase will pretty much keep pace with the growth in the population (14%). The improved socio-economic position helps explain this, in that the better a person's socioeconomic position, the fewer demands he/she makes on informal care, but the more such care is able to be provided (De Boer, 2005).

Table 2.4 Trend in the number of informal care providers aged 30 and over, by type of help need, 2000-2020 (index: 2000=100)

	Population	Total supply	Long-term help	Short-term help	Help to the dying
2000	100	100	100	100	100
2005	106	106	109	106	105
2010	109	110	112	110	110
2015	112	113	117	113	114
2020	114	115	120	114	117

Source: SCP (Amenities and Services Utilisation Survey '99 & Elderly people in institutions survey '00)

The supply of informal (= family) care to the chronically ill and the handicapped is rising faster than the average (20%). According to the SCP, the increase in the supply side can be explained by the higher standard of education of the future population. The 44-64 age bracket, among whom the largest number of carers are currently to be found, is also undergoing substantial increase. There are hardly any trends that will put the brakes on the supply. It is, indeed, true that carers in paid work are offering less help (that is, a lower volume of care) than those who work part-time or who do not work at all. The SCP concludes that, despite rising participation in the workforce, the proportion of helpers in the population has remained static over the past fifteen years, while the professional supply side has decreased during the same period (De Boer, 2005).

Family caregiving and dementia

There seems to be a range of apparently effective supporting interventions available to carers, such as training professional home carers in the supervision of carers at home and providing meeting centres for people with dementia and their carers. These interventions seem to have a positive effect on carers' feelings of competence and seem to reduce admissions of dementia sufferers. However, there is not just one working model, and the search for more custom-made care is important (personal disease management). People with dementia can remain at home for longer thanks to early diagnosis and interventions (ARN, 2005).

We do not know how many carers are currently caring for people with dementia. It is, however, clear that 60% of the help given to dementia sufferers comes from family members. The question is whether sufficient informal care will be available in the future to cope with the increase in the number of dementia sufferers. A capacity problem certainly will arise in professional care if, 10 years from now, there are indeed 300,000 dementia sufferers and only 29,000 places available in nursing homes (Factsheet Mantelzorg en Dementie, EIZ/NIZW, 2005).

It thus seems to be true that carers can make an important contribution to the care of their loved ones, and that this is a contribution that actually helps to reduce admissions. Informal care is therefore also contributing to efficient care. It is impossible to estimate the exact number of people in need of care in general that, thanks to informal care, do not (yet) need to make demands on formal care, but it probably runs into several hundred thousands per year (De Boer, Schellingerhout en Timmermans, 2003).

Volunteers

What is the situation regarding the number and availability of volunteers? A decline is to be expected, due to fewer opportunities and less willingness to get involved as a volunteer. At the same time, new groups of volunteers are coming forward with a different motivation: not just a desire to care for people but also self-interest, such as acquiring work experience and building up a network of contacts. The proportion of immigrant volunteers could also increase in the future. A higher standard of education and a better socioeconomic position will help bring this about. Making voluntary work attractive to immigrants can also help them to emancipate themselves and to integrate (Klaver, 2004). The Cabinet recently issued a policy statement on voluntary work in which it said that it wanted to encourage voluntary work among immigrants (Beleidsbrief VWS, 2005).

Volunteers are often members of national organisations with local branches, such as the Zonnebloem, the Netherlands Red Cross, the Salvation Army, Humanitas and home care and home-help organisations. Almost all nursing homes also use volunteers and some nursing homes even have their own volunteer pool.

Here is a quick glance at the figures. Thirty-five percent of care personnel are volunteers (in other words, a third of them). The Netherlands Institute for Care and Welfare (NIZW) estimates that some 350,000 volunteers are active in the care sector. The NIZW is, in response to a commission from the Verweij Jonkerinstituut, currently identifying the number of volunteers. Precise numbers are still not known.

The SCP is researching the supply of volunteers in *voluntary home care*. Demand there ranges from 470 to 98,000 requests for help, and there are between 400 and 250,000 volunteers available to respond to them. There is a shortage of voluntary home care organisations in some areas. This is especially true of one-to-one contacts (house visits), especially in the large cities (Devilée, 2005). Volunteers cannot always be found to respond to every type of request for help.

Volunteers can be found everywhere in long-term care, working with the handicapped, the elderly, the chronically sick, the demented, terminal patients and psychiatric patients. Volunteers do the shopping or supervise people in need of care on visits to hospital or the doctor. Requests for help in which relatively passive care is required or where one-to-one contacts are involved fit in rather less well with the profile of what volunteers want to do. In general, the turnover in voluntary home care is not all that high. Many volunteers remain until they are physically unable to do any more. There is, though, a trend among volunteers to more frequently provide short-term help.

One unfortunate fact is that the demand for voluntary home care is increasing, which means that the supply of volunteer carers is not keeping pace with demand. This is due partly to the ageing of the population and partly to the trend towards shorter stays in hospital. As a result, more is being demanded of the existing volunteers (Devilée, 2005).

Although there is a fall in voluntary work in general, the number of informal help providers is increasing. From a European perspective, the Netherlands is actually in first place as regards the amount of provided informal care. Until the year 2000, thirty-one percent of the population provided help of this kind, and in later years it was 33-35%. Women are more active in this area than men and those in the 55-65 age bracket offer the most help (41%).

The situation abroad

The OECD report (LTC, 2005) on long-term care for the elderly suggests that the informal care situation in the Netherlands does not differ substantially from that of other countries. The OECD report says that ‘informal care’ is an indispensable part of long-term care for the elderly. Eighty percent of all long-term care is provided via family caregiving and volunteer caregiving. The care provided is usually 'light' (instrumental help), but it also includes the most demanding forms of care (care for the demented). Women provide the most care (especially personal care), but men are also to an increasing extent providing family caregiving (especially domestic care). Most carers are in the 45-65 age bracket. They provide care primarily to one or both parents or to their partner. Women over 45 shoulder a double burden. Government policy is aimed at increasing participation in the workforce and at rolling back the voluntary early retirement scheme. That means that combining paid work and caregiving is becoming a problem. Finally, there is concern in many countries about the number of children available to provide family caregiving. Research shows, however, that it will only be in 20 years from now that the supply of carers will really be under threat. For the time being, the supply of carers is keeping pace with demand.

The forecasts of Van der Geest (RVZ, 2005) are rather pessimistic. If women have managed to close the gap with men in terms of participation in the job market 10-15 years from now, then an important potential source of carers will disappear. A higher standard of female education in the future could also lead to a situation where they will start doing more paid work and will not be available to the same extent to provide informal care.

Summary
Based on research into the current trend, no capacity problems in informal care can be expected within the next ten years. If, however, women have closed the gap with men in terms of participation in the workforce within a few years from now (and if the amount of paid work they are doing increases), then a less favourable picture emerges. The better socioeconomic position of the elderly and, in particular, a higher standard of education help to explain why supply exceeds demand. A modest increase in the proportion of older informal carers is also to be expected. According to estimates by the SCP, there will be no problems in the supply of informal carers before 2020. The OECD anticipates that it will only be some 20 years from now that the supply of informal carers (especially children providing family caregiving) will really be under threat.

2.5 Conclusion

A number of shifts are taking place in the supply of informal carers. The male/female ratio is developing favourably, but women are still in the majority (65.9%). Another striking fact is that female participation in the workforce has increased, although this has not resulted for the time being in a substantial decrease in the supply of informal carers, except in the 18-34 age bracket. The fact that the supply of informal carers is still sufficient can also be explained by the increase in the number of older informal carers (aged 65 and over). It is open to question whether this favourable development will continue if, in the future, women have part-time jobs of more than 12 hours a week or start working full-time, and if they postpone having children until relatively late as a result of a higher standard of education. The proportion of immigrants in the volunteer caregiving sector could increase as their education and socioeconomic position improve.

The demand for informal care will rise by an average of 5%, but in some areas of care the demand will rise more sharply. In the years to come, demand for informal care combined with a form of professional (especially private) care will therefore rise steeply. This phenomenon can be explained by an improved socioeconomic position. That is, the better the position the less demand for informal care, but also the greater the supply of informal care. The greatest increase is in the combination with home help under the AWBZ (40%), followed by the combination with admission and residential care (30%). The supply of informal care is also increasing, by 15%. Calculated by length of care period, informal long-term care is growing the most, followed by short-term help and help for the dying.

3 Facts about quality

3.1 Introduction

Although it is important to know whether there are sufficient people available to provide informal care, it tells us nothing about whether they can offer sufficient quality of care or whether they are really able to cope. Are informal carers up to the job? Do they have sufficient expertise? Do they stick to their task? What are the factors that most help and hinder them? This chapter seeks to answer these questions.

The questions will be examined from the perspective of the family caregiver/volunteer, as well as from that of his or her environment. The family caregiver or volunteer must not only have certain competences, but must also be supported by certain measures in his or her environment (work/family).

3.2 Can informal carers cope with their task?

What motivates carers?
Motivation is an important assisting or inhibiting factor in enabling a family caregiver or volunteer to appropriately function. Carers are generally positive about the provision of care. Research by the Institute for Medical Technology Assessment (iMTA) and the National Institute for Public Health and the Environment (RIVM) revealed that half of carers say that they would not wish to hand over their task to another (formal or informal) caregiver (Van Exel et al, 2002). Over three-quarters of carers derive satisfaction from providing family caregiving. Other motives include love and affection (32%), natural inclination (32%) and a sense of obligation (13%). The SCP report *Kijk op informele zorg* (A look at informal care) (De Boer, 2005) paints an ambivalent picture of the help that is given, one that is simultaneously natural and problematic. In addition to natural inclination and motives (such as love, affection, a sense of obligation and reciprocity), there are also problems (such as stress, social isolation and financial burdens) that heavily overshadow the positive aspects. Circumstances also arise that can compel people to help others. For example, one quarter of respondents said they began providing family care to prevent the people in need of help from being admitted to homes, while 8% of them said they provide help because there is simply no alternative (De Boer, 2003).

The positive motives of informal carers are an important driving force behind both the quality and the continuity of that care. Perhaps positive, intrinsic motivation is the most important reason why carers and volunteers do not simply give up and why they heed the appeal that is made to them. How fortunate carers feel themselves to be is dependent on both the degree of stress that they experience and the degree of satisfaction that they derive from providing care (Van Exel et al, 2002). It is, however, the less happy side of family caregiving that tends to receive more attention in most studies. The present study is no exception.

Stress

Family caregiving is most intensive among out-patients and transmural clients, and among patients who are not receiving professional care. However, family caregiving often continues after people are admitted to hospital. The person's type of housing unit has relatively little effect on the help they receive from family members. Tasks performed by informal carers include:

- domestic help (75%),
- personal care (34%),
- psychosocial support (81%),
- and combinations of these (67%).

carers do not usually perform nursing tasks[11]. Carers do indeed often act as the protector or representative of the person in need of help or they manage the care recipient's Personal Care Budget and obtain any required information and help.

The SCP (De Boer, 2005) is researching the level of stress. Their research reveals that 7% (i.e. 150,000 to 200,000 carers) are very heavily stressed or overstressed. Almost half of carers help more than one person in need of care. Most carers are children living away from home (45%), who are caring for parents or in-laws. The degree of stress increases as the social distance between the helper and the help-seeker decreases, and is especially great when alternative sources of help are lacking (De Boer, 2003). Earlier research by iMTA/RIVM among 950 carers revealed that, according to an objective yardstick, two out of three carers were under considerable stress (Van Exel, 2002).

Stress can increase as a result of trends on the demand side, such as the increasing length of care, longer dying processes and the increased complexity of care. If epidemiological trends such as an increase in excess weight and obesity continue, then these also will lead to more chronic health problems such as diabetes and cardiovascular disease.

There are further indications that immigrant carers are under more severe stress than those of Dutch origin. Factors that often impose extra stress on immigrant carers include:

- Language problems of the older generation that often impose extra tasks in supervision and interpreting. It is also an extra burden if professional carers are repeatedly visiting the patient.
- Long-term care, which is a new challenge for everyone involved. People often remain alive for a shorter time after a myocardial infarction, stroke or other major health problem in their country of origin than they do in the Netherlands.
- The fact that older immigrants tend to underestimate their future health care needs. The dilemma of whether to return to the land of their origin plays a greater role than does the approach of old age.
- The fact that the expectation among older immigrants that their children will care for them later on is no longer being matched by what their children are actually able to do. This is often a difficult subject to discuss, because it can be misunderstood as a lack of respect for the elderly, and family relationships can come under pressure as a result (EIZ, website 2005).

Table 3.1 High level[a] of stress among carers by various characteristics, 2001 (in percent)

Informal care for	
partner	44
child	45
parent	30
brother/sister	15
grandparent	4
other family member	14
other relation	11
Intensity	
1-4 hours per week	7
5-8 hours per week	18
9-16 hours per week	33
≥ 17	46
The people in need of help have	
No/slight/moderate limitation	16
Severe limitation	27
Motivation: there was no one else available	49
Total	26

[a] High level of stress: quite severe, very severe or excessive stress

Source: SCP (Timmermans, 2003)

Excessive stress
'Excessive stress' is understood to mean a situation in which the burden exceeds the capacity to cope. The 'burden' then becomes something with which a person psychologically and/or physically copes. Excessive stress cannot be wholly measured by objective yardsticks because there are also subjective factors involved (such as how carers assess a care situation).

Carers who provide help for more than 17 hours per week (46%) are under particularly severe stress.

Abusive care
Excessive stress can lead to what the Dutch call *'ontspoorde zorg'*, in other words, family caregiving that turns into abusive care with harmful consequences (mistreatment and neglect) for the person in need of help. This is a form of mistreatment that does not arise from vindictive motives, but from a lack of expertise, weakness, frustration, ignorance or excessive stress. It is not always clear in such a situation who the victim is and precisely when a normal care relationship turned to mistreatment. There is no question of malice and both parties would have liked things to have been very different. The NIZW (Bakker, 2001) carried out an investigative study among 68 professionals working at family caregiving support centres, regional assessment organisation (RIOs), community mental health centres (RIAGGs), home care organisations, psychiatric centres and in general social work. One of the problems was that carers waited too long to call in professional care. The (inadequate) situation in professional care and the isolation of the family caregiver (the feeling that they are facing the world alone) were mentioned as the most likely causes of care becoming abusive. Respondents also said that the affected carers are often those who have not deliberately chosen their care tasks, but those who felt obliged to take them on or saw them as a duty (Bakker, 2001).

Research has shown that approximately one-third of carers of people with dementia are guilty of some form of mistreatment of the elderly (Pot et al., 1996). However, professional people are also guilty of mistreatment. Mistreatment of the elderly is expected to increase with the ageing of the population and as the elderly spend more time living at home. Recently, a request to once again focus attention on combating the mistreatment of the elderly has been made[12] to the local authorities and local organisations who deal with old people (such as the regular health service [GGD] psychiatric centres [GGZs], home care organisations, GPs and family caregiving support centres). A hotline for reporting the mistreatment of the elderly has also been set up (Van Heerwaarden & Schaafsma, 2005).

Health problems
Excessive stress can also lead to health problems for the family caregiver. These can take a physical, psychological or behavioural form. Carers generally enjoy good health, but a small group do have major problems (Van Exel et al., 2002). For example, over 40% of carers who help one of their loved ones with a severe form of dementia

suffer themselves from physical or psychological problems. Caring for the demented is demanding and has an impact on the psychological, physical and social wellbeing of carers. Depression, burn-out and stress do occur. Medication intake is three to four times higher and visits to the doctor three times more frequent than among other people of the same age. Partners (46%) (especially female partners) are more likely to have symptoms (Alzheimer Nederland, 2003; Factsheet Mantelzorg en Dementie, EIZ/NIZW, 2005).

Table 3.2 Impairments and health experience of carers by age, 2001 (percentages in vertical columns)

	Age of family carers					
	18-34 years	35-44 years	45-54 years	55-64 years	≥ 65 years	total
handicaps or impairments						
not present	91	82	68	70	56	74
present, but nog impaired by them	1	1	2	6	4	3
present and slightly-impaired by theml	6	13	19	19	37	18
present and severely impaired by them	2	4	11	6	3	6
health experience						
very good	28	16	10	15	7	15
good	52	68	60	60	64	61
moderate	20	15	25	23	26	22
poor	0	1	4	1	3	2
total	100	100	100	100	100	100
(n)	(137)	(185)	(271)	(143)	(107)	(843)

Source: SCP (Timmermans, 2003)

Almost three-quarters of carers (74%) do not themselves have any impairment, but one quarter does and 6% of all carers are severely compromised in their daily activities. The problems they experience get worse as they get older.

Time problems

More than four out of every five carers (83%) struggle with one or more time problems during the period that the need for help is at its greatest. This also finds expression in difficulty with their own housework, reduced leisure, not being able to find time away from care or shortcomings in their work (*Factsheet Mantelzorg* [Factsheet on Family Care], EIZ/NIZW, 2003).

Financial burden

From a financial perspective, caring for family members involves extra expenditure (travelling expenses, telephone bills, and household expenses). These extra expenditures also mean financial problems for one quarter of carers. In total, 72% of carers incur extra expenditures. For most carers, the amount is less than 230 euros per month. This can sometimes rise to more than 460 euros per month. The longer the period of care, the more the increase in extra expenditure. Expenditure is at its peak when the person in need of help lives with the family caregiver at home or with friends (*Factsheet Mantelzorg*, EIZ/NIZW, 2005; Timmermans, 2003 . The nature of the extra expenditure also varies very widely from one care situation to the other[13].

According to the SCP, carers spent 0.45 billion euros in income in 2001. If all family caregiving was remunerated, then that would amount to a cost item of 4.2 to 7 billion euros per year (Van den Berg, 2003, VWS, 2004). Apart from these costs, carers also suffer loss of earnings. Some working carers lose 7,000 euros per year in income (Timmermans, 2003).

To what extent, and by whom, are carers compensated for extra? Carers receive compensation via the following channels:

- the people in need of help: out of their own pocket or the Personal Care Budget[14].
- fiscal compensation via income tax: Carers can claim certain expenses as exceptional expenditure on their income tax assessments. In 2001 this fiscal compensation had an income-dependent threshold of 11.2% of the gross taxable income.
- Special assistance: special assistance forms part of the National Assistance Act (ABW) and is the safety net of the social security system. Special assistance covers the exceptional circumstances that lead in individual cases to unavoidable expenditure that is not covered by the ABW and that partly or wholly exceeds the carer's ability to cope.

Of carers who had to incur extra expenditure, 87% received no reimbursement and 13% did receive reimbursement. Of the 86 interviewees, 73 were reimbursed by the person in need of help, 6 (also) received something back from their income tax, 6 (also) received something via special assistance and 20 received something from an unidentified unknown source (Timmermans, 2003). Those who received something back from their income tax or special assistance sometimes received this amount in addition to a partial reimbursement by the person in need of help. Recent research by ITS has shown that two-thirds of Personal Care Budget-holders pay for family caregiving, whether or not in combination with professional care or unpaid family caregiving. This is hardly commercialisation, because in many cases part of the family caregiving is paid and part is unpaid. In 18% of cases it is fair to speak of commercialisation, because unpaid family caregiving was entirely replaced by paid family caregiving after the award of a Personal Care Budget (Ramakers & Van den Wijngaart, 2005)

Table 3.3 Number of carers who were reimbursed for their extra expenditure on family caregiving (selection of carers who incurred extra expenditure and who received reimbursement; percentages in vertical columns; more than one answer possible)

Reimbursement received via:	
people in need of help	73
income tax	6
special assistance	6
unidentified source	20
(n)	86

Source: SCP (Timmermans, 2003)

Social isolation

Many carers (for example, people who care for dementia sufferers) struggle with social isolation. The central family caregiver (usually the partner) spends an average of 17 hours a day on the total care required for a demented person. The overwhelming majority of dementia patients are cared for by carers and home care, while approximately 35% are admitted to an institution. Family caregiving for a demented person is physically and emotionally demanding, and often long-term, task that must be performed every day. The shortage of professional care and of places in care institutions are two factors that increase social isolation. There are, however, also successful support facilities available (such as the Alzheimer cafés and the meeting centres for people with dementia and their carers) that can reduce social isolation (Gezondheidsraad, 2005).

Sandwich generation
The so-called 'sandwich generation' is a risk group for excessive stress. This is the group of parents who had children relatively late in life. At present, women have their first child at an average of 29.1 years of age. A 40-year-old woman has an average of 1.75 children, mostly aged 10 or under, and her parents or in-laws are often aged 70 and over. For 'old mums and dads' the risk of a doubling of the care task increases (the sandwich generation): they have to care for both their own family and their parents or in-laws. "Whose needs and rights prevail when push comes to shove? Do you have to let one loved one down to meet the needs of another? What's in it for the carers themselves if they try to run with the hare and hunt with the hounds? (...) These are the dilemmas that often present themselves as one big jumble. A family caregiver therefore has to strike a balance on several different fronts: between the person requiring care and the family caregiver, between the person requiring care and other family members, and his employer" (quotation from the CEG publication 'Mantelmeeuw' 2004).

Smaller family units
The care-needing elderly with few children are an especially vulnerable group because there are fewer people among whom to divide the care tasks and because the risk of excessive stress is greater. Given that the average number of children per family is decreasing, this risk will increase in the future (De Boer, 2005).

With or without support
Many carers (40%) provide care alone, i.e. without the support of other carers. The other 60% receive support from one or more (secondary) carers from the family network, extended family or network of friends (De Boer, 2005). If the family caregiver is unable to carry on, then formal care is often unable to provide a replacement.

According to the SCP, a comfortable majority of informal carers do not receive any support. More than two-thirds of them have no need for it, while between 12 and 35% of people in need of help said that they were not aware of the available options (De Boer, 2005). Forms of support for which need exists are primarily information and advice, emotional support and respite care.

iMTA is investigating the respite care needs of 273 carers. Research suggests that respite care is currently reaching the carers that are most in need of it. However, there is also a group of carers that need respite care but who seem to be less well informed about the available opportunities and how they can apply for them. Approximately one-third of carers currently use some form of respite care. These are the carers who, relatively speaking, experience the greatest subjective stress, which would increase substantially without respite care. Approximately half the people who do not use respite care are in need of it. This group is under greater stress than the group that does not want respite care. The majority expect to be able to reduce their amount of stress by using respite care. Use of respite care is sometimes also hampered by the attitude of the care recipient (Van Exel et al, 2005).

Table 3.4 Use of support by carers, 2001 (in percent)

discussion with help providers about the burden of helping	17
discussion with help providers about caring for the person in need of help	31
discussion with help providers about the approach to care	28
discussion with help providers about dealing with the person in need of help	26
group discussion with other carers	5
total: advice	38
(n)	(1089)
use of a granny-sitter[a]	17
(n)	(1072)
use of day care[b]	10
(n)	(706)

[a] To have part of the day free.
[b] A day care or day activity centre where people in need of help can go one or more mornings or afternoons a week.

Selection from among carers looking after independently-living people in need of help.

Source: SCP (Timmermans, 2003)

The SCP also reported that, of the various forms of available support, carers make most use of advice (38%), and that the most frequently used form of advice is individual discussions with professional carers about the person in need of help (31%), the approach to care (28%)

and dealing with the person in need of help (26%). Almost one in five make use of 'granny-sitters' to give themselves some free time during the day (17%). The use of granny-sitters increases as the care burden increases. The care burden is probably a determining factor in the decision to make use of support. The greater the burden, the more support is obtained in the form of granny sitting and advice.

Summary
Carers do not quickly give up, but instead find ways of coping with the problems that result from the extra stress. Approximately 7% of carers felt that they were severely stressed or overstressed. There are also risks of abusive care (mistreatment), health problems, time management problems, additional financial costs, social isolation and extra stress for the 'sandwich generation' and for the child or children from small families who have to care for their parents. There is a great need for more support for carers, especially advice from professional carers regarding the right approach to care and questions of how to deal with the person in need of help, as well as the use of granny-sitters to give the family caregiver some time off.

3.3 Combining work and care

Carers are increasingly combining their care tasks with a paid job, and then there is a dual burden that arises. Increased participation by women in the labour market has not led to the anticipated decrease in the number of available carers or volunteers, except in the 18-34 age bracket (see Chapter 2). The combination of work and care does sometimes lead to excessive stress for the family caregiver.

Combining paid work and care turns out badly for 31%, 9% of whom find the combination too burdensome. The latter phenomenon particularly affects women providing intensive personal and psychosocial care to a partner. It often appears to be difficult to secure the cooperation of employers, for example by arranging flexitime or leave (Isarin, 2005; RVZ expert meeting, 2005).

Leave regulations are not always well understood, either by the employer, the company doctor or the employee**.** Even when they are well understood, advantage is not always taken of them. New leave regulations recently came into force[15], but in the case of long-term family caregiving in particular (longer than 3-4 months) it has to date proved difficult to combine care and work. If the care tasks start to make greater demands, then the amount of absenteeism through illness increases. In practice, carers would rather report sick than make recourse to the leave regulations. This is due, in all probability, to the fact that reporting sick is financially more beneficial than taking advantage of the leave regulations.

Leave regulations do not work on their own. There is, in particular, a need for a culture change among employers (and among employees as well). Employees find it a nuisance to have to explain matters to their employer and thus make too little use of the leave opportunities that are available. Employers still too often lack a family caregiver-friendly policy. A more fundamental question is whether recognising family caregiving within the work situation should be regulated at the general or individual level. There are too few opportunities for combining part-time work with care. On the other hand, there is something to be said for making individual (customised) arrangements with the employer,

Family caregiving and paid work have a negative impact on each other. Doing paid work does not mean that providing family caregiving is impossible, but it does limit the amount of caring that can be delivered. Conversely, providing family caregiving also has a negative impact on the amount of paid work that can be done (Van den Berg, 2005).

Combining tasks is important because it means that the family caregiver does not lose social and work contacts outside the care situation. Doing paid work alongside family caregiving seems to be an important survival strategy (Isarin, 2005). It also prevents excessive stress because working outside the home prevents social isolation. Paid work also has a therapeutic effect by helping relieve the stress experienced by the family caregiver.

With the increase in labour market participation by women and by older employees, better arrangements are necessary for combining work and care. Dropping-out and excessive stress are not being adequately prevented. There are also no facilitating regulations (such as those that are to be found in some other countries) to make it easier for the employees providing family caregiving to return to (full time) work after a period of care.

What is possible in the Netherlands?

- The Self-Employed Disability Insurance Act (WAZ) contains leave regulations. These relate primarily to short-term leave and, a more recent introduction, to long-term care leave as well. ‘Long-term’ in this context, however, means a maximum of 12 weeks.

- The Daycare Law (*Wet Kinderopvang*) does not currently include a government contribution to the costs of child care incurred in family caregiving. However, the local authorities can reimburse child care costs occasioned by family caregiving within the framework of a sociomedical needs assessment (B&A, 2005).
- Exemption from the obligation to seek work: unemployed people entitled to benefit who are aged 57.7 years or above, who have been out of work for more than three years and who provide family caregiving for at least 20 hours a week, can be exempted from the obligation to seek work[16].

Participation in the workforce by both men and women has generally increased, while their participation in the provision of informal care has not changed. This is noteworthy and runs counter to general expectations. One possible explanation for this phenomenon is that both working and non-working people know how to fit informal care into their daily routine, while those who cannot do that are working less or have stopped working altogether. Isarin (2005) came to the same conclusion on the basis of her research and said that carers in work are creative at finding solutions and are also prepared to sacrifice their free time and their own social activities.

Van den Berg (2005) has confirmed this finding of the SCP and Isarin. He investigated the relationship between involvement in paid work and the provision of family caregiving. He focused on the so-called endogeneity problem, i.e. the reciprocal impact of paid work and family caregiving. His research suggests that providing family caregiving has a negative effect on the amount of paid work done. *Engaging in paid work* also has a negative effect on the amount of family caregiving provided, but the *quantity of paid work* does not have any effect on it. In other words, carers provide the demanded care despite the extent of their labour market obligations.

Summary

The combination of work and care is increasingly common, especially among carers working part-time. The combination of work and care offers both advantages and drawbacks. The advantage is that it can prevent social isolation and have a therapeutic effect by relieving pressure. The drawbacks are that stress increases (perhaps to excessive levels) and that the general and working environment are still not sufficiently geared to carers who work.

3.4 Conclusion

Various problems might make it impossible to maintain or increase the potential for informal care. First, there is the risk of severe stress, which can sometimes even manifest as excessive stress and which can degenerate into abusive care. Some 7% of carers feel they are under severe or excessive stress. Then there is the risk of social isolation, especially among those who offer intensive family caregiving (for example, to people with dementia). The number of people who combine paid work and care is certainly increasing, but the combination of tasks can also work out badly (31%) and lead to excessive stress (9%). The general and working environments are also as yet not very favourable for the family caregiver who wishes to combine work and care. There are also advantages in combining work and care. The continuity of social and work contacts can help prevent social isolation and excessive stress, and alternating working and caring tasks also has a therapeutic effect. carers have a considerable need for professional support, especially advice, emotional support and respite care. Professional carers are still too often falling short in this regard. Finally, financial burdens can have an adverse effect through extra expenditure and wage attrition.

4 Relationship between informal and formal care

4.1 Introduction

The close interrelationship between informal and formal care makes it important to investigate how carers, volunteers and professionals cooperate. In this chapter the relationship between informal and formal care will be delineated from various perspectives, including those of informal care, formal care and the care recipient. Problem areas and possible solutions will be identified.

4.2 From the perspective of informal care

Formal and informal care complement each other and sometimes even replace each other. Family caregiving and professional care should perhaps be seen as two different types of care that cannot be compared or judged by the same yardstick. Family caregiving has a certain something that professional care is often unable to offer (individual attention, knowledge of the person in need, as well as a personal affective relationship) mean that family caregiving has its own distinctive quality**.** Family caregiving is not professional care, and that is precisely what makes it so special. According to Isarin (2005), there is no public equivalent to family caregiving, and the SCP (Social and Cultural Planning Office) and the Nidi (Netherlands Interdisciplinary Demographic Institute) also attach importance to the 'bit extra' that family caregiving has to offer, the 'icing on the cake'. According to Van der Lyke (2000), there is a danger that sight will be lost of the uniqueness of this care because of the increasing trend towards the professionalisation and formalisation of care (CEG 2004). In practice, carers and helpers from the home care sector often have dealings with each other, and attention is focused on this below.

Positive and negative experiences
Carers have a positive view of practical help, the accessibility of home care and the integration of home care with the help offered by family caregiving. After all, they sometimes prevent or at least postpone admission to an institution. "I'm so pleased with the home care service. They consult with me about what has to be done and they always write down neatly who is coming and when. Without their help, my husband would have been admitted to a nursing home a long time ago." (Mulder-Boers 2004)

However, the perspectives from which professional care and family caregiving operate can differ so widely that they can be at odds with one another and have a negative effect on the objectives of the care process. A good example of the gulf between family caregiving and professional care is cited by Morée:

Seventy-eight-year-old Mrs. Koper cares for her husband, who has suffered a myocardial infarction and a mild brain haemorrhage. The home care service has tried to activate him as much as possible, but she finds this objectionable. She cannot see the use of all these walking exercises and finds the exhaustion that he suffers after them very upsetting (...) (Morée, 2004).

The family caregiver, in this case Mrs. Koper, is evaluating her husband's situation from a completely different perspective to that of the home carer. She is looking at the care situation primarily in terms of the past, and just sees her husband going downhill. The home carer sees the situation with an eye to the future and is trying to foster self-reliance. Things did not work out too well in this example. The home carer did not seem to be able to build a bridge between her vision and Mrs. Koper's world of experience. Mr. Koper finally had to go into a nursing home, even though his state of health was relatively better than that of his fellow residents.

Carers are less positive about the organisation and coordination of care. Problems include the lack of harmonisation and consultation, the absence of flexibility in dividing tasks between home care and family caregiving, the fact that the family caregiver and the professional have different ideas about the correct approach, and the lack of continuity in home care (i.e. different carers on different occasions). "I thought I'd have less work to do, but I always have to explain everything all over again each time a different home carer comes. They also use lots of hand towels and change the bed a very great deal. As a result, I've actually got more work to do because of all the laundry." (Mulder-Boers 2004). The family caregiver does not therefore always experience the deployment of home care as a lightening of the burden, and sometimes it even makes their own care task more burdensome (De Boer, 2003; Gezondheidsraad, 2005). The professional carers often have a clearly demarcated task package, whereas the family caregiver is a 'Jack or Jill of all trades.' Carers more often feel dependent on the professionals than *vice versa* (Morée, 2004).

Harmonisation of tasks

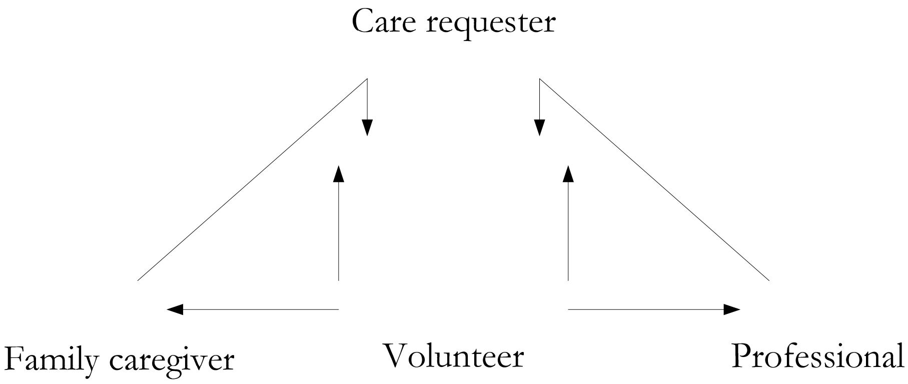
One not unimportant finding that emerged from the SCP study (De Boer, 2003) is that the increased burden on the family caregiver is closely associated with the lack of harmonisation with the home care service. Forty-three percent of the overstressed carers say that there is hardly any (or only occasionally) harmonisation with the provision of home care. Only 17% of the unstressed carers share that opinion. Working carers also state that there is a lack of harmonisation. The call for improved harmonisation and cooperation has, incidentally, been picked up and developed by the sector organisation for the care for the elderly in the Netherlands, Arcares, as is apparent from an as yet unpublished guide (Arcares, 2004). The lack of harmonisation is also affected by the type of care situation involved. If the care involves a dying person, then there seems to be a relatively high degree of harmonisation between the carers and formal care, whereas the lowest level of harmonisation is found in situations where the need for help varies. Therefore, the greater the degree of stability in the demand for care, the greater is the degree of harmonisation. The physical closeness or distance of the family caregiver also plays its part, of course. Harmonisation proceeds more smoothly when the family caregiver lives with the person in need of help.

Should respite care be provided by a care professional or a volunteer?

One frequently heard complaint is that there is no replacement or adaptation of formal care if the family caregiver falls sick or if his or her situation changes. Perhaps the family caregiver has to (or wants to) take a weekend off or go on holiday. The home care service may assume from this that the informal carer has solved his or her own problems, but often this degree of flexibility is lacking. Solutions then have to be found within the person's own family or social circle.

Volunteers occupy an intermediate position between professional helpers and carers. They are sometimes deployed to replace carers on a temporary or longer-term basis (respite care) or to lighten the care burden of the family caregiver. The tasks of the family caregiver can then be shifted onto the volunteers or can be supplemented. For example, the volunteer can take the care recipient to the doctor or for a walk or can do the shopping. However, volunteers can also support the professional carers by, for example, taking over the evening care from the home service on certain days. Volunteers have their own place in the care triangle, between the professional carers and the family caregiver.

Figure 4.1



Source: Van Gorp & Steenbergen 2004: 169

Deployment and continuity
The deployment of family caregiving and home care differs substantially. Carers provide primarily domestic help and supervision (33%) or domestic help plus personal help plus supervision (47%). Home care, on the other hand, frequently offers just one kind of help, either just domestic help (33%) or just personal care (23%) (De Boer, Schellingerhout en Timmermans, 2003). In situations in which carers perform the same tasks as the help providers of the home service, it is carers who provide more hours of help. Another difference is in the continuity of the care. Whereas this is something that is somewhat lacking in professional care, it is one of the great strengths of informal care.

Summary
Informal carers often cannot cope without the deployment of professional carers. Cooperation with the home care service and other forms of outpatient care is important because it prevents or postpones admission to institutions. Carers have both positive and negative experiences of their collaboration with professional carers. Problem areas are primarily to be found in organisation, coordination and differences of viewpoint regarding the approach to be adopted to care. Volunteers also have their own distinctive position. The task allocation has to be matched to the family caregiver, the home carer and, last but not least, the person receiving care.

4.3 From the perspective of formal care

The family caregiver's valuation of the professional varies widely. Care professionals often also have to cope with resistance from carers. The latter still have to get used to the fact that (part of) the care is going to be ‘taken away’ from him or her. It can also be the case that the family caregiver plays a part in the health problem of the person requiring care. That can hamper the care process in which, after all, the family caregiver and the care professional have to collaborate with one another.

Recognition of the family caregiver by care training courses and care institutions

It seems that a great deal of work still needs to be done on the acknowledgement and recognition of the family caregiver and the contribution that he or she makes to care provision. Although more and more attention is being focused in care training courses on how to deal with family caregiving, structural and systematic attention is still lacking. It is not an obligatory part of the lecture programme and is it hardly ever listed as a required competence for professional qualifications. A happy exception is the professional partial qualification for nurses working in social heath care, such as home care (Morée, 2005).

There are some home organisations among the care institutions that specialise in supporting family caregiving. Some home care organisations or nursing homes also have their own pool of volunteers or are starting to build them up. Professionals, though, generally focus on the person in need of help and therefore do not pay sufficient attention to the (sometimes excessive) stress experienced by the family caregiver or to the caregiver’s need for support. Mutual valuation, acknowledgement of each other's expertise and the unavoidable inequality of the relationship still create fairly frequent problems in cooperation. Professional carers are nonetheless also realising the importance of informal care. "Of course I see the family caregiver as a co-helper. If there was no family caregiving, then we wouldn’t in many cases be able to give any help at all and the client would have to be admitted. I therefore discuss with the family caregiver what has to be done and we make agreements on who does what." (Mulder-Boers 2004). The importance of collaborating with carers is also coming more and more to the fore at the institutional level. Many professional care institutions already have a volunteer policy, but a policy that is aimed at carers is often still lacking. The belief that volunteer policy and family caregiving policy deserve an integral place in the quality system is indeed being recognised by some client and caregiver organisations, and by some professional groups (Arcares et al 2005).
Three roles of the family caregiver

It can sometimes be a problem for formal carers to decide just how to approach the family caregiver. Carers are, of course, often not just co-providers of care, but are themselves in need of help, support and supervision. The carers sometimes themselves become patients or clients with psychological or physical health problems and therefore need care. For that reason, a family approach is chosen in some sectors of health care. That is quite usual in psychiatry. A plea for such an approach, in which the family also receives support or care, is also being made in rehabilitation medicine. That is because the more problems the 'healthy' parent has in coping with the situation, the more severe the child's problems become (Visser-Meily 2005).

The different identities of the family caregiver are often simultaneously manifest. That makes the relationship between the professional and informal care providers even more complex. There is even a third identity that can also have an influence. The family caregiver is also the partner, the parent or child of the patient or the client. If there is to be an effective matching of the care available to what is required in the care situation, then the professional will have to make allowance for the different roles and relationships that can simultaneously arise in the family caregiver's world.

The care professional in the role of supporter must have due regard for what the family caregiver can do (ability to cope) to prevent excessive stress (a care burden greater than the ability to cope) and what form of support is therefore required for the family caregiver. The family caregiver can sometimes need expert encouragement, knowledge transfer or advice. For the professional care provider the art is to strike a balance between cooperation and harmonisation on the one hand, and timely and appropriate support on the other. Both underestimation and overestimation can be pitfalls. Professional carers, for example, often do not allow for the fact that the family caregiver is also a parent, employee or volunteer (Morée, 2004).

The support that professionals provide for family caregiving can assume many different forms, from advice about the approach to be adopted, to caring for the carers themselves. Home care situations that support carers do not have any structural financing for such support, and the same is true of hospitals. The care provided to carers is usually charged to the client.

Summary
Care professionals still do not always acknowledge the contribution made by informal carers or else they find it difficult to strike the right balance between cooperation and task allocation on the one hand (the family caregiver as co-provider of care) and timely and careful sup-

port on the other hand (the family caregiver as an indirect client). In addition, the family caregiver is also a partner, child or parent or has another affective relationship with the person in need of help. The two perspectives are often found together. A volunteer can also be involved in the care process and, due to his own position in the care triangle, also has a multiple relationship with the care professional.

4.4 From the perspective of the care recipient

How do the people needing help feel about the care they get informal carers in their environment? Do they prefer informal care over professional care?

Interpersonal relationships out of balance
Being on the receiving end of family caregiving changes the nature of the existing relationships between partners, as well as between children and parents (but also *vice versa*, between parents and children). Roles change, and the balance (also called the interpersonal balance) is lost. The receiver of family care becomes more dependent. In this changing pattern of social interaction, family caregiving is sometimes defined as a 'social transaction.' This is not just a process in which one party merely gives and the other party merely receives. Instead, satisfaction can be found in gratitude, in social approval from the environment or in the fulfilment of a moral obligation. The family caregiver therefore also has an interest in providing care, because not providing care can lead to a poor reputation, to feelings of dereliction of duty and to falling short in the eyes of those who most cherish the family caregiver. In this process, the recipient of family caregiving is confronted with the task of maintaining, from a position of dependency, the best possible balance between giving and taking. A number of areas of tension or dilemmas can arise in those who are receiving family caregiving within this context (Van den Akker & Luijkx 2004):
The acceptance of family caregiving implies loss of autonomy and can affect one's sense of self-worth.
Family caregiving can lead to a stronger dependency relationship that cannot be avoided. Family caregiving imposes a burden on one's surroundings, whereas the recipient of family caregiving does not want to be a burden to other people.

Do people prefer family caregiving or professional care?
The perspective of the care recipient is often overlooked in discussions about family caregiving. Just like the carers themselves, those for whom they care often do not have much choice in the matter. Although government policy supports demand-driven care and free-

dom of choice, little justice is often done in practice to these ideas in long-term care.

For most Dutch people, caring for the elderly is, in the first instance, a responsibility of society as a whole, as revealed by the study by the Nidi in which people were asked their opinion about family caregiving (‘*Bevolkingsvraagstukken in Nederland anno 2003’* ; ‘Population issues in the Netherlands in 2003’). The majority think that they need to avoid being dependent on their children as much as possible. They would prefer to be in a nursing or residential home rather than with their children at home or entirely dependent on their children. The local authority jointly pays for this solution and the government is obliged to offer it to whoever needs it (Nidi 2003).

It appears from the debates on the future organised by the NIZW in 2003 that the majority of elderly people prefer professional help to family caregiving. They want to enjoy primarily a ‘cosy relationship’ with their children and friends, and would prefer not to make structural demands on that relationship for the provision of care (Van Overbeek & Schippers, 2004). The chronically ill have a more positive view. Research among members of the Patient Panel for the Chronically Ill (*Patiëntenpanel Chronisch Zieken*, PPCZ) by the National Research Institute for Health Care in the Netherlands, NIVEL (2004), showed that the chronically sick usually see the family caregiving they receive in a positive light (80%), although they sometimes have problems with it. Approximately 40% find it difficult to obtain family caregiving or say that they find it hard to accept help from a loved one or acquaintance, especially when it comes to domestic help. Thirty to forty percent of the chronically ill think that offering family caregiving is perfectly natural, compared with 80% of the Netherlands population as a whole. Two-thirds of the chronically ill who receive some form of care at home are receiving family caregiving. That is primarily (approximately 90%) domestic help, but it also includes personal help or attentive care.

Summary

A great deal changes for care recipients when they are called upon to receive care from someone in their immediate environment. Loss of autonomy, a switch to a dependency relationship and the feeling of being a burden upon someone else mean that receiving family caregiving is not always a welcome experience. The Dutch usually prefer to use professional care rather than being dependent on their children or loved ones, but that is somewhat less true of the chronically ill. Many people also consider long-term care of those requiring it to be being primarily a responsibility of society as a whole and not a matter of personal responsibility.

4.5 Conclusion

Cooperation between informal carers and professional carers offers attractive possibilities, if we want to continue providing long-term care. Although formal and informal carers have an insight into the importance of each other's contribution in providing care, that relationship still seems to have its defects in practice. Care professionals are still slow to acknowledge the contribution made by informal careers and they do not always have a clear understanding of the support that informal carers need to perform their care task. Again, a volunteer has a completely different position and can support both the family caregiver and the care professional. The changes that the care recipient has to deal with are radical ones and sometimes inspire resistance that can hinder a care relationship in which the family caregiver and the professional caregiver are supposed to work together.

5 Is there room for improvement? Competences and conditions in informal care

5.1 Introduction

What do we need to do to safeguard informal care (family caregiving and volunteer caregiving) for the future? A number of possibilities will be examined, such as family caregiving support, measures to better regulate the combination of work and care, and measures that foster collaboration between formal and informal care. This will involve making occasional forays across the border. How have neighbouring countries regulated informal care and what lessons can we learn from them?

5.2 Family caregiving support

Good basic conditions and support facilities are necessary to maintain both the quantity and quality of informal carers in long-term care. These matters have already been regulated in the case of volunteers, but for carers things are still at a beginning stage. What forms of support can be considered? The Expertise Centre for Informal Care (EIZ) suggests that a varied package of measures and initiatives is important if it is going to be possible to continue to provide family caregiving in the future in the context of a care policy that makes heavier demands on people's own sense of responsibility[17]. The most important forms of support are discussed below. Some are dealt with in a separate section.

Information, advice and support
Under this heading spring to mind support centres providing information and advice about the various facilities for the support of both carers and clients. Examples include a family caregiving line, contact with people in the same situation, a website or information kiosk, and training courses. Knowledge and information can be disseminated via family caregiving support centres, but some care institutions also make their own provision for informal carers or have a knowledge centre through which clients and their carers can be supported.

Respite care
Respite care is the collective term for replacement arrangements whereby family caregiving is temporarily taken on by professionals or volunteers to give the family caregiver some time off for leisure pursuits or to enjoy a social life. Respite care can be assessed as a need

under the AWBZ. In the handicapped sector and in psychiatry, the financing of respite care under the AWBZ, especially for lodging functions, has been standard procedure for quite some time. Of more recent date are opportunities for financing respite care for other target groups, such as the demented elderly. Many respite care facilities are dependent on less structural sources of financing such as the CVTM grant (*Coördinatie Vrijwillige Thuiszorg en Mantelzorg:* Coordination of Voluntary Home Care and Family-caregiving), waiting list funding, and flexible institutional budgets (EIZ, 2003). It is an important form of support that needs to be organised and financed in a more structured way. It is important because respite care is a good way of preventing carers from becoming overstressed.

The Dutch situation:
- Care outside the home (day care or care in a residential or nursing home, care farms or short-stay hostels, or with host families). Replacement in the home situation by voluntary home help (volunteer work).
- Replacement by professionals (granny-sitters in the client's home), replacement family caregiving or professional family caregiving support. There are many initiatives that are still beset with problems associated with financing and with cooperation with regular carers (EIZ/NIZW, 2003).

Foreign examples:
- Finland: carers are entitled to two days off a month (respite care).
- Ireland: an annual holiday allowance of approximately 1000.00 euros can be granted.
- England: a carer's grant is shared out among the Local Authorities. These authorities can decide, in accordance with national guidelines, either to award family caregiver's vouchers or to themselves hire organisations that can provide replacement care (Pijl memorandum, 2005).

Financial support
This covers reimbursement of expenses and compensation for loss of earnings in connection with the provision of family caregiving. There is still a great of controversy about whether carers should be paid. This subject is therefore dealt with separately in Section 5.4.

Summary
Support for family caregiving takes many forms. In particular, information and advice as well as replacement via respite care are forms of family caregiving support for which there is a considerable need in order to increase the family caregiver's expertise and prevent exces-

sive stress. Foreign examples show that respite care is sometimes a recognised form of family caregiving support that people can claim.

5.3 Combining paid work and care

'Work' and 'care' are in competition with one another in practice, and the relationship between paid labour tasks and informal care tasks is sometimes a bumpy one. Measures have, however, been taken to make it easier to combine work and care, such as leave arrangements, experiments with a needs assessment and staffing policy that shows carers more understanding. There is also however a need for a business climate in which more understanding is shown to employees who are providing family caregiving. The question remains whether that can be more easily achieved with general measures or with individualised ('customised') ones[18].

It is easier for carers to keep going if they can combine paid work with family caregiving. It can help overcome the various adverse effects of family caregiving. If the family caregiver can fit their care tasks around their working hours, then work remains an important survival strategy. Once again, it is important to have adequate support measures in place to facilitate the combining of work and care (Isarin, 2005).

It is not always possible to continue combining work and care in the same way. Care can become more intensive and more long-term. In general, working carers can juggle their two tasks well and can economise on their own leisure time, but this does demand creativity, flexibility and self-discipline.

A successful and much-quoted example of how easy it is regulate the combining of family caregiving and paid work is the so-called '*mantelzorgmakelaar*' (family caregiving broker' project. The family caregiving broker provides support for people who have to combine family caregiving and paid work.

The family caregiving broker takes over regular tasks from the family caregiver that can save him or her a lot of time, e.g. by knowing how to navigate through the maze of care-providing bodies and the regulations relating to leave. At company level, the family caregiving broker ensures a satisfactory harmonisation between work at the concerned company and the care tasks at home in order to prevent excessive stress, the need for reintegration or even incapacity to work. The family caregiving broker has a specialised role, is at home in the world of care and benefits, and offers the family caregiver precisely the resources that he or she needs.
Source: *www.mantelzorgmakelaar.nl* from Bureau Taps.

The family caregiving broker acts as an intermediary between the family caregiver and the employer. In mutual consultation, the family caregiving broker analyses the care tasks, the course of the disease process and the tasks that he or she can take over. These tasks can include acting as an intermediary in obtaining or adjusting the Personal Care Budget, obtaining welfare payments or getting the welfare amounts adjusted. They can also include supervising the process of obtaining a needs assessment for specially adapted housing, nursing and care facilities (perhaps provided externally), searching for alternative forms of care such as day treatment or weekend admissions, or concluding agreements with the employer regarding care at home and a possible adaptation of working hours, holidays and respite leave. Aftercare can also be provided to ensure that agreements once made are adhered to. This seems to be a successful project, which was started at local level and which has now acquired nationwide recognition and dissemination. A one-year postgraduate course for people who wish to become family caregiving brokers has recently been launched in Rotterdam.

The '*levensloopregeling*' scheme, which will be introduced on 1 January 2006, allows employees to set aside up to 12% of their salary to fund paid leave. This should result in a better spread of care and work throughout the entire lifespan and will also offer opportunities for combining work and care. Various projects are being set up and financed aimed at facilitating and encouraging the combining of work and care in the framework of the *Stimuleringsregeling Dagindeling* (introduced by the Ministry of Social Affairs and Employment). The following project has a similar aim:

Turkish or Moroccan women who care for their parents or for sick or handicapped family members can become employees in home care and can continue to care for their family members from this role. They can also be deployed to help other clients with home care. The home care organisation is setting up a special programme that involves intensive advertising, a suitable contract of employment, training (including a language course, 'Dutch on the home care work floor') and a mentor system. The results? A more racially diverse staff, immigrant women get the chance to do paid work, and immigrant clients obtain access to regular home care. (Example of a Dagindeling experiment by the Ministry of Social Affairs and Employment).[19]

Summary
Combining family caregiving and paid work is a major burden that can easily lead to a situation where the family caregiver

suffers excessive stress. As there are more and more ‘task combiners’ and as this trend will continue in the future, it is very important that measures are taken precisely at the interface between work and care to prevent the dropping-out and excessive stress of carers. Leave arrangements and individual agreements with employers – for example through the mediation of the family caregiver – offer opportunities for implementing such measures.

5.4 Financial support

There is much controversy regarding whether carers should receive some sort of remuneration.

The following types of financial consideration could be contemplated:
- Compensating costs incurred
- Compensating loss of income
- Financial remuneration of family caregiving

1. A financial consideration takes various forms:
2. Directly to the family caregiver (such as an allowance).
3. Indirectly to the family caregiver (such as tax relief).
4. Directly via the care recipient (such as via the Personal Care Budget).
5. Indirectly via the care recipient (such as free accompanied travel).

Opportunities to date have been limited in the Netherlands. There is more scope in other countries, so a number of examples will be mentioned.

1: Directly to the family caregiver
Some countries (for example, Ireland, Finland, England and Sweden) offer the family caregiver an allowance. The Netherlands does not offer this possibility.

In Finland this arrangement is based on a contract between the local authorities and the family caregiver. The contract includes a care plan that states who is responsible for performing which tasks. The local authority, the family caregiver and the care recipient must all agree to this plan. The allowance can be in monetary form, can consist of services or a combination of the two. There are plans for changes in and improvements to the existing arrangements. For example, there is a proposal to centralise responsibility for the family caregiving allowance due to complaints that allocation of the family caregiving allowances is currently too much of a lottery. The new allowance

will have three levels (300, 600 and 900 euros per month) and offer tax discounts.
Source: Pijl memorandum, 2005.

2: Indirectly to the family caregiver
Various facilities (free travel and training grants), discounts (tax relief) and opportunities for building up social security entitlements (pension rights) are offered in various countries (such as Germany, Sweden, Finland, Ireland and England). This is regulated as follows in Ireland:

- Building-up of social security entitlements after the expiry of the care period for carers with Carer's Allowance or Carer's Benefit.
- Facilities to ensure that the basis of insurance is not eroded.
- Family caregiving leave.
- Household Benefits Package: allowance for gas/electricity, telephone bills and exemption from TV and radio licence for receivers of the Carer's Allowance.
- Free travel for recipients of the family caregiving allowance, except during the rush hour.
- Contribution to the costs of full-time training as a lay carer, if the family caregiver has not yet reached the age of 66 and if the period of provision of care has ended.
- Tax measures: diverse, including Allowance for Employing a Carer.
- and a few other compensatory schemes of this kind.

The following possibilities exist at the present time in the Netherlands:

- compensation via the tax authorities for certain expenses incurred.
- compensation via the special assistance.

3: Via direct financial subsidies paid to the care recipient
Personal Care Budgets are used in the Netherlands to a considerable extent to pay carers who formerly would not have been paid at all, who would have been paid out of the care recipient's own pocket or who would formerly not have provided any care. Research by Van den Berg (2005) also showed that paying carers out of the Personal Care Budget does not have any negative psychological effects in terms of self-esteem, emotional relationship between family caregiver and care seeker, or pleasure in the provision of care. There does, however, seem to be a positive correlation between paying for family caregiving and the chances that a family caregiver will say that the provision of care is important. For policy-makers, this fact does not pose a stumbling block to compensating carers financially or allowing

carers to be paid out of a Personal Care Budget. This is confirmed by recent research by ITS for the CVZ (Ramakers & Van den Wijngaart, 2005).

There are also structures like the Personal Care Budget abroad, For example, there are opportunities to purchase care for oneself in Denmark, Finland and England. The payment of the financial subsidy is often arranged via the local authority. An example of this is England, where there is:

- Disability Living Allowance: an allowance for people who have suffered a handicap before their 65th year. This consists of a care component and a mobility component. The payment is dependent on income or assets.
- Attendance Allowance: this arrangement is for people over 65 who find it difficult to care for themselves. The family caregiver can also receive a personal grant via this payment. The allowance is dependent on income or assets.
- Direct payments: this arrangement is similar to the Personal Care Budget. In consultation with the local authority, people in need of care receive money to purchase care for themselves instead of receiving care in kind. All sorts of rules apply. For example, the budget-holder may not use the money to pay his or her partner or a close family member living with him or her. However, the local authority can decide that this may be done in exceptional cases.

4) Indirect financial subsidies for the care recipient

This is less relevant to this study and is therefore not discussed in detail.

Financial reimbursement

Expenses can be partially reimbursed via the tax authorities. Approximately 6% of carers receive reimbursements of this kind. A number of tax measures apply to family caregiving. Thus, for example, there are schemes for claiming for exceptional payments and weekend expenses for handicapped children via the income tax. This form of reimbursement has an income-dependent threshold (in 2003: 11.2% of the gross taxable income). A second reimbursement possibility is via special assistance. Approximately 6% of carers claim for this. This scheme has an income-support facility (for example, an extra payment for special diet, extra bedding or telephone expenses) for people with a handicap. Finally, some of the carers have their additional expenditure reimbursed by the care recipient out of his or her own pocket or via a Personal Care Budget.

The financial remuneration of family caregiving is increasingly being handled via the Personal Care Budget. The CVZ recently commissioned an investigation of the payment of family caregiving out of the Personal Care Budget (Ramakers & Van den Wijngaart 2005) and concluded that budget-holders spend some 370 euros per year on purchasing family caregiving (in other words, 38% of their budget). The other 62% of the allocated Personal Care Budgets goes to the regular and commercial carers. Making it impossible to pay for family caregiving out of the Personal Care Budget would not deliver any major savings. The CVZ has therefore advised State-Secretary Ross to maintain the existing Personal Care Budget policy. That means that budget-holders can continue to pay their carers out of the Personal Care Budget. The following arguments for and against are put forward in the controversy over whether family caregiving should be financially remunerated.

Arguments in favour of a 'care wage' are:

- The care that would be remunerated would normally be eligible for reimbursement under the AWBZ if there was no family caregiver available. Carers often prevent a (much more expensive) admission to a nursing home or other institution.
- Paying for family caregiving would improve the relationship between the family caregiver and the care recipient because the care recipient would no longer be involved in a one-sided dependency on the family caregiver (Kremer 2000).
- Research has shown that paying carers out of the Personal Care Budget would not have any negative psychological effects in terms of self-esteem, the emotional relationship between the family caregiver and the care seeker, or the pleasure derived from providing care (Van den Berg, 2005; Ramakers en Van den Wijngaart, 2005).
- Paying for family caregiving would enable people to put together a care arrangement to suit themselves. The parents of a handicapped child, for example, could continue to care for their child themselves without great loss of income. Paying for family caregiving would give both patient and family caregiver more choice.
- Payment is also necessary to activate sufficient family caregiving in the longer term (Kiers 2002).

Arguments against a 'care wage' are:

- The limits of what is reasonable (what you may expect of carers) can be stretched by paying people and by offering leave arrangements. The patient can start making greater demands and other family members may perhaps feel less called upon to contribute to the care.

- Family caregiving is an important part of social networks and it helps keep these networks in existence. Payment is a form of purchasing of responsibility and that can actually harm social networks (Timmermans 2004).
- Commercialising family caregiving changes its intrinsic nature. The personal relationship changes into a commercial, professional relationship (Schnabel 2003).
- Payment keeps carers off the regular labour market, and there are no related pension or occupational disability entitlements. In addition, returning to work or participating in the normal labour market can be made more difficult, which would have an especially adverse effect especially on women (Kremer, 2000).
- Paying for family caregiving would be financially and economically unfeasible. The expansion of paid family caregiving or the Personal Care Budget would, according to Van den Berg and Shut, be tantamount to putting a time bomb under the AWBZ allowances. They fear a snowball effect, whereby free family caregiving is ultimately driven out of circulation by paid family caregiving (and perhaps other forms of care). This would increase the AWBZ payments by one quarter[20].

Schnabel (2003) has suggested using the tax system to compensate people who bear the extra costs of the care that they provide free of charge over quite a long period, and which in another context would be regarded as professional care. This would mean that responsibility for deciding whether or not to make use of the compensation would remain with the family caregiver. The relationship between the family caregiver and the care recipient would not therefore come under stress. This arrangement would, however, provide relatively little benefit for people on lower incomes.

Compensatory measures for expenses incurred and loss of income are reasonable, certainly in a situation in which quite a considerable demand is made on the services of carers.

Summary
There is little support for the idea of a ‘care wage’ for carers, but reimbursement or compensation of extra expenditure for care given (certainly if this leads to financial problems) should be considered. To achieve this goal, consideration could be given to expanding financial subsidy via fiscal and pension measures, offering a grant for travel expenses and increasing familiarity with existing measures. The experiences of Personal Care Budget-holders who pay their carers are generally positive. However, there are many problems associated with family caregiving, such as the bureaucracy that carers have to deal with or the emotional burden, which would not be removed by pay-

ing them. Paying for family caregiving on a large scale would run up against financial restraints and against the objection that it would bring about a fundamental change in care and in the care relationship.

5.5 Cooperation with formal carers

It is very important to achieve a more harmonious interrelationship between formal and informal care. This would benefit not just the quantity, but above all the quality, of care provision. This could be achieved by mutual recognition, valuation and collaboration. Informal care (both family caregiving and volunteer caregiving) must be seen in care training courses and institutions as an integral part of care. In practice, this means that carers must be involved in the allocation of tasks and in the harmonisation of those tasks from the needs assessment and intake stage onwards. Collaboration during the care process can be encouraged by effective, regular communication about the allocation and harmonisation of care tasks. It is also important that formal carers are seen not only as co-providers of care, but that they are also approached as co-clients and 'partners.' Finding the right balance in this respect can be difficult (cf. Chapter 4). Carers also have a great need for support in the form of advice, information, knowledge and fostering of expertise. Family caregiving policy and volunteer policy deserve a structural and integral place in the quality policy of carers and in education.

5.6 Conclusion

Family caregiving support takes many forms. In particular, information and advice as well as replacement via respite care are forms of family caregiving support for which there is considerable need. Foreign examples show that structural solutions, such as arrangements for respite care, are one possibility.

As there are more and more 'task combiners' and this trend will continue in the future, it is of great importance that measures are taken precisely at the interface between work and care. Leave arrangements and individual agreements with employers (for example, through the mediation of the family caregiving broker) offer opportunities in this area and should be better known.

Reimbursing the extra costs of providing care (compensation), certainly if these extra costs lead to financial problems, seems entirely reasonable. This can be achieved by expanding financial subsidy, such as in the form of fiscal and pension measures, and by increasing familiarity with existing measures. The experiences of Personal Care Budget-holders who pay their carers are generally positive. Paying for family caregiving on a large scale would run up against financial restraints and against the objection that it would bring about a fundamental change in the nature of care and the care relationship.

The continuity and quality of family caregiving and volunteer caregiving stands or falls by the support and cooperation with formal care. A common objective and vision is very important, and communication and cooperation are therefore indispensable components. The contribution made by family caregiving to long-term care deserves a structural place in the quality policy of carers and in the curriculum of care training institutions.

6 Government policy to date

6.1 Introduction

The government is concerned to encourage the innate ability of people to organise themselves and thinks it is very important that carers assume responsibility for a large part of the care so as to enable people in need of help to be able to remain longer at home. Since the publication of the *'Zorg nabij'* memorandum in 2001 the government, in this case the Ministry of Health, has also allocated family caregiving a place in its policy and has focused its attention primarily on the support given to carers. The government is concentrating on encouraging family caregiving and on finding ways of preventing excessive stress and social isolation.

6.2 'Zorg nabij'

The Ministry of Health, Welfare and Sport spends 22 million euros a year on extra subsidies to support family caregiving (Zorg nabij, 2001). These subsidies are given to the organisations involved in family caregiving (such as family caregiving support centres and national family caregiving organisations, including organisations that provide support via respite care). Achieving harmonisation between carers, professional carers and welfare organisations is an indispensable part of this strategy. Respite care is partially delivered by volunteers, some of whom are funded out of the AWBZ. Family caregiving itself is not covered by the AWBZ.

If Parliament agrees, then the Social Support Act (*Wet op de maatschappelijke ondersteuning*, WMO) will become effective on 1 June 2006. Family caregiving will then become the responsibility of the local authorities. The present subsidy arrangement will then lapse and the money will be made available to the local authorities according to an apportionment key. The government acknowledges in its policy document *'Zorg nabij'* that the problems of work and care are no longer an exclusively private matter. Family caregiving as a part of care in general has thus been moved from the private sphere to the public sphere. At the same time, the government is appealing to citizens' own sense of responsibility.

Summary
The government recognises the importance of family caregiving and is assigning it a place in its policy. This policy is still centrally regu-

lated, but after 1 June 2006 (with the introduction of the WMO) the responsibility for supporting family caregiving policy will probably be shifted to the local authorities.

6.3 Focus on the family caregiver

A white paper entitled '*De mantelzorger in beeld*' ('Focus on the family caregiver', 2005) was drafted at the request of the Second Chamber (December 2004). The aim is "to describe what importance should be ascribed to family caregiving in Dutch society, as family caregiving is not only important for the family caregiver and his or her nearest and dearest, but for society as a whole, and to formulate proposals (in view of the added value that not only the family caregiver but also the government attaches to this form of care) for subsidising the burden that carers can experience."

The following points are emphasised in the white paper:

- The provision of family caregiving has significance for society and is consequently a public matter.
- Due to the social importance of family caregiving, excessive stress must be prevented and family caregiving support must be strengthened. The annual subsidy (22 million euros in 2005) will be increased to 32 million in 2007.
- Family caregiving must be offered voluntarily and should not therefore be made compulsory. However, the needs assessment for usual care may make allowance for voluntarily-accepted care tasks.
- Instead of a fiscal subsidy[21], the Cabinet is proposing investigating (at local level via the local authorities [WMO] and in the light of local conditions) whether and, if so, what financial subsidy is possible. Tax relief is not a good idea because it is hard to monitor and hard to implement (fraud-sensitive).

Government policy (Ministry of Social Affairs) is aimed at increasing participation in the workforce. Thus, the aim is to increase female participation in the workforce from 55% to 65% by 2010. Participation by women in the workforce has increased overall, but in 2004 it actually experienced a slight downturn in comparison to the previous year. It is therefore open to question whether the target can actually be achieved. The proportion of immigrants in the labour market also remains below par. It is currently 48%, while the target for 2005 was 54% (Timmermans, De Boer en Idema, 2005). The economic independence of women is, however, lagging behind that of men. This is especially true of Turkish and Moroccan women (CBS 2004, E-quality

2004). The proportion of elderly people on the labour market also has to rise, in that it is now 40% and must be 45% by 2010.

The Cabinet is striving for the economic emancipation of women and for a better distribution of labour and work. This policy is currently under pressure. Due to the ageing of the population and economies in professional care, greater demands will be made on family caregiving. With the introduction of the WMO, people in need of help will be expected to turn first to their immediate environment to see what family caregiving they can obtain. Women, above all, will be inclined to listen to this appeal (E-Quality, Factsheet, 2004).

Summary
The government is confining itself in its policy to measures designed to prevent carers from suffering excessive stress, but it continues (certainly compared with other countries) to do relatively little to subsidise carers in other ways (such as via tax relief to compensate them for expenses or via schemes to regulate combining work and care) or to make family caregiving easier or more attractive.

6.4 Conclusion

Since the *'Zorg nabij'* policy document (2001), family caregiving has acquired a place in government policy. Family caregiving has thus become a policy category and has moved from the private to the public sphere. The desire for cost control means that the government has an interest in retaining carers care and will therefore be investing in family caregiving and family caregiving support. It is now focusing its policy primarily on the support of carers in order to prevent excessive stress. Other measures (such as tax relief, schemes for pension build-up and improvements in arrangements for combining work and care) are still lacking. The discussion regarding whether or not to financially remunerate or compensate family caregiving arises again and again, but remains unsettled and has as yet led to little in the way of results.

7 Conclusions and recommendations

7.1 Introduction

Without informal care, formal care could not properly function. Informal care is therefore also of social and economic importance. It is not for nothing that family caregiving and volunteer caregiving have become a part of government policy. The government is making great demands on the efforts of carers and volunteers. At the same time, government policy is also aimed at increasing participation by women and the elderly in the workforce. From an economic standpoint, too, this is necessary in order to keep running a society that is experiencing an increasing demand for care and increasing care expenditure. Ensuring the availability of sufficient carers/volunteers and the availability of sufficient people on the labour market are therefore important, but competing, policy goals.

7.2 Conclusions

Three questions were put forward at the beginning of this study, in the light of which this study has been drafted. The answers to those questions are briefly summarised in this final chapter.

1. Is a capacity problem to be expected over the next 5-10 years?
2. What is the situation regarding the quality of informal care?
3. What is the situation regarding the interrelationship between formal and informal care?

1. Capacity

Various national and international research studies showed that no shortages are to be expected in the numbers of carers and volunteers over the next 5-10 years (assuming that present circumstances do not change). If the present trend continues, then the provision of informal care may even outstrip demand. At first glance, this seems to be a favourable development. It does, however, call for some comment. There is, for example, the question of whether this assessment makes due allowance for the increasing trend towards extramuralisation, for the fact that this will lead to a labour shortage, that changes in the care system can lead to other developments, and that the pressure under which carers work (more and more often in combination with paid employment) will also increase and negatively affect capacity. The increase in participation in the workforce by women is a policy goal that may negatively affect the availability of carers, especially if more women are more highly educated and take on part-time jobs requiring more than 12 hours a week. Economic and social developments are not always easy to predict. The conclusion that sufficient informal carers will be and will remain available despite increasing labour participation by women must therefore be treated with the necessary caution[22].

2. Quality

Another point is that the fact that a certain number of informal carers are available does not tell us anything about the quality of the informal care provided.

- The risk of excessive stress is increasing. This can be prevented via a wide range of support measures. The government is already deploying measures to deal with this problem.
- Excessive stress can increase the risk of mistreatment of the person in need of help and exacerbate the health problems of the family caregiver. Family caregiving must not, therefore, be made compulsory, and professional carers must check on the family caregiver's ability to cope. The combination of work and care leads to a double burden. There is a need for more structural opportunities for respite care.
- Financial aspects: carers incur extra expenditure and loss of income. For the time, being the government is not offering them any solace. Other countries have found solutions to these problems. Compensatory measures for expenses incurred and for loss of income seem to be perfectly reasonable.
- Lack of professionalism: it is open to question whether carers have sufficient expertise. Solutions to this problem could be found by paying more attention to family caregiving in care training courses and care institutions.

3. Relationship between formal and informal care

The relationship between formal and informal care is still in need of substantial improvement. To begin with, there must be more recognition on the part of formal care of the efforts made by carers and the high quality of their work. Formal and informal care must accept each other as ('unequal') partners in the care process. It is important that carers and professional carers work together right from the moment of intake. If necessary, volunteers can also be involved. Effective, regular communication and a harmonising of the allocation of tasks and the way they are approached will help foster a high quality of care for the care recipient and can prevent or postpone expensive admissions. Carers may be seen through the eyes of formal carers as informal carers, but they can also be seen as people who themselves need support in this role. These varying roles of carers demand specific expertise and skills from the professional carers.

7.3 Recommendations

Capacity and quality of informal care

1. Against a background of extramuralisation, socialisation and cost control of long-term care, informal carers (carers and volunteers) are indispensable, and their availability is increasingly important. The deployment of carers and volunteers (whether or not in cooperation with home care and other peripatetic carers) makes a contribution to a higher quality of long-term care and reduces admissions (and so also saves money). If the government is going to make greater demands on informal care, then it must also invest more heavily in support for carers. This does not, however, discharge the government from the responsibility to also invest in professional long-term care.

2. To maintain and strengthen the potential of informal care at a high standard both quantitatively and qualitatively, government policy will have to recognise informal carers to a greater extent than is currently the case by means of incentives and facilitating measures (such as discounts on public transport, tax relief, vouchers for respite care, subsidies for travelling expenses, opportunities for pension build-up and support for family caregiving). Family caregiving support must also be focused to a greater extent than is presently the case on those carers who have a paid job in addition to their care task.

3. The freedom of choice and (relative) independence that the Personal Care Budget brings with it are very important for care recipients. It provides them with some scope for organising their care according to their own wishes and for perhaps offering to cover informal carers' expenses. This is in line with the trend towards patient emancipation over the past few decades. The government must expand the existing Personal Care Budget facilities and must not stop people from paying for family caregiving out of their Personal Care Budget.

4. In the future, there will be more and more people who will have to combine family caregiving with paid work. The government is also keen to encourage this. If the government wants to encourage greater participation by women and the elderly in the labour market and at the same time make greater demands on carers and volunteers, then structural measures aimed at an employer's policy that is friendly to carers are unavoidable. These should include broad measures aimed at making it easier to combine work and care (for example, the '*levensloopregeling*') but above all also measures aimed at reducing the bureaucracy and red tape

facing carers. That can be achieved both via general and individual (customised) arrangements with employers. Successful mediation projects (such as the family caregiving broker scheme, in which several parties bear joint responsibility and the family caregiver is freed from red tape) will therefore have to be encouraged and financially supported.

5. When formulating incentives for informal care (family caregiving and volunteer caregiving), allowance will have to be made for the multicultural nature of society. Immigrants will still feel called upon to act as a family caregiver (especially Turks and Moroccans, the less well educated and young people), but they are less ready to assume the role of volunteer. The government will have to pay specific attention in its volunteer policy to immigrants. Attracting immigrants to volunteer caregiving will demand extra effort, but it will have an integrating and emancipating effect for the concerned individuals.

6. There are a relatively large potential number of carers among immigrants who are not familiar with family caregiving support, but who can benefit from it. Family caregiving support can help alleviate their care task, which could possibly prevent immigrant women from missing out on an education or on opportunities in the job market.

Cooperation between informal and formal care

7. Stimulate cooperation and harmonisation between informal care and formal care. For professionals, the family caregiver is often an indispensable link in the care offered to the client. Conversely, with the support of professional care the family caregiver can keep going for longer and the admission of the person in need of help can be prevented or postponed.

8. Encourage professional care institutions to see volunteer caregiving and family caregiving as an essential and integral part of their quality policy. This is also necessary to guarantee sufficient quality and capacity in long-term care in the future. Close cooperation between professionals, volunteers and carers is necessary to keep care ticking over, but it will also lead to a significant improvement in the quality of care.

9. Professional care has a great deal to offer informal care, such as advice, guidance, skills training and the sharing of knowledge. Conversely, professional carers also benefit from good communications with the family caregiver. This can be

achieved via regular exchange of information, harmonisation of views and the sharing of care tasks.

10. Give the client and the family caregiver (jointly) more say in the desired task allocation and support. Directly involve the client and the family caregiver in a joint consultation in the needs assessment, and strive to achieve a more flexible harmonisation of vision and tasks between carers and professional carers.

11. Professional home care must not only acknowledge carers as co-helpers, but must first and foremost also support them in this task with knowledge, advice and respite care. In practice, home care still often focuses only on the client. The professional must also pay due attention to the family caregiver, assess his or her ability to cope and, if necessary, offer the appropriate support.

12. Encourage the professional support of informal carers, e specially carers. Ensure that replacement by professional carers or volunteers can be regulated via formal care institutions (for example, via vouchers for respite care).

13. Assign informal care (family caregiving and volunteer caregiving) a structural and systematic place in the training of carers. Ensure that dealing with informal care is included as a competence in the syllabuses for professional qualifications. The professional partial qualification for social health care nurses can act as a source of inspiration for this.

Notes

[1] Informal carers (in Dutch: Mantelzorgers) are defined, in the Netherlands, to include family members, friends and neighbours of the care recipient and hereafter referred to as 'family carers' or 'carers'. The phrase 'informal care' is used in the rest of this study as an umbrella term for what in English is meant by informal caregiving, given by carers (which includes care by family members, friends and neighbours of the care recipient) and volunteers. NB: a wide range of definitions of 'informal care' is used in the various forecasts, thus making inter-study comparison difficult. Alternative definitions are, when necessary, indicated in the text.

[2] A recent study by the ITS research bureau commissioned by the Health Care Insurance Board (CVZ) revealed that two-thirds of all holders of a Personal Care Budget devoted all or part of that budget to paying carers (Ramakers & Van den Wijngaart, 2005).

[3] The Netherlands Cabinet recently announced that it wants to make voluntary activities more tax-attractive. For that reason, the Cabinet's Tax Plan for 2006 proposes increasing the annual exemption threshold for a volunteer's remuneration to 1,500 euros, according to the State-Secretary Ross of the Ministry of Health in her policy statement on voluntary work 2005-2007.

[4] This protocol replaced the Working Document on Usual Care, LVIO, 2003.

[5] This definition of informal care is quite common in the Netherlands but is not used at all in other European country. In England the term Informal Care is equated with family caregiving.

[6] Double ageing' means an increase in the number of old people together with a decrease in the provision of formal care due to labour shortages caused by low birth rates.

[7] Statistics Netherlands expects a continuing increase in life ex pectancy to 78 years for men and 81.1 for women by 2020. The number of old people will consequently increase by 50%, from 2.2 million in 2000 to 3.2 million in 2020 (CBS, 2002). The SCP reports an increase from 10% to 13% incarers over the age of 65 in the period 1991 to 2003.

[8] NB: Statistics Netherlands understands 'informal helpers' to mean people who provide informal help to friends, family or acquaintances. This definition is congruent with the definition of carers used in this study. Statistics Netherlands understands 'volunteers' to mean voluntary help provided by an organisation.

[9] The advice that the RVZ is currently preparing on the labour market and demand for care will pay specific attention to family caregiving and dementia.

[10]. The SCP term Informal care covers only family care.

[11] No data on shifts in the task packages of informal carers in the period 1991-2003 were found in the SCP report *'Kijk op informele zorg'* (2005b).

[12] This request was made by the *Landelijk Platform Bestrijding Ouderenmishandeling* (National Campaign to Combat Abuse of the Elderly) together with Transact and NIZW-Zorg (Knowledge Centre for the Elderly). These organizations will also be starting a publicity campaign in the near future.

[13] External carers incur heavy travelling expenses, while internal carers have to spend a great deal on public transport and the necessities of life. (Timmermans, 2003)

[14] The *College van Zorgverzekeringen* (Health Care Insurance Board, CVZ) recently revealed in a letter to State-Secretary Ross that there was no reason to ban budget-holders from hiring family members, friends, neighbours or acquaintances out of their Personal Care Budget. This element would cover some 38% of the total budget. For the Netherlands, that would mean 370 million euros per year. But that would not be at the expense of unpaid family caregiving, or hardly so, as is apparent from the research that the CVZ commissioned from ITS (Ramakers en Van den Wijngaart, 2005).

[15] From 1 June 2005, a change in the Work and Care Act (WAZ) regulates a right to long-term care leave. The new rules apply only to once-only terminal care for a parent, child or partner or for a child in a life-threatening situation. The leave regulation means a reduction in the working week to half or one-third of a working week for two or three months. Leave is not granted if the work situation does not allow for it. The number of weekly hours of leave can, with the agreement of the employer, be increased or the period lengthened to 18 weeks. Wages/salaries are not paid during the leave.

[16] The Noorman-Den Uijl Proposal seeks an expansion of the group of people who fall under the Disability Benefits Act (WAO) or the WW (Unemployment Insurance Act) and who are eligible for this scheme. This proposal has been submitted to the *Commissie Gelijke Behandeling* (Equal Opportunities Commission). At the local level, people entitled to assistance can request an exemption on an individual basis from the obligation to seek work on the grounds of informal care provision.

[17] The EIZ visualise family caregiving support in terms of a flywheel.

[18] The Dutch Cabinet also seems to be thinking along these lines. It recently became known that the Cabinet is opting not to exempt unemployed people over 57 from the obligation to seek work if they provide care or family caregiving on a volunteer basis. However, the Cabinet is willing to investigate this possibility on an individual basis.

[19] Taken from ‘ CEG signalement Mantelzorg, kostenbeheersing en eigen verantwoordelijkheid.’ CEG, Signalering ethiek en gezondheid 2004: p. 127-151.

[20] The arguments for and against are largely derived from the ‘ CEG signalement over mantelzorg.’ See ‘ Signalering ethiek en gezondheid’ , CEG/RVZ 2004.

[21] The Van der Vlies proposal therefore asked for, and was an important stimulus for, this white paper.

[22] In the longer term, labour shortages will mean that care provision by professional carers may possibly not keep pace with demand. The RVZ is preparing to further investigate this question in the recommendation *Arbeidsmarkt en zorgvraag´* (´The labour market and demand for care´). The contribution that carers and volunteers make to solving this problem will also be discussed.

Appendices

Appendix 1

List of participants in the expert meeting of consulted people

- Mw. drs. L.J.M. Aarnink, Ministerie van VWS
- Mw. J.M.T. Ammerlaan, Ministerie van VWS
- Mw. drs. M.C. Beens, Ministerie van SZW
- Mw. dr. ir. A. de Boer, SCP
- Mw. mr. J. Le Cocq d'Armandville, CVZ
- Mw. drs. M.M.C.M. de Goeij,VNG
- Dr. M.A. Koopmanschap, EUR
- Drs. H.M.H. van Lieshout, Ministerie van VWS
- Dr. H.L.G.R. Nies, NIZW
- Mw. dr. M. Mootz, RMO
- Mw. dr. A.M. Pot, Trimbos-instituut
- Mw. drs. M.C.J. Puhl, Zorgkantoor Noord-Holland Noord
- Mw. S. Sangers, LOT/Xzorg
- D.S.M. Schoenmaekers, Universiteit Antwerpen
- Mw. ir. T. Schreuder Goedheijt, NIZW-EIZ
- Mw. drs. N. Tamsma, RIVM
- Mw. drs. G. Visser, NIZW-EIZ
- Mw. I. Wijnberg, E-quality

Organisatie vanuit RVZ:
- Mw. dr. A.J. Struijs

Overige geconsulteerden:
- Mw. drs. M.A. Pijl, free-lance onderzoeker, oud-bestuurslid van de LOT en lid van het oprichtingsbestuur van Eurocarers
- Mw. drs. M.A.B. Severijns, Arcares

Appendix 2

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Fly-wheel

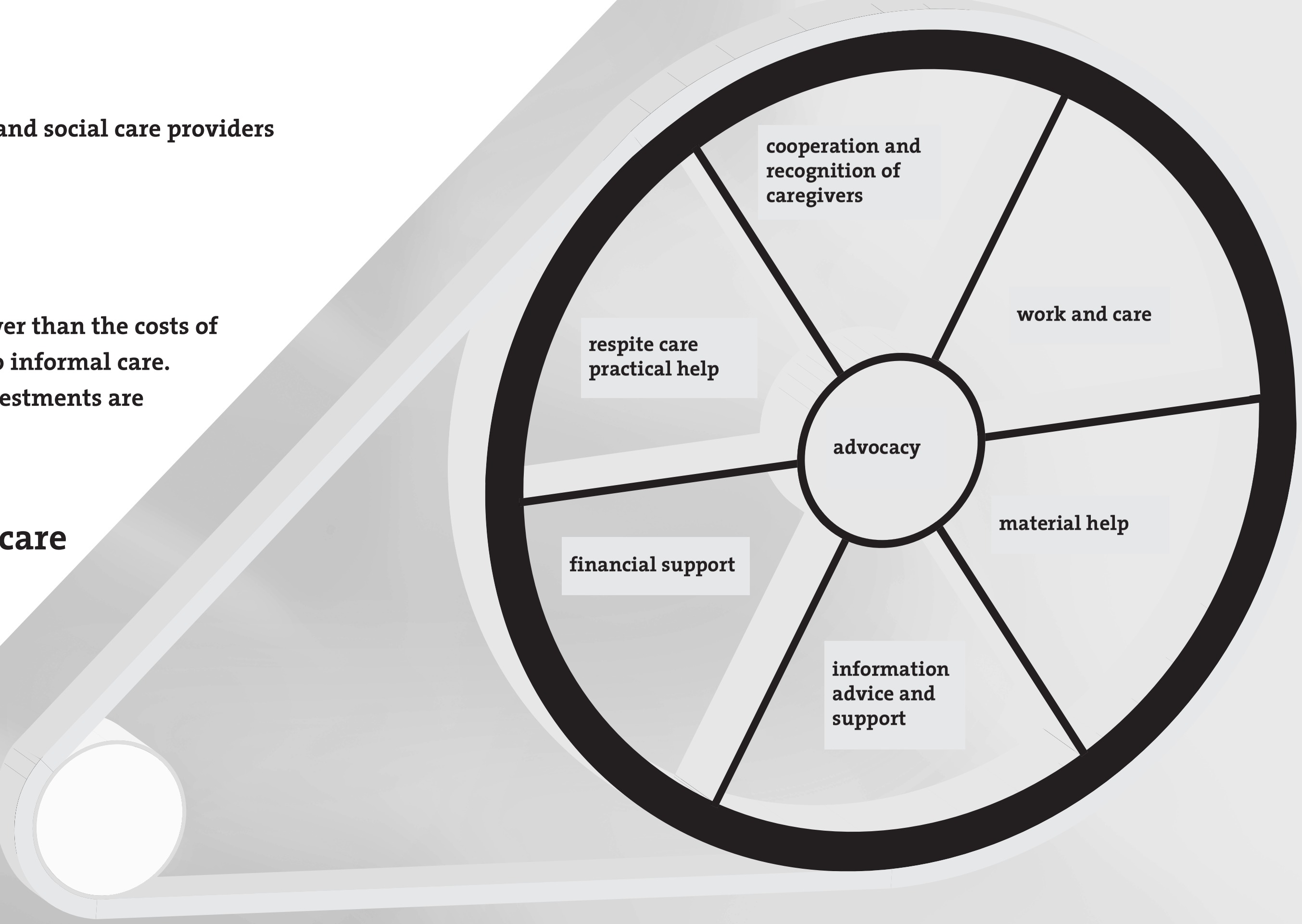
Society is demanding more responsibility from its citizens and is encouraging them to seek sources of care within their own network. Informal care has a position of inestimable value in that process. Considerable efforts have to be made, however, to ensure that informal care remains possible. Policymakers, health and social care providers and financiers must take steps to realise a package of conditions and measures to support informal care.
This package should be diverse and should consist of:

- advocacy
- information, advice and support
- cooperation with and recognition by health and social care providers
- respite care and practical help
- measures for combining work and care
- financial support
- material help

The costs of informal care support are considerably lower than the costs of the formal care that would be necessary if there was no informal care.
It works like a fly-wheel: relatively low supporting investments are sufficient to ensure that informal care retains its great importance for society.

Informal care is more than the usual care within one's own circle:

- a working couple provides for their mentally handicapped son
- a 16-year-old girl assumes a high level of responsibility in caring for her mentally ill mother
- a male pensioner cares for his seriously ill wife
- a mother of growing children cares for her demented father



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[1] Informal care is here not used as an umbrella term, but for care given by family members, friends and neighbours of the care recipient.

Integrated policy & Shared responsibility

Informal care policy forms part of many other policy fields;

- care
- housing
- welfare
- work and income
- emancipation
- education

Informal care support is a responsibility shared by various parties

- government (local, regional and national)
- health and social care providers (wide range)
- financiers
- needs assessment organisations
- employers
- educators
- interest groups

These parties/actors must produce a cohesive package of informal care support in the form of:

- policy
- measures
- terms and conditions
- guidelines
- facilities
- instruments, etc.

All the actors also play a part in informing and raising the awareness of:

- citizens, in general
- caregivers, in particular
- relevant policymakers, helpers and other experts

advocacy	**what?**	bringing the voice and interests of carers to the fore at national and local levels
	who?	carers, the carers organisation MEZZO, regional informal care organisations (platforms), patient organisations, and national regional and local authorities
	how? e.g.	contributing to debate, consultation, surveys and publicity
information, advice and support	**what?**	making carers and care seekers aware of the importance of (and informing them about the opportunities for) informal care support
	who?	MEZZO, informal care/informal care support centres, patient/client organisations, local authorities, carers/helpers (GP, social workers, consultants from community mental health centres, consultants from centres for people living with a limitation (MEE), advice for older peolple, etc.)
	how? e.g.	informal care support, contact with people in the same boat, education, recreation, guides, leaflets, websites and information kiosk
respite care, practical help	**what?**	temporary takeover of informal care (respite care) and practical service provision
	who?	professional and voluntary providers of health and social care, local authorities, informal care support centres, needs assessment bodies and health insurers
	how? e.g.	short-stay hostels, meeting centres for older peolpe and their carers, granny-sitters, emergency care, voluntary palliative welfare services, domestic care, handyman services, meals-on-wheels and shopping services
work and care	**what?**	conditions and measures to combine work and care
	who?	national government, local authorities, employers (organisations), trade unions, and occupational health and safety organisations
	how? e.g.	'saving-for-leave scheme', the Reformed Social Assistance Act (WWB), collective bargaining agreements (leave opportunities, flexitime), company-specific schemes, informal care brokers, convenience services and explanation
financial support	**what?**	reimbursements of costs and compensation for loss of income incurred through informal care
	who?	national government, local authorities and, health insurers
	how? e.g.	tax relief, personal care budget and reimbursement of out-of-pocket expenses (telephone, travel)
material help	**what?**	medical devices and the essentials for performing informal care tasks
	who?	local authorities, housing associations, care organisations, health insurers and researchers
	how? e.g.	portable lifters, alarms, household automation, e-care/camcare, parking permits, collective transport-on-demand and informal care housing
cooperation with and recognition of carers by health and social care providers	**what?**	consciousness raising, identifying and meeting the needs of carers in the field of cooperation and support
	who?	voluntary helpers, professional helpers (GP, nursing, care, social work, supervision), education, and needs assessment bodies
	how? e.g.	include modules on informal care in basic training, in-service and refresher training, methods and attitude

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