

**Services for Supporting
Family Carers of Elderly People in Europe:
Characteristics, Coverage and Usage**

EUROFAMCARE

**National Background Report
for The Netherlands**

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Summary

In this summary the main results are presented of a national study on informal care (in Dutch 'mantelzorg' ≈ 'mantle or coat care') together with developments in supply for and policy on informal care support services (SCP (B), 2003). In addition, key issues are discussed on which informal caregivers, organizations for informal caregivers, professional health care organizations, and policy makers have to work to improve the position of informal caregivers. Main key issue for the Netherlands is to increase the knowledge and to spread information about problems of and support for informal caregivers with informal caregivers, professional health care organizations and policy makers (local, regional and national level).

Informal caregivers and organizations for informal caregivers

Summary

Number of informal caregivers and nature and intensity of care tasks

About 3,7 million – 29% of Dutch population over 18 years – provided care for a relative, friend or neighbor in need in 2001. 750.000 informal caregivers are intensively and for a long period involved with informal care. For a large majority this is a matter of course (80%)¹. More than two million people took care for someone older than 64 years.

They mostly provide domestic help (75%) and psychosocial support (81%). Less often they are involved with personal care (34%), however informal caregivers of terminally ill people do provide much personal assistance (66%). Two third (67%) of the informal caregivers provided multiple types of care.

Importance of social networks for help

Forty per cent of the informal caregivers are providing informal care on their own, without assistance from other family members or friends. The other sixty per cent of the primary informal caregivers receive help from secondary informal caregivers. There are three types of helping networks. First, the *nuclear family network*: (mostly intensive) informal care to partners or children from household members. Second, the *extended family network*: care for parents (or other family members, such as siblings). And finally, the *friends network*: in which people are being cared for who have a small family network or network at all.

¹ Data presented in this report are based on a large study on informal care in the Netherlands carried out by the Social and Cultural Planning Office of the Netherlands (a government agency doing independent scientific research) in 2001 (SCP (B), 2003).

Burden by informal care

Between 150,000 and 200,000 informal caregivers are burdened or even overburdened. Burden increases when the intensity of informal care is high, when people are helping a partner or child or when they are the sole informal caregiver.

Risk group: helping partners / older informal caregivers

Those informal caregivers who are taking care of a partner or spouse are a risk group among informal caregivers: they are often the only informal caregiver, they are involved with informal care for 24 hours per day, seven days per week, they are more often burdened, and they have more expenditures and are more often deprived of income than other categories of informal caregivers. They also do not often use services for informal caregivers, such as information / advice / emotional support services. They, however, are more often supported by formal home caregivers.

Pressure on informal care

The pressure on informal care is increased due to different demographical and political developments. It is expected that the demand for informal care will rise, but the supply of informal caregivers will decline.

In the last ten years the national government observed a disproportional increase in use of professional health care. The government is occupied with cutting these costs, among others by limiting the AWBZ (an obligatory insurance for so-called "grave medical risks", which covers elderly people in need of nursing, the mentally ill and the handicapped), increasing out-of-pocket payments, apply more stringent rules for needs assessment, and by decreasing intramural health care and stimulating extramural care. This leads to extra pressure on informal care and especially to financial problems (particularly for informal caregiving partner): piling of out-of-pocket payments, often in combination with (partly) quitting paid jobs, economizing on relaxation, and the dilemma of providing (more) paid work (to cover all costs for care) or to quit working and providing all care alone and put all professional care off.

Key issues

What are informal caregivers themselves able to do to improve their position?

Important for informal caregivers is to identify themselves as **caregiver, care receiver and promoter of interest**: many caregiving relatives, friends, neighbors do not identify themselves as **caregivers** and do not perceive themselves as partner of discussion with professional caregivers. If they do so – take an active attitude toward professionals – they will be better able to obtain information, for example about the disease, prognosis, and also about (additional) health care services. Next to that, the professional caregiver is forced to com-

municate with the informal caregiver and to distinguish her/him as an expert of the person in need for care.

On the other side, informal caregivers have to identify themselves also more as **care receivers**, particularly in the case of a long and/or intensive care process, for example for chronically ill relatives. Many informal caregivers call for help at a late stage, when they are almost overburdened. It is important for them to become aware of signals of burden (tiredness, headaches, loss of concentration etc.) and that is much better to call for help sooner. They will be able to sustain their role as informal caregiver. Particularly with all developments in mind (increasing aging of the population, smaller number of children per family, increasing female labor participation) there will be less potential of informal caregivers and people have more chance to become an informal caregiver. More and more, they will have to combine this role with other roles, such as a paid job and an own family. Then, it will become even more necessary to call for informal care support at an earlier stage. This is possible with support centers for informal caregivers, with voluntary care organizations, but also with professional home care or general practitioner.

Finally, informal caregivers have to join in organizations for the **promotion of their interest**, both on local as on national level. It is important to have a voice in the matter with national policy makers, because they are responsible for policy on informal care, for example about care leaves and financing health care services. Next to it, local policy makers are becoming more important for informal care support in the new Act on Community Support (WMO, 2006). Local authorities obtain more responsibilities in organizing and financing health and welfare services.

All three roles are not easily performed by informal caregivers. They provide informal care out of love and mercy and this is not easily united with these roles. However, it is important to become aware of this under the recent and future developments!

What are organizations for informal caregivers / informal care support able to do to improve the position of informal caregivers?

Services for informal care support

There are different services for informal care support, such as support centers for informal caregivers (information, practical and emotional support), a telephone service for informal caregivers, voluntary home care, respite care (professional and voluntary) and promotion of interest. They are (partially) financed with funds from the national government (CVTM-fund: coordination voluntary home care and informal care support), often completed with other financial resources/subsidies.

Key issues

The national study on informal care reveals that informal caregivers need (more) support from professional home care (SCP (B), 2003). Accordingly, in their daily tasks they want structural practical support in household and personal care tasks, and not only emotional support and information, or incidental support.

- On a local level, organizations for informal caregivers / informal care support have to *pay more attention at PR (public relations) of existing services*. For this it is important to take into consideration the thresholds that informal caregivers perceive to call for help for themselves.
- *More attention for the promotion of interest of informal caregivers*: informal care organizations have to make informal caregivers aware of the importance of the promotion of interest to inform local policy makers about the problems of informal caregivers.
- *Relation with professional care*: important for informal care organizations is to increase knowledge on the existence of services for informal care support with professional health care organizations (networking).

Professional health care organizations

Summary

Relation informal care and formal care

Informal caregivers provide a considerable contribution to people in need for care. Eighty per cent of the informal caregivers think that another informal caregiver will take over their care when they fall out, for example due to illness. Only 13 % expect that formal home care has to take over and for another 13% admission to a residential or nursing home is the only alternative. The part of informal care is four to five times as high as that of formal care (RMO/RVZ, 1999). Presumably, hundreds of thousands of persons in need for care do not have to appeal to formal care because of the availability of informal caregivers.

Strong division of tasks

If informal care is present, professional home care is restricted to a few tasks: completely washing or bathing, dressing the care receiver and performing heavy household tasks. Other domestic tasks, such as running errands, preparing meals, and doing the laundry are almost totally left to informal caregivers. Formal home care offers this type of care only when no one else is available or when there is a longstanding and intensive care situation and transfer to intramural care is threatened. Thus, formal care is mostly supplementary to informal care: it fills the gaps in social networks (SCP (B), 2003).

Quality of and need for professional home care

Informal caregivers are satisfied with the practical help from formal home care, but complain about the organizations that arrange this care: most criticisms are about lack of flexibility. The organizations, for example, were not able to take over the care when the informal caregiver could not help (e.g. due to illness). The co-ordination between formal and informal caregivers is also lacking.

A quarter of informal caregivers that is not assisted by formal home care thinks that formal home care is necessary. 43% of informal caregivers that are already assisted by formal home care thinks this is insufficient. Remarkable is that 36% does not arrange formal home care because the care receivers do not want strangers in their house (SCP (B), 2003).

Key issues: What are professional health care organizations able to do to improve the position of informal caregivers?

- *Full acceptance of informal care by professional caregivers:* judge the expertise of informal caregivers by its true merits. Informal caregivers are indispensable to the continuity and coordination of the care. This means that professional caregivers have to work less patient-focussed and more sys-

tem-focussed. They have to look also – next to that of patients – at the role, needs and problems of informal caregivers.

- *Prevention of burden by informal care:* Professionals – for example general practitioners or professional home caregivers – have to be aware of the situation of the informal caregivers and refer them to the possibilities of informal care support services. They also have to make them conscious that it is good to call for help in an early stage. Because, if they do so, they will be better able and prepared to provide informal care for a longer time.
- *More attention for informal care in institutional health care facilities:* placement of the care receiver in an institutional health care facility can lead to psychological burden for the informal caregiver, because she/he feels guilty, but can also mean a relief of tasks. Institutional health care facilities, however, call in informal caregivers because of shortages of personnel. The position of informal caregivers in health care facilities is often unclear. Reason is that in provide multiple roles at the same time: they are caregiver, care receiver, partner, child, friend, and when the patient is no longer able also legal representative for medical decisions. The role of caregiver is taken over by professional caregivers. But, when professional caregivers do not acknowledge this role, they deny in fact a part of their identity. Furthermore, informal caregivers are well informed about the history, needs and preferences of the care receivers. This knowledge should be incorporated in the care process.

Policy makers

Summary

The national government has interest in informal care, because collective financial burden has to be decreased. This, however, does not lead to extra means for the support of informal caregivers. The Dutch government is mainly engaged with high cuts on health and welfare services. Citizens have to pay more for their health insurance and the universal public long-term care insurance (AWBZ) is being limited, and people have to pay more out-of-pocket payments.

The government pursues that citizens take as much responsibility for their own care as possible (first in their own family/social networks, and only if this is no longer possible professional care can be called in). Reinforcement of informal care and voluntary care are important aims for the government. With regard to informal care the government aims at:

- better co-operation between informal caregivers and formal caregivers (allocation of tasks, communication,
- more attention for informal care in education programs
- relieve informal caregivers by developing and extending respite care services at home

To support informal care Ministry of Health and welfare and Sport (VWS) provides more than 11 million Euro for extra subsidies. With this money VWS subsidizes support centers for informal carers (and the national organization for these support centers Xzorg), voluntary (terminal) home care organizations, organization for informal caregivers (LOT), and the Expertise center for Informal Care (EIZ).

Key issues: What are policy makers able to do to improve the position of informal caregivers?

- Government has to be aware that different demographical and political developments, such as aging of the Dutch population, economy measures for professional care and stimulation of labor participation, *increase the pressure on informal care*. Consequences may be that more informal caregivers will be burdened, perceive problems with combining multiple tasks (their own family, paid jobs, taking care of parents), or have to admit the persons they have taken care of to an institutional health care facility. To prevent this a good system of health and welfare services and measures for combining work and care is necessary.
- Important is, that *policy makers stimulate the development of respite care services*. Especially for different groups of informal caregivers (now mainly focussed on older people with dementia).

- *More attention for policy on informal care in institutional health care facilities, see the key issues in “Professional Health Care Organizations”.*
- *Study the possibilities to increase the usage of the personal care budget (pgb) for informal caregivers. Necessary is to check the conditions: on one hand the pgb can be a kind of reward / respect for the work of the informal caregiver, on the other hand it can threaten the informal character of informal care.*
- *More conditions to combine work and care* (together with organizations for employers and employees). The government stimulates labor participation (economizing Unemployment Act (WW) and Disability Insurance Act (WAO), early pension measures etc). Now, 71% of the informal caregivers are situated in the productive phase (18-65 years), of which 60% is active at the labor market. This will increase due to labor policy. This makes it important to focus attention on good conditions to combine work and care. For the present, there is a modest possibility to take care leaves. The arrangement for Financing Career break (since 1998) offers the possibility for a palliative care leave. Since 2002, the arrangement is broadened, but compensation is low and there are many rules and conditions that do not stimulate people to arrange this kind of care leave. Under development is a new, unique arrangement for work leaves: the life course arrangement, which will start in 2006. Employees are able and also expected to save days, which they can use for education, sabbatical leave, but also for care leaves. There is much discussion among interest groups, government, and organizations for employers and employees.
- *More attention for intercultural family caregivers and their needs for informal care support.* For the present the use of informal care support among family caregivers of ethnic minorities is low. For many ethnic groups it is unthinkable that strangers take care of their parents, although daughters (in-law) are very much jammed between their parents (in-law) and their own children (Yerden, 2000, Morée, 2003).
- *More attention for financial aspects of informal care.* Informal caregivers have numerous costs for informal care (e.g. travel- and telephone costs) and / or loose income, because they quit their jobs or reduce their working hours. Furthermore they economize on leisure activities and relaxation, with all consequences.
- *Attention for the new Act for Community (WMO):* risks of shifting responsibility from national to local policy makers. There are many doubts about this new act, particularly about local diversity: among other about differences with regard to access to health and welfare services, with regard to these services because of the autonomy for local communities in the spending of money. And there are doubts about supervision on the quality of care and the involvement of clients.

- *Final key issue focuses on the stimulation of investment in social networks.* Since policy makers are striving that citizens take as much responsibility for their own care (meaning from their network) it is necessary that they are stimulated to invest in social networks (through sports, voluntary work, education, etc.)

Introduction

In the Netherlands informal care is described as care which is unpaid and not provided on a professional basis: distinguishable in family care, self help, and voluntary care. More common for the use of the term family care is the term mantle or coat care (dutch: mantelzorg). This saying was introduced in science in the seventies to describe care activities provided by people in informal settings (Hattinga Verschure 1977). The mantle or coat is the metaphor for everything that surrounds us with warmth and affection (Tjadens en Duijnste 1999).

Informal caregivers make up a substantial part of the Dutch care system of dying older people. Due to restricted health care budgets in the past ten years in the Netherlands, formal home care is indicated only if the need for care is very high and / or informal carers are no longer able to perform the required care activities. Only one in five chronically ill or disabled persons uses professional assistance (Duynstee et al., 1997). Shifting its focus from professional to informal care, government policies have then led to an increase of pressure on informal caregivers due to substitution policies (Lyke, 2000; Nijboer, 2000).

In the Netherlands there is no nation-wide registration of informal caregivers. Data presented in this report are based on a large study on informal care in the Netherlands carried out by the Social and Cultural Planning Office of the Netherlands (a government agency doing independent scientific research) in 2001. The SCP, therefore, used a wide definition of informal care: “offering unpaid help to family members or close acquaintances who need help because of fairly severe health problems” (SCP (B), 2003).

In this report we use two sources of data:

- A study on working caregivers (SCP (A), 2001)
- on a large study on informal care in the Netherlands (SCP (B+C), 2003)

Before the main results from this study are presented, a short description of the Dutch health care system is given.

Introduction of the Dutch health care system

In the Netherlands, the three general types of providers of care for older people are home care, residential homes and nursing homes. Older people in need of help or care mostly in first instance apply to the local or regional Home Care Organisation, or to a GP or a community social service centre. These will refer the elder person to a needs assessment agency for clarification of demand, assessment of need and allocation of kind and quantity of care.

Needs assessment

Preceding to admission to home care, residential homes and nursing homes, **needs assessment** is required. This will be performed by regional independ-

ent and integrated needs assessment agencies (RIO). The decision of the need assessment agency states the eligibility of the applicant, which guarantees funding of the provider. It also states the kind and the amount of care the person in need should receive, and the duration of it. With the decision of the needs assessment agency, the person in need can apply to a licensed care provider that can supply the care circumscribed in the decision. Persons assessed and eligible for non-institutional care, can ask for care in cash ("personal budget for care", PGB) or care offered in kind. With the personal budget for care insured care receivers obtain an amount of money, with which they can choose and pay their own caregivers, meaning that they also can pay their own relatives for the care for which they have received a needs assessment.

A needs assessment is not necessary for treatment of a psychiatric disorder, and a stay in a mental health institution in combination with psychiatric treatment shorter than one year. For this you only need a reference from your GP, only for longer stays a needs assessment is necessary.

Home care

Home care is the combination of **home nursing** and **home help**. Mostly home care delivery is integrated, as most home care organisations offer both home nursing and home help. Home nursing and home help include: nursing, care, household help, guidance and consultation in connection with illness or recovery, disability, psychosocial or family problems or old age. The lending of nursing appliances is also part of home care activities.

Residential home

Older persons who are dependent on care and help and cannot any longer cope at home, may apply to be admitted to a **residential home for the elderly** ("care home", "old age home").

Persons being admitted will not need special medical care or nursing (else they might be referred to a nursing home). Consequently, in the staff there are hardly any qualified nurses; most of the employees are "caring staff" with an intermediate or lower education. In case residents might develop dementia later on, it is generally tried to keep these persons in a special dementia care project rather than transferring them to a nursing home.

Nursing home

If a patients' situation is stable but he or she is not able to cope at home and needs non-complex continuous nursing care, he or she may be referred to a **nursing home** (cf. Skilled Nursing Facility in the USA), which is for long term care and nursing. Nursing homes also have an important function in short term rehabilitation of both elderly and younger patients, and in diagnosis and functional assessment. Nursing homes employ qualified medical, paramedical and nursing staff.

Recent developments reveal that in some situations home care organisations provide care in health care facilities, and health care facilities vice versa at the homes of people in need for care. This means that borders between intramural and extramural care are diminishing.

Finance

Everyone living in the Netherlands is insured for care in the case of sickness or invalidity. A well-functioning health service is a constitutional right. In order to provide this care for the inhabitants of the Netherlands, the government plays an active role in legislation concerning health care and the financing of the health service. Insurance packages are compiled on the basis of a number of laws. Law also determines the premiums and content of these packages. This refers to statutory insurance. There is also an additional medical expenses insurance, which is based on private law and is normally referred to as "private insurance".

Mixed system

The financing of medical care takes place within a mixed system of public and private insurance. The system is divided into three compartments:

- The first compartment is the General Exceptional Medical Expenses Act (AWBZ). This legislation regulates an obligatory insurance for so-called "grave medical risks" and covers elderly people in need of nursing, the mentally ill and the handicapped. These are forms of care that are relatively expensive and unaffordable for the individual patient.
- The second compartment is the statutory public health insurance based on the Health Insurance Act (ZFW), the Access to Health Insurance Act (WTZ), and private insurance. This is for normal medical care, such as for the GP, hospital or pharmacy.
- The third compartment is supplementary (private) insurance.

The first compartment

The AWBZ was created in order to ensure that all the inhabitants of the Netherlands have insurance cover against serious medical risks. This refers to risks, which cannot be covered on an individual basis, since, in many cases, it is a question of a chronic condition. In brief, it refers to areas such as nursing homes, care for the handicapped, home care, and care for the mentally ill. AWBZ is a national insurance, which means that all inhabitants of the Netherlands participate compulsorily.

The second compartment: Health Insurance Act

By means of the Health Insurance Act, the following categories are compulsory insured (ziekenfonds): employees with an income below the income level gauge (for 2002 this has been set at €30,700), their (non-earning) partners and their children, people over 65 years (with an income up to €19,550), re-

recipients of social insurance benefits, and the self-employed and their (non-earning) partners and children, with an income up to €19,650.

Approximately 65 percent of the Dutch population is insured via the statutory health insurance fund. The insurance covers basic medical care, such as general practitioners and medical specialists, hospital care, medicines, physiotherapy and dental treatment for children. The size of the premium is to a large degree income-related; only a small portion of the premium is set by the care insurer (the nominal premium). The rest of the population – about 30 % - are not eligible for this compulsory Health Insurance and have to arrange a private health insurance (second compartment).

Second compartment: private medical expenses insurance

In addition to statutory health insurance covered by the Health Insurance Act, the second compartment also includes private medical expenses insurance. A certain category of the privately insured is insured on the basis of the Access to Health Insurance Act (WTZ). This guarantees entitlement to a standard package for people who do not qualify for statutory health insurance. This package is largely in line with the statutory health insurance package. In addition to a nominal premium, the privately insured also pay a statutory solidarity supplement: a WTZ supplement known as the MOOZ Act which refers to the co-financing of the over-representation of older people in the statutory health insurance fund. Since the number of older people covered by public insurance is far greater than those covered by private insurance, the State tries to compensate for this by means of MOOZ Act.

The third compartment

The third compartment is formed by supplementary insurance, which can be effected voluntarily as a supplement to the statutory health insurance fund or the standard package policy. The content of these packages varies greatly as does the premium and any own risk cover (information on Dutch health care on www.zn.nl).

The **funding system** is complicated. Providers are private not-for-profit organisations (with very few exceptions), but are funded in the framework of AWBZ. Funds are collected on a national level through premiums that are collected along with income tax. Care supplying organisations receive money according to the capacity (number of institutional beds, number of clients in home care) for which they have a license or agreement. The agency that they have to negotiate with about funding, is the **care office**. This is the regional branch office of the national AWBZ framework. The care office is responsible for capacity and quality of care in its region.

Hospitals are not under the rule of the care insurance, but rather of that of the health insurance. Hence, no needs assessment by RIO is required. Elderly patients with multiple health problems whose condition unstable or uncertain,

may be referred to a **geriatric department** of a hospital, for comprehensive geriatric diagnosis and therapy.

Modernisation AWBZ and health care

In the new AWBZ (since April 2003) the demand of the client is the central focus, whereas in the old system this was determined by the supply of health care services. The regional integrated needs assessment agencies (RIO) assess for seven functions for which the client needs care independent from supply. These are: household care, personal care, nursing care, supportive care (e.g. day-care facilities, respite care), activating care (e.g. consultation for behavioural or mental problems), treatment (e.g. rehabilitation after a cerebrovascular accident), and admission to intramural health care facilities (e.g. nursing home / residential home etc.). For the last two functions a personal budget for care (PGB) is not possible.

Because of increasing medical expenses and budget deficits the government is cutting down the AWBZ and people have to pay more co-payments themselves. Local authorities will become more responsible with regard to the provision of health and social services. Therefore, a new act is being developed: Community Support Act (Wet Maatschappelijke Ondersteuning). The policy plans for this act (presented in the government on April 23 2004) describe the own responsibility for care for citizens and the shift for community support and care to local government. The policymakers think that people have their own responsibility within the health and welfare system for themselves and their relatives.

When self-competence and informal care are no longer possible local governments offer support under the Community Support Act. Care under the General Exceptional Medical Expenses Act (AWBZ). Are restricted to situations in which professional care and nursing is necessary.

In the Community Support Act the local governments have responsibility to provide support and help to citizens with physical, mental and / or psychological limitations and stimulate their social participation.

The Community Support Act (2006) capture the actual Welfare Act, Disabled Persons Act (WVG), and parts of the General Exceptional Medical Expenses Act (AWBZ) (household care, parts of personal care, supportive counselling with independent living).

Restrictions in care under the Community Support Act?

- No rights for clients such as under the AWBZ
- Differences in access to services, because of different policies between local governments
- Differences in services because of the choice of local governments to spend their funds

- No control for quality of care
- Participation of clients is not organised as in the old system (Wet Medezeggenschap Cliënten Zorginstellingen (WMCZ))

Review system of care insurance

In the Netherlands, great efforts are underway to achieve a new system of medical expenses insurance. At the moment, the Netherlands still has a dual system of public insurance (ziekenfonds) and private medical expenses insurance. The size of the income of the consumer determines the form of insurance that is effected. The plan is that the dual system will be transformed into a system with an obligatory public basic insurance.

Main results from the SCP-study on informal care

The data presented in this summary below are focussed on the group of informal caregivers caring for people of all ages (of which 65 % is 65 years and older) In chapter one also data are presented for the selection of informal care receivers of 65 years and older.

Number of informal caregivers and types of care

About 3.7 million Dutch people provided care for a relative, friend or neighbour in need in 2001. For a large majority this is a matter of course (80 %). Affection, sense of duty and a good relationship with the person in need for care are the most important motives for providing informal care.

They mostly provide domestic help (75 %) and emotional support and psychosocial accompaniment (81 %). Less often they are involved with personal care (34 %), however informal caregivers of terminally ill people do provide much personal assistance (66 %). Two third (67 %) of the informal caregivers provided multiple types of care.

About 750,000 informal caregivers are intensively (more than eight hours per week) and for a long period involved with informal care (longer than three months). Parents and partners received more help than friends or acquaintances.

Helping networks

Forty per cent of the informal caregivers are providing informal care on their own, without assistance from other family members or friends. Sixty per cent of the primary informal caregivers receive help from secondary informal caregivers. There are three types of helping networks:

The *nuclear family network*: (mostly intensive) informal care to partners or children from household members.

The *extended family network*: care for parents (or other family members, such as siblings).

The *friends network*: in which people are being cared for who have a small family network or network at all.

Burden

Between 150,000 and 200,000 informal caregivers are burdened or even overburdened. Burden increased when the intensity of informal care is high, when people are helping a partner or child or when they are the sole informal caregiver. Remarkable is that informal caregivers who are combining care and employment and / or an own family do not feel more burdened than other caregivers without such a combination.

Risk group: partners

Those informal caregivers who are taking care of a partner or spouse are a risk group among informal caregivers: they are often the only informal caregiver, they provide many hours of care per week, they are more often burdened, and they have more expenditures and more often deprived of income than other categories of informal caregivers. They also do not often use services for informal caregivers, such as information / advice / emotional support services. They, however, are often supported by formal home caregivers.

Informal care and formal care

Informal caregivers provide a considerable contribution to people in need for care. Eighty per cent thinks that other informal caregivers take over their care when they fall out, for example due to illness. Only 13 % expect that formal home care has to take over and for another 13 % admission to a residential or nursing home is the only alternative. Presumably, hundreds of thousands of persons in need for care do not have to appeal to formal care because of the availability of informal caregivers.

Strong division of tasks

If informal care is present, home care is restricted to a few tasks: completely washing or bathing, dressing the care receiver and heavy household tasks. Other domestic tasks, such as running errands, preparing meals, and laundry are almost totally left to informal caregivers. Formal home care offers this type of care only when no one else is available or when there is a longstanding and intensive care situation and transfer to intramural care is threatened. Thus, formal care is mostly supplementary to informal care.

Informal caregivers are satisfied with the practical help from formal home care, but complain about the organisations that arrange this care: most criticisms are about lack of flexibility. The organisations, for example, were not able to take over the care when the informal caregiver could not help (e.g. due to illness). The co-ordination between formal and informal caregivers is also lacking.

Additional help from formal home care is required

A quarter of informal caregivers that is not assisted by formal home care thinks that formal home care is necessary. 43 % of informal caregivers that are already assisted by formal home care thinks this is insufficient.

Remarkable is that a third does not call for formal home care because of waiting lists, and even more remarkable is that 36 % does not arrange formal care because the care receivers does not want strangers in his or her house.

1 Profile of family caregivers of older people

1.1 Number of carers

Using a wide definition of informal care (offering help to family members or close acquaintances who need help because of fairly severe health problems) the Social and Cultural Planning Office of the Netherlands (SCP) estimated that in 2001 almost one in four (about 3.7 million people of the 16 million Dutch citizens) provided informal care (29 % of Dutch population over 18 years). 2,1 million people took care for someone older than 64 years.

The large group of 3.7 million, however, is divided into four types of caregivers selecting for duration (shorter or longer than three months in 2001) and intensity (less or more than eight hours per week) (table 1). About 2,4 million people (19 % of the Dutch population over 18 years) provided informal care longer than three months or for more than eight hours per week. This is consistent with an estimation of number of informal caregivers in 1991 (De Boer et al., 1991). This means that there is no decrease in the number of informal caregivers, which is very often assumed due to the increasing labour market participation of women, the increasing age of the Dutch population and the decreasing percentage of younger people, smaller families, decreasing number of children per family, more generations within families, which means less potential availability of informal caregivers.

Table 1: Number of informal caregivers distinguished by duration and intensity of informal care

Duration and Intensity	number of all informal caregivers ^{2, a}	number of informal caregivers caring for people 65 years and older ^b
short, not intensive	1,400,000 (37)	780,000 (36.6)
short, intensive	300,000 (8)	120,000 (5.6)
long, not intensive	1,300,000 (35)	830,000 (39 %)
long, intensive	750,000 (20)	400,000 (18.8 %)

Duration: > / < 3 months; Intensity: > / < 8 hours per week

Sources: ^a SCP, 2003(B), p. 34

^b data processed by SCP for the selection of informal caregivers of older care receivers

² Note: This study performed by the SCP was not only intended to study informal care of older people. However, the percentage of older people (65 years and older) in the care receiver group was large (65 %) (table 2). Differences between the group all informal caregivers and those caring for people 65 years and older do not differ very much.

Table 2: Age of care receivers (%)

Age of care receiver	%
0-39 years	13
40-64 years	21
65-79 years	31
80 years and older	34

Source: SCP, 2003(B), p. 37

1.2 Age of carers

The group of informal caregivers differs significantly from the general Dutch population. Informal care is less often provided between ages of 18 and 34 years and more often between 45 and 65 years between the age of 45 and 65 (table 3).

Table 3: Age of informal caregivers (%)

Age	age of all informal caregivers (%) ^a	number of informal caregivers caring for people 65 years and older (%) ^b
18-34 years	17	7.9
35-44 years	23	21.1
45-54 years	31	36.1
55-64 years	17	18.5
65-74 years	9	11.5
≥ 75 years	4	5.0

Sources: ^a SCP, 2003(B), p. 36^b data processed by SCP for the selection of informal caregivers of older care receivers (Selection)

1.3 Gender of carers

Informal caregivers are more often female than male (60 % vs. 40 % in the total group, and 62 % vs. 38 % in the group of informal caregivers caring for older people) contrary to normal gender division in the Netherlands (51 % female and 49 % male). Daughters and daughters-in-law are the most frequent female caregivers.

1.4 Income of carers

These data are an estimation of the net household income of informal caregivers, and it is shown that most of the informal caregivers are in the highest income group. This calls for more scientific attention for the relationship between income and providing informal care: are people with a lower income less able

to provide informal care? Do they have less resources due to low income and / or worse health? Do people with higher incomes have more resources to care (healthier, more financial resources (for example for travelling to the care receiver or other costs related to informal care))?

Table 4: Net household income categories of informal caregivers in 2001 (%)

Income in Euro's	all informal caregivers (%) ^a	selection (%) ^b
< 10,891	12	16
10,891-18,605	21	21
18,606-24,958	20	17
> 24,958	47	46

Sources: ^a SCP, 2003(B), p. 201^b data processed by SCP for the selection of informal caregivers of older care receivers (Selection)

1.5 Hours of caring and caring tasks, caring for more than one person

Caring tasks

Informal care was classified into three types of caring tasks:

- Domestic tasks: e.g. cleaning, doing the laundry, groceries
- Personal care tasks: e.g. bathing / showering, dressing
- Psychosocial tasks: e.g. arranging and organising care / financials, giving comfort, listening

Hours of caring

On average informal caregivers provide help for 17.9 hours per week.³ More than half of the caregivers provides more than one care task (67 %), mostly a combination of domestic and psychosocial tasks (table 5 and 6). In this study there was also a distinction in types of care receivers (terminal illness, temporary illness, chronic illness, other (more than one illness but none dominant)). Informal caregivers of dying care receivers differed significantly from the other three groups and provided more often personal care tasks.

³ Maximum hours per week were set on 112 hours, because informal caregivers themselves also have to eat and sleep.

Table 5: Number of types of informal care provision (%)

Number of types of care	all informal caregivers (%) ^a	selection (%) ^b
1 type	33	31
2 types	44	44
3 types	23	25

Sources: ^a SCP, 2003(B), p. 47^b data processed by SCP for the selection of informal caregivers of older care receivers (Selection)**Table 6: Type of care according to care situation (more than one type possible) (%)**

	terminal illness	chronic illness	temporary illness
Domestic care	79	73	79
personal care	66	37	34
psychosocial care	92	85	80

Caring for more than one person

45 % of all informal caregivers provide care to more than one person at the same time or respectively (table 7). These are most often female caregivers helping their parents and / or parents-in-law. This may suggest that there is something like an informal care career, which is more often performed by women than men (48 % female caregivers provide care to more than one person vs. 39 % of male caregivers). This is not explained by the labour market participation: women provide care to more persons in need than men do whether they have a paid job or not.

Table 7: Number of care receivers per informal caregiver (%)

Number of care receivers	all informal caregivers (%) ^a	selection (%) ^b
1	55	57
2	18	16
3	19	20
4 or more	8	7

Sources: ^a SCP, 2003(B), p. 60^b data processed by SCP for the selection of informal caregivers of older care receivers (Selection)**Informal caregiving and support from secondary informal caregivers**

Many informal caregivers provide care on their own (40 % of all informal caregivers and 36 % in the selection), without support from other informal – secondary – caregivers. They are mostly without a paid job, partner of the care receiver, caring for someone with a stable need for care, and / or are providing personal care.

The other 60 % (64 % in the selection) are often supported by one or more secondary informal caregivers. Three types of helping informal networks are distinguishable:

the *household member network* or *close family network*: provision (often intensively) informal care to partners or children, almost entirely offered by resident family members;

the *larger family network*, which provides care to older parents in need for care or also for example for siblings;

the *friends network*, which provides care to people who supposedly have a small or no family network available.

1.6 Level of education and / or profession / employment of caregiver

Informal caregivers are as much employed as the general population (64 % of the people between 18 and 65 years), and have also the same education level.

1.7 Generation of caregiver, relationship to OP

Middle-aged children caring for their non-resident parents (mostly daughters and daughters-in-law) are the most frequent informal caregivers (44 % of all informal caregivers, and 61 % in the selection) (table 8).

Table 8: Relationship with care receiver (%)

Care receiver is:	all informal caregivers (%) ^a	selection (%) ^b
Parent (non-resident)	44	61
Partner	14	9
Friend / acquaintance	12	8
Other family	6	9
Neighbour	6	9
Sibling (non-resident)	6	1
Grandparent (non-resident)	4	5
Other	8	4

Sources: ^a SCP, 2003(B), p. 41^b data processed by SCP for the selection of informal caregivers of older care receivers (Selection)

1.8 Residence patterns

Household structure

Twenty percent of the informal caregivers share the same household with the care receiver (12 % in the selection group). Eighty percent is living outside the household (80 % in the selection group).

Relatively, informal caregivers have most often a household consisting of two adults, with or without children. Singles people less often provide informal care (table 9).

Table 9: Household structure of informal caregivers (%)

Household structure	Informal caregiving population ^a (%)	selection (%) ^b	General population (%) ^c
Single	11	12	34
2 adults, no children	41	41.8	29
Single parent	3	2.8	6
2 adults with children	45	42.7	30
other	1	0.6	1

Sources: ^a SCP, 2003(B), p. 36

^b data processed by SCP for the selection of informal caregivers of older care receivers (Selection)

^c CBS, Statline, 2003

<http://statline.cbs.nl/StatWeb/start.asp?LA=nl&DM=SLNL&lp=Search/Search>

Informal care in health care institutions

Approximately 5 % of the older people in the Netherlands live in residential homes, and about 2,5 % in nursing homes. This means that most older people live independently. From literature it is known, however, that informal caregiving does not end when a person is admitted to a residential or nursing home. Many family members continue to provide care (Van Westerhoven and Van Loveren-Huyben, 1997; Knipscheer, 2004). They help with financial affairs, groceries, transport, but also with more complex care activities, such as washing / bathing, (un-)dressing en feeding.

One in ten informal caregivers provide informal care to people living in health care facilities or special housing facilities. Informal care to institutionalised people is mostly shared with other informal caregivers. The help is also not very intensive (less than 8 hours per week) (SCP (C), p. 43).

Proximity

On average, non-resident caregivers travel 22 (selection group 22,5 minutes) minutes to get to the houses of their care receivers.

1.9 Working and caring

About 66 % (selection 63 %) of the informal caregivers under 65 years of age carried out paid work in 2001. Sixty percent of them did not find difficulty in this combination of working and caring (selection 56 %). 31 % (selection 34 %) had trouble combining both tasks, and for nine percent (selection 11 %) it was too difficult. Women have more often trouble combining working and caring, maybe because they usually spend more time doing the household and taking care of the children. When people take care for a partner or an older person the combination is also more often troublesome. This may be explained by the higher need for care of this group of care receivers. And furthermore the type of care provided seems important for the burden of care; informal caregivers have more trouble combining work and care when providing personal care (like washing, bathing, and feeding the care receiver), and / or psychosocial or emotional support. (Data concern informal caregivers under the age of 65 years.)

1.10 General employment rates by age for general population

In another study on working informal caregivers (18-65 years) it was shown that informal caregivers are more often without a paid job or are more often working part-time than working fulltime (Timmermans, 2001). In the general population about 65 % of the people between 16 and 65 years of age had a paid job. In the informal care study the percentage was 66 % of the caregivers between 18 and 65 years. That is almost equal tot the general population. 39 % of the working caregivers was female and 61 % male.

Women, who work fulltime, provide less often informal care than women with a part-time job or without a paid job do. However, in multivariate analysis it is shown that labour market position does not have a significant effect on the provision of informal care. Age, gender and travelling time are the most important aspects: people over 45 years of age have almost three times more chance to become an informal caregiver than younger people; women have 2,5 more chance to provide care than men, and people who do not live within 10 minutes from the person needing care have less chance to provide care (Timmermans et al., 2001). Thus, not as much the labour market participation determines whether a person is going to provide informal care, but much more the age and gender. In particular young women work fulltime, and these women provide less help than older women, who work more often part-time.

Among working caregivers only one aspect of work was of importance: people in medical or nursing professions provide more help than others. Other characteristics, such as having an executive function, branch of industry, having irregular workdays, and having authority over working hours did not have a significant effect on the provision of informal care.

Caregivers, however, who work fulltime provide less hours per week than caregivers with a part-time job or caregivers without a job. But, more than labour market position, it seems that (objective) pressure of time is of more importance whether a person is going to provide informal care: among people who spend 55 hours or more on labour, education and / or household informal caregivers are underrepresented (De Boer et al, 1994).

Table 10: Number of hours spent in informal care according to labour market position (%)

labour market position	average number of hours of informal care
no paid job	14.2
part-time job (1-32 hrs)	11.7
fulltime (≥ 33 hrs)	10.5

Source: SCP, 2003(A), p. 67

1.11 Positive and negative aspects of caregiving

Positive aspects

In most Dutch studies the negative aspects of informal caregiving are being emphasised. Little is known about the possible positive aspects or gains. However, when informal caregivers are asked about burden only a small percentage (7 %) reports a very heavy burden. And, when you look at motives for informal care, people become an informal caregiver because of love, affection, and it often happens without saying. This suggests that positive effects of informal care are possible. Informal caregivers report different aspects, which give satisfaction (Nolan et al., 1996):

- it gives meaning and life fulfilment
- pride when people discover new unforeseen possibilities (e.g. someone who discovers that he likes to cook!)
- give in to someone's wish to die at home
- to maintain dignity of the care receiver

Negative aspects: pressure of time, caregiver health, caregiver burden and abuse

Pressure of time

Providing informal care has mainly consequences for the (leisure) time of informal caregiver's, not as much for their jobs or family life. Caregivers lack time for hobbies, they experience a shortage of time, and they have more trouble organising their own household. Informal caregivers who combine informal care with a paid job and / or a family have more chance to experience pressure of time. 83 % of the informal caregivers experienced one or more time

problems. These problems vary from "I could not release myself from the situation of the care receiver" (51 %), "I couldn't do the activities that I normally carry out in my leisure time" (43 %), to "I had more trouble than else to arrange my own household" (29 %). About 9 percent became ill or overburdened by too many commitments at the same time.

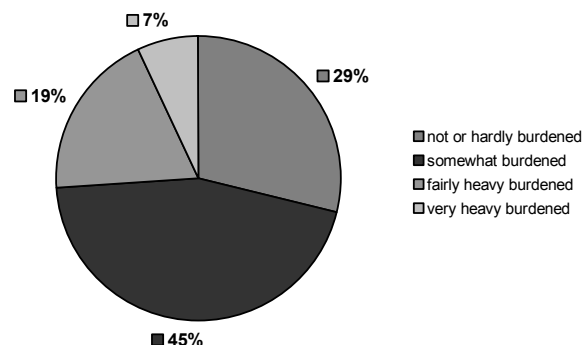
Caregiver health

Almost three-quarters of the informal caregivers (74 %) do not have any physical limitations or handicaps. A quarter of the informal caregivers has restraints and six percent is severely limited in daily functioning. This increases with age. On average, informal caregivers perceive their health as good (61 %).

Caregiver burden

There are several ways to distinguish caregiver burden; a third of the informal caregivers for example is psychologically or mentally burdened (for example "I am never released from my responsibilities", "I can never let go the situation of the care receiver"), about a third perceives (leisure) time pressure, and one in ten informal caregivers feels burden with regard to family and / or job. With regard to overall burden, a small group of informal caregivers (7 %) reported that they were heavily burdened or overburdened by the care they provided (figure 1). In numbers this is between 150,000 and 200,000 informal caregivers! Informal caregivers who have a small social distance to the care receiver (i.e. taking care of a partner) are most heavily burdened (12 % of them is overburdened and 32 % is fairly heavy burdened). Having other – secondary – informal caregivers did not have an effect on burden, and also combining work and care was not related to burden.

Lack of health care services (for example lack of home care, waiting list for residential or nursing home) seems to be of relevance for burden: 49 % of the informal caregivers who perceive a lack of health care services are fairly or heavily burdened.

Figure 1: Burden of informal care (%)

Source: SCP, 2003(B), p. 78

Data of the selection group did not differ from the group of all informal caregivers with regard to burden of care.

Abuse

In the SCP-study there are no data available about abuse of the care receiver by the informal caregiver. But in another Dutch study on caregiving and dementia it was shown, that about 11 % of informal dementia caregivers had actually engaged in physical aggression by shaking, hitting or pushing the dementia patient. 30 % of the caregivers reported chronic verbal aggression only, by shouting, swearing, threatening or insulting the patient (Pot et al., 1996).

Informal caregiver's needs for care and support

One in three informal caregivers actually receive information, advice and emotional support. They receive this help mainly in conversation with formal caregivers, and they talk about dealing with the care receiver and worries about the care receiver. With regard to practical support 17 % (selection 14 %) uses care attendance facilities and 10 % (selection 13 %) reports that the person they care for visit day care facilities or activity centres (table 11).

Table 11: Use of support for informal caregivers (%)

	All informal caregivers ^a	selection ^b
Total information, advice and emotional support:	38	not available
conversation with formal caregiver about burden of care	17	17
conversation with formal caregiver about worries over the care receiver	31	35
conversation with formal caregiver about approach of care	28	32
conversation with formal caregiver about dealing with the care receiver	26	29
group conversations	5	5
care attendance services ("granny-sitting")	17	14
day care facilities / activity centres (only for independently living people)	10	13

Source: ^a SCP, 2003(B), p95

^b data processed by SCP for the selection of informal caregivers of older care receivers (Selection)

It is remarkable, that informal caregivers who take care of someone who is also receiving formal home care more often use support services for informal caregivers (information, advice and emotional support services) (48 % vs. 29 % of the care receivers without formal home care). This indicates that they have better access to these types of support services. Support centres for informal caregivers often work together with formal home care organisations.

Reasons for non-use of the different support services are mostly that informal caregivers do not need this support. A small group is not familiar with this kind of support. Another group has other reasons, maybe referring to shortages in support services or to the efforts for informal caregivers to arrange these services (SCP (B), p. 106).

Most support services for informal caregivers are provided to severely burdened informal caregivers.

5.12 Profile of migrant care and domestic workers (legal and illegal). Trends in supply and demand

Intercultural family care

Little is known about (numbers of) informal caregivers from non-western or migrant cultures living in the Netherlands (e.g. Turkish, Moroccan, Antillean, Surinam, Chinese cultures). The migrant population is younger than the native Dutch population, however, until 2015 it is expected that the number of older people from non-native origin will increase from 85,000 (in 1997) to 300,000. This will be of consequence for the need for care. Research shows that older

people from other cultures are less healthy than native older people. This may be explained by lower socio-economic status (SES), heavier working circumstances, and / or stress caused by migration. Non-native older people visit the general practitioner sooner and earlier, and use more medication than native older people (Tesser et al., 1998). Altogether, this will have its influence on their informal caregivers.

In more than one respect with regard to health care attention has to be paid to this ethnic minority group. First, they are unfamiliar with the Dutch health care system (Nelissen & Morée 2001). Second, their attitudes towards care differ from native people (Verbiest, 1999, Van der Lyke, 2000; Morée 2001). Third, the health care system and policy are saturated with native values. And finally, there may be a lack of understanding due to barriers of language. Additionally, it has to be noted that among the different ethnic cultures there are many differences with regard to care attitudes and values (Morée et al., 2002).

Labour market participation of migrant carers

Although there is no nation-wide registry of labour market participation of formal caregivers from migrant cultures, different studies show that the labour market participation of migrant people in health care services is low. Hingstman et al. (2000) show that in 1998 only 4.15 % of the migrant population is working in nursing and caring jobs. In 2001 Bekker & Meihuizen (2003) report that six per cent is working in health care services. The greatest impediment for entering this part of the labour market is the requirement for higher education and the poor command of the Dutch language.

Keeping in mind the increasing number of non-western older people policy makers are more and more aware of the necessity to recruit professional caregivers from non-western cultures: Not only to aim for a better reflection of the people in need for care and the person providing care, but also to decrease the lack of health care personnel, and because of the social responsibility for employers to give different groups in society the same chances for labour market participation.

1.13 Other relevant data or information

Formal and informal care

Informal caregivers provide a considerable contribution to people in need for care. Eighty per cent thinks that other informal caregivers take over their care when they fall out, for example due to illness. Only 13 % expect that formal home care has to take over and for another 13 % admission to a residential or nursing home is the only alternative. Presumably, hundreds of thousands of persons in need for care do not have to appeal to formal care because of the availability of informal caregivers.

A part of the persons receiving informal care also receive professional care at home or in institutions.

Table 12: Help from professional caregivers (%)

	terminal illness		chronic illness		temporary illness		other		total	
	all ^a	selection ^b	all	selection	all	selection	all	selection	all	selection
home care	65	59	47	54	30	44	40	56	43	54
private care	36	32	37	39	32	37	30	34	33	36
admission to hospital	76	75	56	56	71	69	45	47	56	57
temporary admission to intramural (health) facility	10	10	9	10	11	17	8	9	9	11
permanent admission to intramural (health) facility	10	14	29	38	7	10	18	25	19	26

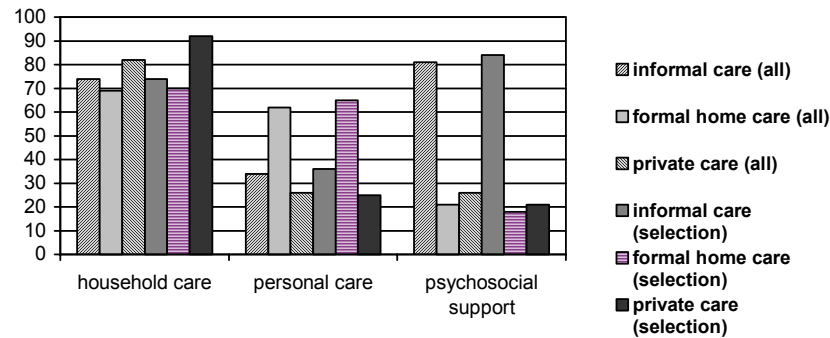
Source: ^a SCP, 2003(B), p112

^b data processed by SCP for the selection of informal caregivers of older care receivers (Selection)

In 43 % (54 % in the selection group) of the informal caregiving situations informal caregivers have to deal with professional home care, particularly in the category of people with a terminal illness. Informal caregivers of dying people and people with a temporary illness are also often confronted with hospital admissions (table12).

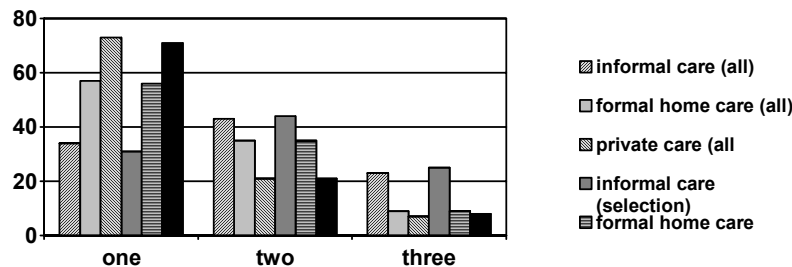
Burden of informal care

Figure 2: Type of help provided by informal care, home care and private care for all informal caregivers and the selection group of older care receivers(%)



Source: SCP(B), 2003

Figure 3: Number of types of help provided by informal care, home care and private care



Source: SCP(B), 2003

In figure 2 and 3 it is to be noticed that informal caregivers give more household and psychosocial care, and that professional home care provides more personal care. Furthermore, informal caregivers provide more types of help than professional caregivers.

Home care

Informal caregivers and home care partly provide the same type of help (in only 13 % of the cases), and therefore there is an apparent division of tasks. If informal care is present, home care usually limits itself to a few tasks: complete washing / bathing and dressing and heavy household tasks. Other do-

mestic tasks, such as running errands, preparing meals, doing the laundry are almost completely left to informal caregivers. Home care services are used more frequently where the resilience of the social network is low (no other help is available), or if the burden imposed by providing the help is large (great need for help, longer duration, danger of admission to institution). Home care is thus supplementary to informal care. 'Reality thus deviates from the regulations, because the Exceptional Medical Expenses Act (AWBZ) from which home care services are funded is a national insurance scheme which entitles every individual inhabitant of the Netherlands to professional help when needed' (SCP(B), 2003, p. 234).

Additional help from formal home care is required

No less than a third stated that (more) input from home care services would be desirable. Among those who are already sharing the provision of help with professional home care, the percentage is higher than among providers of informal help who are not yet doing so (43 % versus 25 %). Remarkable is that 31 % does not call for formal home care because of waiting lists, and even more remarkable is that 36 % does not arrange formal care because the care receivers do not want professional home care (non strangers in the house).

Informal caregivers are satisfied with the practical help from formal home care, but complain about the organisations who arrange this care: most criticisms are about lack of flexibility. The organisations, for example, were not able to take over the care when the informal caregiver could not help (e.g. due to illness). The co-ordination between formal and informal caregivers is also lacking.

2 Care policies for family caregivers and the older person needing care

The focus should be on policies for caregivers and if there are local variations in such policies, or local autonomy in implementation. When there are no policies for family caregivers, they may be using all available policies for dependent or disabled OP, to obtain support in caring; therefore, these policies are important and need to be documented.

2.1 Introduction: family ethics and expectations – the national framework of policies and practices for family care of dependent older people

The Dutch government is engaged with high cuts on health and welfare services. Citizens have to pay more for their health insurance and the universal public long term care insurance (AWBZ) is being limited (people have to pay an extra contribution). In the national policy is the term 'own responsibility' a very important and often mentioned word. The government is looking for cheaper or more affordable solutions for the increasing need for care. Reinforcement of informal care and voluntary care is a logical move.

With regard to informal care the government aims at:

- better co-operation between informal caregivers and formal caregivers (allocation of tasks, communication)
- more attention for informal care in education programmes
- relieve informal caregivers by developing and extending respite care services at home

The Ministry of Health and welfare and Sport subsidises nation-wide approximately 80 support centres for informal carers (CVTM-funds). These centres provide carers with advice, information and emotional and practical support.

2.1.1 What are the expectations and ideology about family care? Is this changing? How far are intergenerational support and reciprocity important? Do minority groups have different ideologies?

Expectations and ideology about family care are to be seen from three different angles:

- from the general population
- from the (potential) care receiver
- from the (potential) informal caregiver

The general population

When people are asked about the value of informal care a minority, however considerable, of 29 per cent consider children to be obliged to care for their ageing parents. But children are not to be released from their duty to help their parents. And only few would appreciate it that their parents would move into their own homes. The privacy of the own family is very important and older parents seldom live with their children.

These attitudes did not change much since the mid-eighties. Although the responsibility in the course time is something more laid down at the government, at the same time the understanding grows that children have their task for family care. But this must not be seen as an obligation.

The (potential) care receiver

People seem to prefer professional care over informal care. They do not like to be dependent, especially not with regard to personal or intimate care from family members. Results from a study among 501 parents (60 years and older) and 500 children (20-50 years) show that parents do not want to be dependent from their children when they need care (Bureau Intomart, GFK, 2004).

Table 13: If there is increasingly less money for care, what would you think about your children taking up (a part) of this care? (%)

It goes without saying, I always took care of them	9.6
My children are much too busy to take care of me	13.8
I don't like to be dependent from my children	69.9
I don't know / no opinion	6.8

Source: Bureau Intomart GFK

Furthermore, 91.4 per cent does not want to live with their children and does not want to be taken care of by their children (to a large extent because they do not want to be a burden for their children (58.7 %), because they will have too little privacy (17.5 %), or because they do not want to be dependent on them (14.2 %), and they think that it is old-fashioned, something that happened in the past (61.3 %).

The (potential) informal caregiver

Children, however, in the same study (Bureau Intomart, GFK, 2004) perceive caring for their parents as an act of love (64.6 %), or duty (24.8 %). 49.2 per cent is prepared to take them into their household when formal home care is not sufficient anymore.

Family members are still willing to provide informal care out of naturalness, love, and reciprocity. In the Netherlands we use the word 'mantelzorg' ('coat care' or 'mantle care') for informal care. This calls for much wordplay: "You need to have a coat. For many people the coats are thin and often worn-out."

"The older you get, the less you are surrounded by people" (Meulenberg, 2004).

This willingness is hindered by three demographic and cultural changes:

- increase of female labour participation
- migration (children live further away from their parents)
- people grow older and need care for a longer period (this does not only appeal to the intensity of informal care, but informal caregivers themselves also grow older)

Another problem arises in national policy: the government wants as many people as possible to be employed, but also as many people as possible providing informal care.

2.1.2 Are there any legal or public institutional definitions of dependency – physical and mental? Are these age-related? Are there legal entitlements to benefits for caring?

In the Netherlands there is no legal or public institutional definition of dependency. People who are in need for care have to go to a regional independent and integrated needs assessment agency (RIO) in order to obtain an objective indication for care. The decision by the RIO is based on the individual situation: personal circumstances of the client and his or her living environment, such as consideration / respect for informal care, housing situation are being taken into account. But the objectivity of the needs assessment asks for an identical procedure and judgement of the requests for care. Therefore, an AWBZ-wide protocol is developed with forms for an independent and integrated needs assessment.

The care offices (zorgkantoren) are the regional branch offices of the national AWBZ-framework. They are responsible for capacity and quality of care in its region.

2.1.3 Who is legally responsible for providing, financing and managing care for older people in need of help in daily living (physical care, financial support, psycho-social support or similar)?

In the Netherlands, the three general types of providers of care for older people are home care, residential homes and nursing homes. Older people in need of help or care mostly in first instance apply to the local or regional Home Care Organisation, or to a GP or a community social service centre. These will refer the elder person to a needs assessment agency for clarification of demand, assessment of need and allocation of kind and quantity of care.

2.1.4 Is there any relevant case law on the rights and obligations of family caregivers?

There is no case law on the rights and obligations of family caregivers. However, in the recent changes and modernisation of health care indirectly family members are expected to provide more care for their relatives. The most important theme of the national government is 'own responsibility', which aims at people providing more work and more care for their relatives. With regard to the needs assessment a new form is being used: the usual or common care-form (gebruikelijke zorg). The needs assessment advisor has to distinguish between what is normal or usual care and what is extra care (i.e. informal care). This calls for a lot of discussion among care receivers, informal caregivers, and different organisations for the protection of interests of clients and informal caregivers. Many informal caregivers have complained about the amount of care they have to provide according to the needs assessment (LOT, 2002; rapport van klachtencommissies, 2004).

2.1.5 What is the national legal definition of old age, which confers rights (e.g. pensions, benefits etc.)?

The age at which a person is eligible for a state pension (AOW) is 65 years. This state pension is the main source of income for three-quarters of the 2.2 million people over the age of 65.

2.2 Currently existing national policies

2.2.1 Family caregivers

The national government has great respect for efforts of many informal caregivers. In 2001 the Ministry of Health, Welfare and Sports presented the report Care Close By, report on support of informal care (Zorg Nabij, notitie over mantelzorgondersteuning). In this report there is much attention for reinforcement of support for informal caregivers, the needs assessment, stimulation of voluntary work, crisis care, respite care, monitoring of the effect of informal care, financial aspects, combination of work and informal care, and raising more attention for informal care among professional caregivers.

The Ministry of Health, Welfare and Sports provide a yearly subsidy of 11.34 million Euro for the support of informal caregivers. Through this subsidy among others support centres for informal carers are financed and three national organisations for informal care:

- LOT, organisation for the informal caregivers
- Xzorg: organisation for the support centres for informal carers, voluntary home care and buddy care

- EIZ: national centre of expertise and knowledge on informal care

In 2003 the Ministry of Health, Welfare and Sports aims at:

- better co-operation between informal caregivers and formal caregivers (allocation of tasks, communication, attitude)
- more attention for informal care in education programmes
- relieve informal caregivers by developing and extending respite care services at home

2.2.2 Disabled and / or dependent older people in need of care / support?

National policy is to keep older people independent as long as possible, and to stimulate social participation (for example to do voluntary work). Therefore under different acts (Welfare Act, Disabled Persons Act) services and support aids are provided to people when they need this kind of help (see introduction of the Dutch health care system, page 17).

2.2.3 Working carers: are there any measures to support employed family caregivers (rights to leave, rights to job sharing, part time work, etc.)

There is a set of different types of care leaves, which enable the informal caregiver to provide care next to his or her job. A short care leave and calamity leave are developed in order to take leave when acute care is needed. There is no legal right on these care leaves. However, employers have to make arrangements possible in collective labour agreements (CAO), and employees have to negotiate care leaves with their employers.

Since October 1998 the Act Financing Career Break (Financiering Loopbaanonderbreking) allows employees for at least half of their working hours to take care for a terminally ill relative (two to six months, possibly protracted via CAO to 18 months), while receiving an allowance for the hours they care. This arrangement, however, is not used very often. It will be ended when the life course arrangement is introduced.

Under development is the life course arrangement (levensloopregeling), which will start in 2006. Employees are able and also expected to save days, which they can use for education, sabbatical leave, but also for care leaves.

2.3 Are there local or regional policies, or different legal frameworks for caregivers and dependent older people?

In 1997, the government announced the introduction of the 'Regional vision'. This is a policy framework that is developed by each provincial government for its own province, in close collaboration with the insurers, patients / consumers

organisations, care providers and the local governments. The purpose of the framework is to determine which provisions are needed in the region and where. It is assumed that in this way, the use of financial and other means can be better tailored to the needs of the region. If this new instrument is fully implemented everywhere (not yet the case), it will result in regional differences.

2.4 Are there differences between local authority areas in policy and / or provision for family caregivers and / or older people?

There are no great differences between local authority areas. However, on a local level there are some differences with regard to support for informal caregivers. For example the municipality of Amsterdam offers parking tickets for informal caregivers, and the municipality of Rotterdam offers a compensation for respite care. Furthermore municipalities carry out the special social security (bijzondere bijstand) and the Disabled Persons Act (Wet Voorzieningen Gehandicapten) (e.g. housing adjustments (high toilet), walking aids, etc.).

3 Services for family caregivers

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Needs assessment (formal – standardised assessment of the caring situation)			X	X				
Counselling and Advice (e.g. in filling in forms for help)			X					
Self-help support groups ^{3,4}			X		X	X	X	
“Granny-sitting” ¹		X						
Practical training in caring, protecting their own physical and mental health, relaxation etc. ³		X			X	X	X	
Weekend breaks ¹		X			X	X	X	X
Respite care services ¹		X			X	X	X	X
Monetary transfers ²		X		X				
Management of crises								
Integrated planning of care for elderly and families (in hospital or at home)		X		X				
Special services for family carers of different ethnic groups		X			X	X	X	
Other:								
Support centres for informal carers (Xzorg: organisation for the support centres for informal carers, voluntary home care and buddy care)		X			X	X		
LOT, organisation for the informal caregivers								

¹ These services are called respite care services in the Netherlands. There are services from formal home care organisations and / or institutional care (e.g. Logeerhuis (guesthouse), professional supervision at home, day care facilities) which are financed by the AWBZ (with formal caregivers, often in combination with volunteers) and services which are funded through CVTM-funds or other funds (only with volunteers): ‘granny-sitting’ or supervision at home, intensive terminal home care.

² Informal caregivers can be compensated for the costs caused by informal care through income tax measures, special social security, financing career break (care leave), insurers (e.g. compensation for respite care), local authority measures, and / or the personal care budget. Research, however, shows that few informal caregivers arrange these monetary transfers, because they do not want to

hold out their hand, because they are unfamiliar with these compensations, or because they find the measure to complicated (SCP (B), 2003).

³ Support centres for informal carers: provide information, counselling, advice, practical training, self help support groups, etc. for informal caregivers

⁴ LOT, organisation for the informal caregivers: provides an informal caregiver phone line, information, brochures, protection of rights of informal caregivers, offers weekends for informal caregivers (respite care) etc.

3.1 Examples⁴

3.1.1 Good practices

Guest House Amsterdam (Het Logeerhuis Amsterdam)

The guesthouse is part of a large organisation for intramural health care (Fontis), with different nursing homes and residential homes in Amsterdam. Aim of the guesthouse is to relieve the direct surroundings (i.e. the informal caregivers) of community-dwelling demented elderly. The organisation has a service and hotel function. Guests receive care 24 hours per day and different activities are organised for the demented elderly. Informal caregivers are able to go on holidays, have time to take a break etc.

There is room for 12 guests and also for 10 day guests, and they can stay for a maximum of three to four weeks. Elderly who have been discharged from hospital, but who need extra care can stay for a maximum of six weeks.

Criterion for a stay is that the older person has to have a diagnosis of beginning dementia. Older people in a severe state of dementia are not able to stay. Informal caregivers are mainly referred to this guesthouse by social workers, GPs and formal home care. The guesthouse is AWBZ-institution. Guests have to pay co-payment.

Factors for success are flexibility (short intake procedure, diversity in lengths of stay), domestic sphere and hospitality (the guesthouse has hostesses (volunteers)), good contact of personnel with informal caregivers who provide information and emotional support.

3.1.2 Innovative practices

POM-method (Preventieve Ondersteuning Mantelzorgers) is a preventive method to support informal caregivers practically, systematically and methodologically. In the mental health sector prevention work is very important, not only for patients, but also for their informal caregivers. Therefore, with every new intake of patients the informal caregiver is also part of the care plan. House visits are carried out by trained social workers to provide information to the informal caregiver about the illness of the patient and also about the sup-

⁴ A list of services is provided in the appendix.

port services for informal caregivers. Mediant, the organisation for mental health care in the eastern part of the Netherlands has received a prevention award for this method!

Main objective: prevent informal caregivers of older people with problematic behaviour from severe burden and low well being, by:

- reinforcing personal resources by improving knowledge, attitude and capacities of the caregivers
- strengthening social resources
- reducing objective burden by facilitating respite care, day care, admissions, support form volunteers and by sharing care with other members from the social network

Method

As soon as a client is in contact with a health service for elder care the informal caregiver is also involved in the process of care. A private conversation with the informal caregiver is arranged by a trained POM-worker. In this conversation problems and needs for support are discussed (for example with the EDIZ-scale, Pot et al., 1995). After this, information adjusted to the needs of this particular informal caregiver is provided. Also a guide for informal caregivers is offered, and if necessary the POM-worker refers the informal caregiver to other specialists. If necessary a second conversation will be arranged.

Two weeks after the last conversation the POM-worker calls the informal caregiver to inform about the informal caregiver's actions to arrange support. Three months later another call will be made. All this will be filed in a special informal caregiver record.

Total investment of time: max. 1 ¼ hours with one conversation, and max. 2 ¼ with two conversations.

Table 14: Scheme POM-method

1st conversation	Introduction objective and working method of the conversation
	Assess informal caregiver's burden with EDIZ-scale
	Inventory of problems and needs of the informal caregiver
	Provide information on support services adjusted to the needs of the particular informal caregiver
2nd conversation	Making appointments and closing of conversation
	If necessary
After-care / supervision	Call 2 weeks after the last conversation
	Call 3 months later

4 Supporting family caregivers through health and social services for older people

4.1 Health and Social care services

4.1.1 Health services:

4.1.1.1 Primary health care

The general practitioner (GP) is the gate-keeper of the health care system. They refer patients to for example home care, physiotherapists etc. GPs, however, are not used to focus attention to problems of informal caregivers, but concentrate mostly on patients needs. Therefore, problems of informal caregivers are not often observed, whereas the GP is mostly the first formal caregiver who could prevent informal caregivers from burden.

Problems with regard to formal home care (personal care) are the large number of different home caregivers who enter the house of the patient and informal caregiver. There is often no regular worker, which makes it difficult to coordinate care, to build a basis of trust. Due to production agreements these formal caregivers have tight schedules leaving no time to talk with informal caregivers. These formal caregivers, however, are the only caregivers who can observe the home situation and spot problems of informal caregivers. They are important actors who can refer informal caregivers to supportive services for them.

Recently home care organisations are more aware of these problems and provide training programs for their personnel with regard to informal caregivers.

4.1.1.2 Acute hospital and tertiary care

In 1998 12 % of the people between the age of 65 and 74 has been admitted to hospital and 13 % of people older than 75 years. Contrary to people between the age of 55-64 (7 %) and people between 35 and 54 (5 %). A quarter of the people older than 75 years has contacted a medical specialist, and 27 % of the people between the age of 65 and 74. Contrary to people between the age of 55-64 (19 %) and people between 35 and 54 (14 %) (SCP (D), 2001).

The problem of Wrong beds

Problems of 'wrong beds': older people who are discharged from hospital care and who should be admitted to a nursing home or residential home often stay in a hospital bed, because of waiting lists.

Rural / urban differences: in the western part of the Netherlands (Randstad, mostly urbanised) there are more hospitals than in the more rural eastern,

northern and southern part. Informal caregivers in rural parts, therefore, have longer travel time to visit their relatives.

Hospital policy is to admit patients as short as possible. This means extra pressure on informal care. Informal caregivers are often confronted with persons with high and complex need for care. Social workers in hospital are to arrange formal home care, but this is not always possible due to waiting lists.

Many hospitals have geriatricians and special geriatric units.

4.1.1.3 Long-term health care facilities (including public and private clinics)

The two most general types of health care facilities for older people are the residential home and the nursing home. Recently, on a small scale there have also been build private clinics / nursing homes for the elderly. Another new development in long-term care is the small-scale housing facilities for demented elderly: houses within the vicinity in which a small number of demented elderly are taken care of by professional caregivers.

Residential home

Older persons who are dependent on care and help and cannot any longer cope at home, may apply to be admitted to a **residential home for the elderly** ("care home", "old age home"). Persons being admitted will not need special medical care or nursing (else they might be referred to a nursing home). Consequently, in the staff there are hardly any qualified nurses; most of the employees are "caring staff" with an intermediate or lower education. In case residents might develop dementia later on, it is generally tried to keep these persons in a special dementia care project rather than transferring them to a nursing home.

Nursing home

If a patients' situation is stable but he or she is not able to cope at home and needs non-complex continuous nursing care, he or she may be referred to a **nursing home** (cf. Skilled Nursing Facility in the USA), which is for long term care and nursing. Nursing homes also have an important function in short term rehabilitation of both elderly and younger patients, and in diagnosis and functional assessment. Nursing homes employ qualified medical, paramedical and nursing staff.

4.1.1.4 Hospice / palliative / terminal facilities

Palliative care providers

Palliative care in the Netherlands is in the last ten years rapidly changing. Since 2003 on many places palliative care is provided: in the own living environment of the patient (palliative home care provided both by volunteers and professional caregivers), in residential homes, hospitals, nursing homes, and

in facilities particularly designed for palliative care, such as low care hospices (bijna-thuis-huizen) en high care hospices (Spreeuwenberg, 2002). Informal caregivers and volunteers play an important part in palliative care.

Table 15: Number of general practitioners, informal caregivers, and voluntary organisations

	Number of palliative care providers
General Practitioners	7,932 (1)
Informal caregivers of terminally ill patients	6 % of the Dutch population over a period of 3 years (2)
(Organisations of) volunteers	4,747 volunteers from the association of Voluntary Terminal Care (VTZ) (172 VTZ-organisations (3)) unknown number of other voluntary organisations

Table 16: Number of care providers of palliative care and their capacity

	number of organisations	number of organisations with palliative units	Total capacity in palliative units (number of beds)	Total capacity (number of beds)
Formal home care organisations	130 AWBZ-financed unknown number of other organisations	not applicable	not applicable	not applicable
Nursing homes	333	49	200	59,610
Residential homes	1,346	34	78	109,885
Independent hospices	58	58	304	304
Hospitals	129	2	14	53,247

Source: Palliative file of the Dutch Institute for Research of Health Care (Nivel), <http://www.nivel.nl/>

4.1.1.5 Are family caregivers expected to play an active role in any form of in-patient health care?

Help from family caregivers are not explicitly mentioned within policies of in-patient health care, however, when family caregivers are present implicitly their help is expected. They help most of the time with excursions, with eating, with contact with health personnel etc. It is known that in holiday periods particular nursing homes and residential homes call for extra help form informal caregivers, because of shortages on personnel.

4.1.2 Social services

On grounds of the Welfare Act local governments are since 1988 responsible for welfare policy for older people. There are about 500 social services for the elderly (Stichting Welzijn Ouderen, SWO's), that are mainly funded through the Welfare Act and co-payments from users. Three major functions of these social services are:

- social participation / integration: stimulating to do social tasks, interest / pressure groups and self help organisations
- social prevention: preventing from social isolation, and reinforcing possibilities for bringing meaning to life
- personal company and support: individual support with regaining or keeping balance between the older person and his or her surroundings (Graveland et al., 1996)

These SWO's work autonomously and are to a certain degree free to decide what activities they offer. A large part of these activities are provided by volunteers, who are very important for these organisations. They are also mostly older than 55 years. SWO's often work together with intramural health facilities.

Table 17: Summary of welfare activities for older people

Category	Activity
Practical support	meals (on wheels), alarming services, services for odd jobs, special transport services, telephone circles, grocery services
Meeting place, recreation, culture	Sport activities for older people, hobby activities, choirs, (folk) dancing, visiting museums, walking trips, excursions
Education	Computer courses, language courses, memory training
Information and advice	Advisor for older people, house visits, consultation, referring to health care services
Day care / night care	Day care facilities, guesthouse for older people (see chapter 3), vacation services, granny sitting

Source: SCP (D), 2001

4.1.2.1 Residential care (long-term, respite)

Long-term residential care is part of the health care system: see paragraph 4.1.1.3; respite care, see chapter three.

4.1.2.1.1 Basic data on % of > 65's in residential care by age group and type of residential care (sheltered housing, residential homes)

Five per cent of the older people live in residential homes, and 2.5 per cent live in nursing homes (see paragraph 1.1.8).

4.1.2.1.2 Criteria for admission (degree of dependency, income etc.)

Admission to residential care is made possible after the needs assessment (see Introduction of the Dutch health care system, page 17-18).

4.1.2.1.3 Public / private / NGO status

Almost every care providing organisation is a private legal entity (usually a foundation or association) that pursues social goals. It is their task to organise delivery and provide services. Public goals are therefore pursued by private organisations. Consequently, care delivery is largely not-for-profit. The fact that the organisations are private bodies does not imply that they are protected from public (government) interference. Almost all financing is regulated by government legislation. Before they are allowed to provide services, and to be eligible for funding, the Ministry of Health, Welfare and Sports, with the exception of a few cases, must admit providers. For admission, it is required for the organisations to meet certain criteria. Among other things, these criteria involve the type of services they should deliver. Government also develops health policy at a national level, for example on the distribution of care, the position of the different care sectors etc.

Insurers act as intermediates between the government and the care providers. They are the conduits of government finance to the providers. They execute the AWBZ and the ZFW (see Introduction of the Dutch health care system, page 19), and in this capacity they handle 75 % of the financing of care. Local and regional governments are rather new players in the field. An important feature of their role is the responsibility to organise need assessments (Mur-Veeman et al., 2003, p. 123). In the near future their role will be more important, with regard to planning and organising social and care services (see Introduction of the Dutch health care system, page 21).

4.1.2.1.4 Does residential care involve the participation of caregivers or work with caregivers?

See section 4.1.1.5.

4.1.2.2 Community care services (statutory coverage and whether aimed primarily at older people living alone or including support to family caregivers)

4.1.2.2.1 Home help

A needs assessment is necessary to obtain domestic help from professional home care organisations. People can receive care in kind or they can buy their own care with a personal care budget. So, if they want, they can pay their own informal caregivers for the domestic care for which they are assessed.

Recently, many older people have stopped their home care, because since April 2003 people have to pay a higher co-payment and home care then becomes too expensive. This will put extra pressure on family and friends.

4.1.2.2.2 Personal care

Personal home care is part of the health care system: see section 4.1.1.1.

4.1.2.2.3 Meals service

See section 4.1.2.

4.1.2.2.4 Other home care services (transport, laundry, shopping etc)

No relevant information with regard to informal care.

4.1.2.2.5 Community cares centers

See section 4.1.2.

4.1.2.2.6 Day care ('protective' care)

Residential and nursing homes offer day care facilities for older people. There are day care facilities for demented elderly and elderly suffering from physical illnesses (e.g. Parkinson). They are part of the health care system.

4.1.2.3 Other social services e.g. counselling agencies, technical aids, home adaptations, training of care-personnel and / or family caregivers for providing care at home

Support centres for informal carers: provide information, counselling, advice, practical training, selfhelp support groups, etc. for informal caregivers. Xzorg is the national organisation of these support centres.

LOT, organisation for the informal caregivers: provides an informal caregiver phone line, information, brochures, and protection of rights of informal caregivers, offers weekends for informal caregivers (respite care) etc.

See table and notes in chapter three.

4.2 Quality of formal care services and its impact on family caregivers: systems of evaluation and supervision, implementation and modelling of both home and other support care services

4.2.1 Who manages and supervises home care services?

Mostly large independent providers of formal home care services (many smaller organisations are merging) manage most of the formal home care.

However, with the personal care budget, with which people can by their own care many small private home care organisations are arising. These organisations are not monitored and controlled by government (see introduction, page17-18).

4.2.2 Is there regular quality control of these services and a legal basis for this quality control?

Who is authorised to run these quality controls?

- An independent organisation monitors home care organisations and when results are positive they receive a quality sign
- Organisations work with care plans (set up together with patient)
- Workers are to follow extra training
- Privacy guarantee
- Client / residents' committees
- Independent Complaints committees

On national level the Inspection for the health care (Inspectie voor de Gezondheidszorg) is responsible for monitoring quality of care.

4.2.3 Is there any professional certification for professional (home and residential) care workers? Average length of training?

There are different levels of professional home and residential workers. For the lowest level in home care (alphahulp) no training is compulsory, but for all other levels training / education is necessary. This can be in-company training (working and learning at the same time) or in school. Length of education differs between 2 to 4 years. The professional workers are also yearly able to follow complementary training.

4.2.4 Is training compulsory?

Training / education is compulsory for all levels except the lowest level.

4.2.5 Are there problems in the recruitment and retention of workers?

No information provided.

4.3 Case management and integrated care (integration of health and social care at both the sectoral and professional levels)

4.3.1 Are family caregivers' opinions actively sought by health and social care professionals usually?

Although there is not much information from research on this subject, it is known that family caregivers' opinions are not actively sought by professional caregivers. They complain that doctors do not provide adequate information about the (process of) illness of the care receiver and they also complain about communication (Van der Lyke, 2000?).

Informal care is also not often part of educational and / or training programs. The national government in co-operation with LOT, Xzorg, EIZ, organisations for professional workers, and organisations for education are talking about this subject to incorporate problems of informal care in initial education and in training programs.

5 The Cost-Benefits of caring

Introduction

Informal care has many expenses: Helping cost informal caregivers who are providing long-term and intensive care about 1.3 billion Euro per year: 0.83 billion Euro for expenditures and 0.45 billion Euro due to loss of income (SCP (B), 2003).

About 150 to 200 thousand informal caregivers ($\pm 7\%$ of all informal caregivers) perceive financial problems. It concerns mostly resident caregivers and / or informal caregivers with a low income. Consequences of these financial problems are unknown. It is, however, to be expected that this may cause extra burden.

Almost seven on ten informal caregivers have extra expenses, on average 514 Euro in 2001. These are mostly expenses for travelling, telephone, transportation of the care receiver, washing, cleaning and costs of living (SCP (B), 2003).

Without informal caregivers much more care receivers would have to call for professional care. However, shifting its focus from professional to informal care, government policies have led to an increase of pressure on informal caregivers due to substitution policies. From economic point of view informal care can be seen as unpaid work. An indication for the meaning of informal care for the society is to be found in its economic value: all long-term and intensive informal care provided in 2001 represents a value of 7.7 billion Euro. For comparison: formal home care: 2 billion and the whole sector of care and nursing: 9 billion Euro.

Only 13 % of the informal caregivers with extra expenses, receive a financial compensation, of which 73 % from the care receiver. Only 6 % from social security (bijzondere bijstand), 6 % via taxes, and 20 % mentioned an unknown source. On average the compensation was 285 Euro in 2001 (SCP (B), 2003).

Table 18: Reasons for not receiving a compensation

16 %	Did not know about possibilities for compensation
7 %	Application was too difficult
23 %	Did not want to hold their hands
5 %	Care receiver could not afford payment
53 %	Expenses were no problem

Source: SCP (B) p. 198

About a quarter did not know about possibilities for compensation or thought that it was too difficult to fill in application forms (table 18). And about a quarter also needed compensation. That is remarkably more than the 7 % who perceive financial problems.

5.1 What percentage of public spending is given to pensions, social welfare and health?

In 2002 11.9 % of the gross national product (BBP) is spent on social security insurance and services (EUR 53.4 billion) (Ministry of Social Affairs&Employment, Sociale Nota 2003, p. 26). 9.5 % of the gross national product (BBP) is spent on health and social care (Ministry of Health, Welfare and Sports, 2003, Financieel Beeld Zorg, p. 296).

For 2002 it is estimated that of the total amount of health care expenditure (EUR 40.5 billion) 77 % is financed through the AWBZ (Exceptional Medical Expenses Act) and the ZFW (Health Insurance Act). Only 4 % is directly financed by the government. The other sources are private insurance and e.g. out-of-pocket payments (Mur-Veeman et al., 2003, p. 125).

5.2 How much – private and public – is spent on long term care (LTC)?

In the Netherlands 2.5 % of the gross national product is spent on long-term care (EPC, 2001 % OECD Health Data, 2003).

5.3 Are there additional costs to users associated with using public health and social services?

People have to pay out-of-pocket payments for different types of care:

- For AWBZ care (for example for household and personal care from formal home care, for day care facilities, for stays in nursing or residential home)
- On voluntary basis with private insurance
- Compulsory out-of-pocket payments in the Health Insurance Act (ZFW) (maternity care, (medical) supplies, transport to hospital etc.)

Through different income tax measures people with low income can be compensated for high health care costs (Tegemoetkoming Bijzondere Uitgaven TBU).

5.4 What is the estimated public / private mix in health and social care?

out-of-pocket payments	AWBZ	Private Insurance	ZFW
7	42	15	36

Source: Begroting 2003-2004, bijlage Financieel Beeld Zorg, 2003, p. 291

5.5 What are the minimum, maximum and average costs of using residential care, in relation to average wages?

Costs for using residential care are income-related. People who stay in a residential facility and who receive care (under the AWBZ) and who are older than 18 years are legally required to pay a co-payment. There are two co-payments:

- Low co-payment (*max.* €685.40 per month)
- High co-payment (*max.* €1,700.- per month)

First half of the year people pay the low payment. After this period it is assessed (dependent from circumstances of the care receiver) what type of co-payments needs to be paid. People in (psychiatric) hospital or in a facility for rehabilitation pay co-payment after one year. Dependent from circumstances it is assessed whether the low or the high co-payments needs to be paid. People who stay in a nursing home for rehabilitation, however, have to pay co-payment from the beginning.

The level of co-payment is income-related.

5.6 To what extent is the funding of care for older people undertaken by the public sector (state, local authorities)?

It is funded through taxation or / and social contributions. National government provides conditions for elder care, and local authorities are responsible for the funding of social / community services and care aids. Many volunteers are also supporting older people in the community and residential care.

5.7 Funding of family caregivers

5.7.1 Are family caregivers given any benefits (cash, pension credits / rights, allowances etc.) for their care? Are these means tested?

In the Netherlands there are no arrangements such as attendance allowance for informal caregivers and caregivers' allowance. There are some arrangements for care leave. Most leaves are arranged within the Act Care and Employment (Wet Zorg & Arbeid, 2001). In addition to these legal agreements also in Collective Labour Agreements and in agreements on organisational level services are created to combine work with care supplementary to legal arrangements (SCP (E), 2004). With regard to the most problematic situation for working caregivers, namely caring for someone who suffers from a long illness, the care leave for a long period is described in the table below. See also chapter 3.

	Attendance allowance	Carers' allowance	Care leave
Restrictions	Not applicable	Not applicable	Maximum of 6 months, in CAO (Collective Labour Agreement) possibly up to 18 months. Employer has to find replacement (with the exception of palliative leave)
Who is paid?			Employee=Informal caregiver
Taxable			Yes?
Who pays?			Social Security (government)
Pension credits			No?
Level of payment / month			Approximately €13 (gross) per hour per month, max. €490 per month
Number of recipients in 2002			4 % of rightful claimants

5.7.2 Is there any information on the take up of benefits or services?

There is little information about financial compensation of informal caregivers. Approximately 7 % receives a compensation, mainly from the care receiver. See introduction chapter 5.

5.7.3 Are there tax benefits and allowances for family caregivers?

See chapter 3.

5.7.4 Does inheritance or transfers of property play a role in caregiving situation? If yes, how?

No information available.

5.7.5 Caregivers' or users' contribution to elderly costs

	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
a. Medical, nursing and rehabilitation services						
General practitioner	X					
Specialist doctor ¹						X
Psychologist ¹						X
Acute Hospital	X					
Long-term medical residential care (for terminal patients, rehabilitation, RSA, etc.)						X ³
Day hospital	X					
Home care for terminal patients ²						X ³
Rehabilitation at home						X ³
Nursing care at home (Day / Night)						X ³
Laboratory tests or other diagnostic tests at home	?					
Telemedicine for monitoring	?					
Other, specify: home help						

b. Social-care services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Permanent admission into residential care / old people's home						X ³
Temporary admission into residential care / old people's home in order to relieve the family carer						X ³
Protected accommodation / sheltered housing (house-hotel, apartments with common facilities, etc.)	?	X				
Laundry service			X			
Special transport services ⁴						? X ³
Hairdresser at home			X			
Meals at home			X			
Chiroprapist / Podologist						
Telerescue / Tele-alarm (connection with the central first-aid station)	?					
Care aids	?					
Home modifications	?					
Company for the elderly	? ⁸					
Social worker	X					
Day care (public or private) in community centre or old people's home						X ³
Night care (public or private) at home or old people's home						X ³
Private cohabitant assistant ("paid carer")	?					
Daily private home care for hygiene and personal care						X ³
Social home care for help and cleaning services / "Home help"						X ³
Social home care for hygiene and personal care						X ³
Telephone service offered by associations for the elderly (friend-phone, etc.)		X				
Counselling and advice services for the elderly		X				
Social recreational centre			X			
Other, specify						

c. Special services for family carers	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Training courses on caring ⁵	X					
Telephone service offered by associations for family members						
Internet Services			X			
Support or self-help groups for family members ⁵	X					
Counselling services for family carers ⁵						
Regular relief home service (supervision of the elderly for a few hours a day during the week)		X				
Temporary relief home service (substitution of the family carer for brief periods of time, for example, a week) ⁶		X				
Assessment of the needs			X			
Monetary transfers						
Management of crises			X			
Integrated planning of care for the elderly and families at home or in hospital						
Services for family carers of different ethnic groups ⁵						
Other, specify						

¹ Reference from GP necessary.

² Also about 180 voluntary organisations involved with terminal home care (free access, no contribution necessary) (VTZ).

³ Financed from AWBZ: users have to pay income-related out-of-pocket payments.

⁴ Transportation: ambulance 100 % reimbursed through ZFW, taxi partly reimbursed / partly privately paid, own transportation partly reimbursed / partly privately paid, public transport completely privately paid. (Maximum total out-of-pocket payment is EUR 81,- per 12 months).

⁵ Social recreational centres for elderly and organisations for caregivers are often financed with money from for example local or national government. They can offer recreational activities and services for caregivers for small prices. Users have to pay for these activities themselves.

⁶ Also voluntary organisations involved with relief or better respite care (free access, no contribution necessary).

⁷ There are not many services for caregivers of different ethnic groups. However, caregiver organisations are actively developing these services and the EIZ is publishing a brochure on this subject.

⁸ often voluntary?

6 Current trends and future perspectives

6.1 What are the major policy and practice issues debated on family care of the elderly in your country from the caregivers' point of view? Are older people and / or caregiver abuse among these issues?

A very important policy issue is own responsibility! The national government persuades citizens to participate more intensively on the labour market – by restricting social welfare measures – and in informal care – by limiting compensation for care (e.g. no compensation for: physiotherapy, birth control for people 21 years and over, dentist for people 18 years and over) and increasing out-of-pocket payments (e.g. for household care and personal care).

In line with this subject is the discussion on what is usual or customary care from relatives and what is extra care and thus informal care. Caregiver organisations (e.g. LOT) often hear complaints from caregivers about needs assessments in which their role and input as caregiver has to be large.

Another important issue is the decentralisation of responsibility of health and social care services, which are not financed through the AWBZ, from national government to local government. This means that local government is among others responsible for support of family caregivers.

6.2 Do you expect there to be any changing trends in services to support family caregivers, e.g. more state or more family support, more services or more cash?

With this decentralisation of responsibility to local government it is expected that more regional differences with regard to support of informal caregivers will occur. This means that social care (e.g. respite care for informal caregivers) can no longer be compelled, which was the case with the AWBZ. It is possible that this will stimulate the discussion of the role or responsibility of local governments in health care.

With all economy measures in health and welfare services (such as budget cuts on health and welfare organisations, and increasing out-of-pocket payments) it is to be expected that more informal care is necessary.

6.3 What is the role played by caregiver groups / organisations, "pressure groups"?

The LOT, organisation for informal caregivers, is one the 'pressure groups' which are actively organising discussions about the problems of informal caregivers with national and local government and providers and insurers of care.

In this organisation informal caregivers are actively participating, as well as on national as on regional level. In co-operation with Xzorg, organisation of support centres for informal care, voluntary home care and buddy-organisations and regional and local organisations of informal caregivers they attend to interests of informal care with local, regional and national government and health care policy makers.

Other organisations, such as pressure groups for patients, and organisations for older people are alert to attend to interests of informal caregivers.

The LOT has composed a Manifest for informal caregivers.

In this manifest (2000) the LOT mentions 6 demands and wishes for informal caregivers:

- the informal caregivers decide themselves to what degree they will provide care
- the informal caregivers have to be able to temporarily hand over their care to others
- the informal caregivers have rights for good support
- the informal caregivers have rights for financial compensation
- the informal caregivers have to be able to combine both care and work
- the informal caregivers have a role in health care and have rights for participation

6.4 Are there any tensions between caregivers' interests and those of older people?

Although for many people it is still normal and 'without saying' to provide informal care for their loved ones, there is a growing tendency that more people may choose not to care. Especially with demographic developments of social mobility (children moving away from their parents for education and work), more female labour participation, households with two wage earners, more single households, and rising living costs (e.g. for mortgages).

Also, the preference of people with regard to informal care will change. Independence is important for many people and they will wait as long as possible to call for help (i.e. showing dependency). The preference for help from relatives / acquaintances has declined especially among higher educated people. They more often call for assistance from private caregivers. Also children will have more trouble with the duty to take care of their parents and parents will prefer not to be dependent from their children (Vollenga et al., 2001).

6.5 State of research and future research needs (neglected issues and innovations)

There is an increasing attention for informal care in the Netherlands, for example with regard to informal care for dementia patients, terminally ill people, and CVA-patients. Unfortunately, there is little exchange of knowledge between researchers and universities on a national level, and also little exchange between researchers and health care services and policy makers. The Expertise centre for informal care (EIZ) has recently started a network for research on informal care, which is stimulating the exchange between all of those groups. The EIZ also stimulates research on informal care, for example for mental health care and effects of respite care.

6.6 New technologies – are there developments which can help in the care of older people and support family caregivers?

Many efforts in technology are being accomplished to improve housing for older people (domotica). Houses are created in which people can live throughout their whole lifespan (levensloopbestendige woningen) with alarming systems, ICT-technology etc. Some professional home care organisations are offering computer technologies for older people and their caregivers to ask nurses by the use of webcams and internet questions about care (thuiszorg online).

Furthermore, care aids such as wheelchairs, stair elevator (traplift) and walking aids are under constant development.

6.7 Comments and recommendations from the authors

- strong tendency to moderate the Dutch welfare state
- in order to keep the expected rise in costs limited
- so, strongly budget drive
- focussing on sharing the costs of health, care and social services
- this will increase the relevance of supporting family caregivers to maintain and promote the willingness of informal caregivers

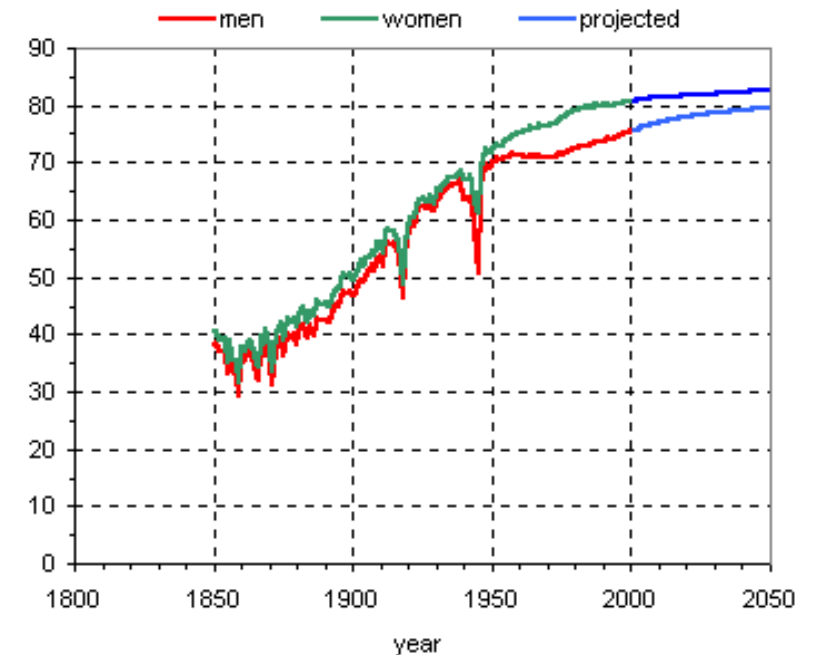
7 Appendix to the National Background Report for The Netherlands

7.1 Socio-demographic data

7.1.1 Profile of the elderly population – past trends and future projections

7.1.1.1 Life expectancy at birth (male / female) and at age 65 years

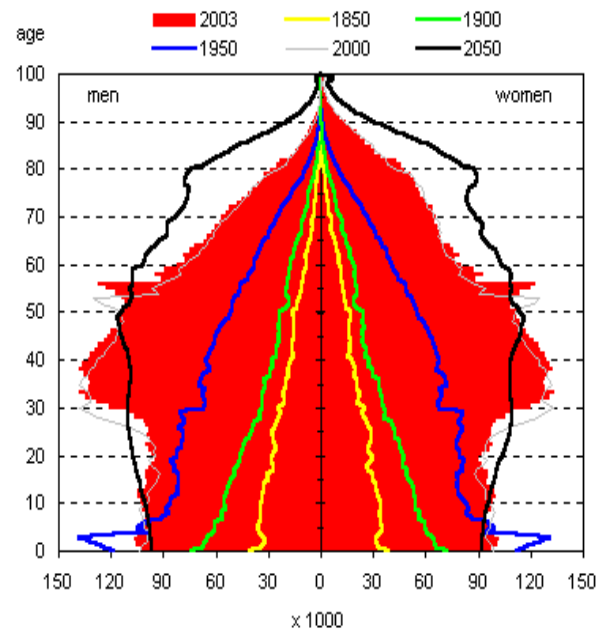
Figure 4: Life expectancy at birth in the Netherlands by sex, 1850-2050



Source: Netherlands interdisciplinary demographic institute (NIDI)

7.1.1.2 % of > 65-year-olds in total population (by gender and age group)

Figure 5: Population in the Netherlands by age and sex on January 1, 1850-2050



Source: Netherlands interdisciplinary demographic institute (NIDI)

There are about four million people of 55 years and older. From the age of 65 years the women are overrepresented. Almost one million people is 75 years and older (quarter of the 55+-population). The oldest age group (80+) counts 540,000 people and consist for 69 % of women.

Table 19: % people 55 years and over, 2003

Age category	%
55-59	25,8
60-64	19,2
65-69	16,1
70-74	14,2
75-79	11,3
80-84	7,7
85-89	4,0
90-94	1,5
95 and older	0,3

Source: Central Bureau for Statistics, Statline (cbs.statline.nl)

7.1.1.3 Marital status of > 65-year-olds in total population (by gender and age group)

Table 20: Population aged 65+ and 85+ by marital status and sex (%) in 2000

	65+			85+		
	Men	Women	Total	Men	Women	Total
Single	6	7	7	5	11	9
Married	75	41	55	47	8	18
Widowed	14	46	33	45	78	70
Divorced / separated	5	6	5	3	3	3
N	2,152,442			225,713		

Source: Central Bureau for Statistics, Statline (cbs.statline.nl)

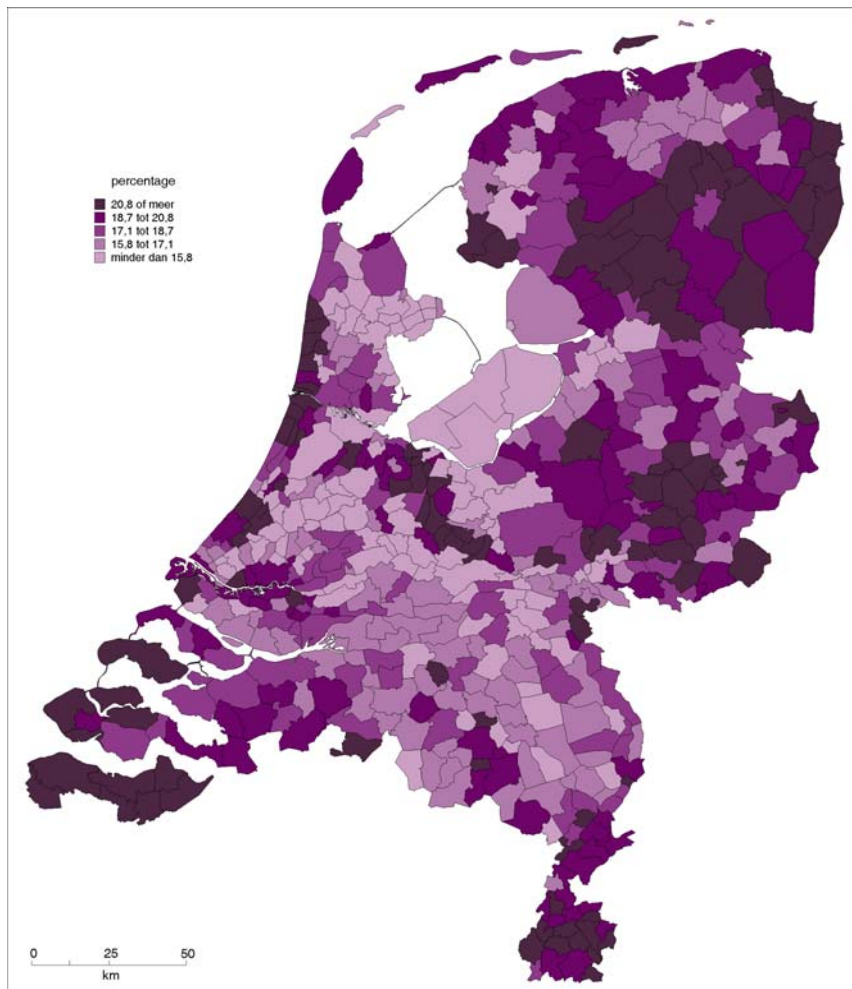
7.1.1.4 Living alone and co-residence of > 65-year-olds in total population

Table 21: Living arrangements of people 55 years and older (2003)

	55+	65+	75+
Alone	29	39	55
With partner	67	57	40
Other	4	4	5

Source: Central Bureau for Statistics, Statline (cbs.statline.nl)

7.1.1.5 Urban / rural distribution by age



7.1.1.6 Disability rates amongst > 65-year-olds. Estimates of dependency and needs for care

The increase of physical limitations proceeds gradually. Not until the age of 70 half of this age group suffers from (slight) limitations and round the age of 80 half of the people suffer from moderate to severe limitations.

Table 22: Gravity of physical limitations in age groups, 2000 (%)

	55-64	65-74	75-84	> 84	Total
No limitations	64	50	27	5	49
Slight limitations	20	25	21	12	21
Moderate limitations	11	15	22	25	15
Severe limitations	5	10	30	68	15

Source: Central Bureau for Statistics, Statline (cbs.statline.nl)

7.1.1.7 Income distribution of older people

Twenty-one per cent of people older than 75 years have a low income (net yearly income of ≤ EUR 9030), and 12 per cent of people between the age of 65 to 74 in 1998 (SCP (D), 2001). Six per cent of people 75 and older and eight per cent of people between the age of 65 and 74 have a high income (net income ≥ EUR 27,091).

7.1.1.8 % of > 65 year-olds in different ethnic groups

The total group of non-western ethnic elderly makes up 2.9 per cent of the total elderly population. However, the number of ethnic older people will increase in the near future. The number of ethnic older people in large cities is already higher than in rural areas. More than 40 per cent of the non-western older people live in the four largest cities (Amsterdam, Rotterdam, Utrecht, The Hague).

Table 23: % of > 55-year olds in non-western ethnic groups, 2003

Ethnic groups	Absolute number	% of total elderly population
Non-western ethnic groups, of which:	116,445	2.9
Turkish elderly	26,164	0.6
Moroccan elderly	22,953	0.6
Surinam elderly	32,614	0.8
Antillian elderly	9,162	0.2
Other non-western elderly	25,552	0.6
Total elderly population	4,031,644	

Source: Central Bureau for Statistics, Statline (cbs.statline.nl)

Table 24: Prognosis of number of non-western elderly (55+)

	2005 (%)	2010(%)	2015 (%)
Turkish elderly	29,394 (0.7)	36,226 (0.8)	46,017 (0.9)
Moroccan elderly	25,530 (0.6)	32,342 (0.7)	40,666 (0.8)
Surinam elderly	37,118 (0.9)	51,870 (1.1)	70,316 (1.4)
Antillian elderly	11,141 (0.3)	16,598 (0.4)	22,925 (0.5)
Total non-western elderly	136,320 (3.2)	191,315 (4.1)	216,995 (5.2)
Total elderly population	4,229,909	4,644,826	5,073,268

Source: Central Bureau for Statistics, Statline (cbs.statline.nl)

7.1.1.9 % Home ownership by age group

Home ownership of older people has increased from 38 % in 1990 to 43 % in 1998. However, this percentage is lower than that of the total population (50 %).

7.1.1.10 Housing standards / conditions

Amplly 30 % of older people do not have to walk the stairs to reach their houses and also not inside their houses. With increasing age more people live in zero-stairs houses: half of 75 year single old people and 40 % of 75 year old living in multi-person households. In the near future the increasing number of older people will create problems on the housing market (SCP (D), 2001).

7.2 Examples of good or innovative practices in support services

Support services for informal caregivers are divided into four categories:

Table 25: Categories of support services for informal caregivers

Information, advice and emotional support	Support groups, courses for caregivers, information meetings, written information, telephone service for caregivers, digital information, counters with local governments, support centres for informal caregivers, care broker, take care of yourself-weekends (respite care).
Practical help	Meals- and groceries services, handyman services, respite care services
Material support	Different arrangements for care aids, financial compensation and care leave
Representation of interests / interest groups	Patient- and organizations for older people, interest group for informal caregivers (LOT)

Bron: Morée et al. (2002)

Examples of services in these categories:

- Information, social / emotional support, and advice
 - Support centres for caregivers (co-ordinated by Xzorg) are an important source for caregivers for information and advice about different aspects of caregiving (e.g. training about caregiving, information about financial aspects, care aids etc.), but also for social and emotional support (e.g. support groups).
 - The telephone number for caregivers (Mantelzorglijn) (LOT) is an important source for information.
- Practical support
 - Respite care: different formal and voluntary organisations provide respite care. This can be at the homes of the care receiver (professional and / or voluntary respite care at home) or in health care institutions (e.g. day care facilities, care hotels (Zorghotels)) or in the community (e.g. Respite Pensions (Logeerhuizen), day care facilities in the community).
 - Vacation / holidays for caregivers: there are a number of organisations involved with organising vacations for caregivers and the people they take care of. Together they will go on holiday and part of their care will be taken over from them by formal and / or voluntary caregivers. Costs usually are high (e.g. Nederlandse Rode Kruis, Zonnebloem, Nederlandse Hartstichting, Stichting Mens en Samenleving, Alzheimer Nederland).
 - Travel organisations Holiday & Care (Vakantie & Zorg) has selected different hotels in the Netherlands where they can stay and receive the same type of care as they have at home.
 - Take care of yourselves-weekends (Zorg voor jezelf weekenden: LOT): weekend stay in hotels with other informal caregivers.
- Material support
 - Care leaves
 - Financial compensation through different tax measures
 - Personal Care budget
- Promotion / attendance of interests for caregivers / pressure group
 - Manifest
 - National representation of interest: LOT
 - Local / regional representation of interest for informal caregivers belangenbehartiging (for example Brabantse Raad voor mantelzorgers, Leidse vereniging voor mantelzorgers)

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