There is a broad range of palliative care available in the Netherlands. There are many options for obtaining palliative care at home. The care that terminally ill patients need can also be provided in nursing homes, care homes, hospitals and hospices. Government policy in this field is one of the reasons for rapid change in the palliative care sector in recent years. Since the middle of the nineteen-nineties the Dutch Ministry of Health, Welfare and Sport has initiated measures aimed at the stimulation and further development of palliative care. This publication gives an insight into these policy measures and their implications for care provision, training and research in the field of palliative care.
Palliative care for terminally ill patients in the Netherlands

Dutch Government Policy

International Publication Series Health, Welfare and Sport No 16
This series provides information on the Netherlands’ policy that specifically relates to the health, welfare and sports sectors. In addition, the series reproduces the full text of relevant Acts. The target groups are counterparts of the Ministry of Health, Welfare and Sport in other countries, international organizations, embassies of the Kingdom of the Netherlands abroad, foreign embassies in the Netherlands, researchers and other experts.
## Table of contents

1 Introduction  
1.1 Definition of palliative care and the purpose of this publication 4  
1.2 Number of patients and where they die 4  
1.3 Providers and financing of palliative care 5  

2.1 General 13  
2.2 ZonMw Palliative Care in the Terminal Phase Programme 14  
2.3 Centres for the Development of Palliative Care 15  
2.4 Hospice Care Integration Project Group 18  

3 Government Policy 2001-2002 21  
3.1 General 21  
3.2 Further network formation 22  
3.3 Organizing palliative care departments 23  
3.4 National support point 24  
3.5 Increase of financial resources 24  
3.6 Monitoring 25  

4 Euthanasia policy 27  

5 Conclusions 31  

References 33  

List of Abbreviations 36  

Publications in the series on policy items and legislation available from the Ministry of Health, Welfare and Sport
1 Introduction

1.1 DEFINITION OF PALLIATIVE CARE AND THE PURPOSE OF THIS PUBLICATION

The population in the Netherlands, and in other Western European countries, is growing and ageing rapidly. As of 1 January 2002 there were 16.1 million people living in the Netherlands, approximately one million more than ten years ago (1). During this period the number of people in their fifties grew substantially, from 1.5 million to 2.1 million. Consequently in the coming decades progressively more people will need care and will ultimately die.

If people do not die from acute disease but from cancer, for instance, they usually need palliative care. The term palliative care is derived from the Latin word ‘pallium’, which means a garment or cloak. Palliative care can therefore be seen in figurative terms as a mantle that provides heat and protection – a mantle that is provided to incurably sick people by professionals, relatives and volunteers working together. In this publication we use the World Health Organization's (2) definition of palliative care:

‘An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by treatment of pain and other problems, physical, psychosocial and spiritual’.

The primary purpose of this publication is to provide insight into Dutch government policy in regard to the palliative care of terminally ill patients in the last months, weeks or days of their lives. For the purposes of readability this is referred to as ‘palliative care’ in the rest of this publication. However, it always refers to palliative care during the terminal phase.

In order to provide a backdrop against which to position Dutch government policy, the following sections examine subjects that are directly associated with the current provision of palliative care in the Netherlands, namely the number of people who die, where they die, and the providers and financing of palliative care.

1.2 NUMBER OF PATIENTS AND WHERE THEY DIE

More than 140,000 people died in the Netherlands in 2000 (3). Approximately 55,000 of them died after a period of illness as a result of a non-acute disease (4). Cancer is the most common non-acute cause of death – nearly 40,000 Dutch
people died from cancer in 2000 (3). Other common non-acute causes of death are chronic heart failure, COPD and cerebrovascular disease.

People who are suffering from incurable cancer or another terminal non-acute disease can be expected to need palliative care to a greater or lesser extent. However, there are no national statistics in the Netherlands about the degree to which these people actually make use of palliative care services. There are figures about where certain groups of patients die. It is known, for example, that of the approximately 40,000 people a year in the Netherlands who die of cancer, 65% die at home, over a quarter die in hospital and around 6% die in a nursing home or a care home. The number dying in an independent professionally staffed hospice or a volunteer-run hospice (see 1.3) is under 1% (4).

In the Netherlands palliative care is part of regular health care. In other words it is not a specialism. The approach of the Dutch government is that palliative care should be provided as much as possible by generalists (general practitioners + nurses + care workers). This is in line with the needs and wishes of terminally ill patients. Recent research indicates that most terminally ill patients in the Netherlands prefer to die in their own home environment (5).

1.3 PROVIDERS AND FINANCING OF PALLIATIVE CARE

The following sections discuss where and by whom palliative care is provided in the Netherlands and who finances these services. An overview is given in table 1.

- General practitioners

The general practitioner is usually the main care provider for people who receive palliative care at home. In principle everyone living in the Netherlands has his own general practitioner, who can be consulted without the need for referral. There are altogether some 7800 practising general practitioners in the Netherlands for a population of over 16 million (8). The care provided by the general practitioner is paid for through a patient's compulsory health insurance fund insurance or private medical insurance. People with a relatively low income have health insurance fund insurance whereas people with a higher income have to take out private medical insurance.

The palliative care provided by the general practitioner relates largely to managing pain and other symptoms, including psychosocial symptoms and problems. Emotional support of patients and families is an essential element of the palliative care provided by general practitioners.
**Table 1** Providers and financing sources of palliative care in the Netherlands in mid-2002

<table>
<thead>
<tr>
<th>Providers of palliative care</th>
<th>overall number</th>
<th>most important sources of finance</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practitioners</td>
<td>approx. 7800&lt;sup&gt;1&lt;/sup&gt;</td>
<td>patient’s private insurance or health insurance fund insurance</td>
</tr>
<tr>
<td>Home care organizations</td>
<td>registered financed under the AWBZ approx. 120</td>
<td>national insurance (AWBZ) and small patient personal contribution</td>
</tr>
<tr>
<td></td>
<td>miscellaneous number not known</td>
<td>financing by patient</td>
</tr>
<tr>
<td>Nursing homes</td>
<td>without hospices unit (n = approx. 293) approx. 330</td>
<td>national insurance (AWBZ) and small patient personal contribution</td>
</tr>
<tr>
<td></td>
<td>with hospices unit (n = 37)</td>
<td>incidental donations, sponsorship, grants etc. (in the case of hospice unit)</td>
</tr>
<tr>
<td>Care homes</td>
<td>without hospices unit (n = approx. 1339) approx. 1365</td>
<td>national insurance (AWBZ) and small patient personal contribution</td>
</tr>
<tr>
<td></td>
<td>with hospices unit (n = 26)</td>
<td>incidental donations, sponsorship, grants etc. (in the case of hospice unit)</td>
</tr>
<tr>
<td>Independent professionally staffed hospices</td>
<td>16</td>
<td>private or health insurance fund insurance, AWBZ insurance (for medicines, care from doctors or other professionals etc.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>incidental donations, sponsorship, grants etc.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>often also patient contribution towards cost of maintenance and accommodation</td>
</tr>
<tr>
<td>Volunteer-run hospices</td>
<td>21</td>
<td>patient’s private or health insurance fund insurance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>incidental donations, sponsorship, grants etc. (in the case of hospice unit)</td>
</tr>
<tr>
<td>Hospitals</td>
<td>without hospices unit (n = approx. 134) approx. 137</td>
<td>patient's private or health insurance fund insurance</td>
</tr>
<tr>
<td></td>
<td>with hospices unit (n = 3)</td>
<td>incidental donations, sponsorship, grants etc. (in the case of hospice unit)</td>
</tr>
<tr>
<td>Volunteer organizations</td>
<td>members of the VTZ approx. 170</td>
<td>government grant (for coordination of volunteers)</td>
</tr>
<tr>
<td></td>
<td>miscellaneous number not known</td>
<td>incidental donations, sponsorship, grants etc.</td>
</tr>
<tr>
<td>Informal carers of terminally ill patients</td>
<td>over a period of 3 years: 6% of the population</td>
<td>usually unpaid</td>
</tr>
<tr>
<td></td>
<td></td>
<td>in some cases payment under a client-linked budget (PGB)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>informal carers can receive contributions under the Career Break Financing Act&lt;sup&gt;3&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>1</sup> In around 2006 the Dutch health care insurance system will be radically changed, see Ministry of Health, Welfare and Sport (6). This implies that the financing sources for palliative care will also undergo important changes.

<sup>2</sup> Including GPs without practices

<sup>3</sup> A monthly maximum of about € 490.45<sup>7</sup>
Recent research (9) has revealed that a Dutch general practitioner has contact a total of 26 times with a cancer patient in the palliative phase – these contacts are usually initiated by the general practitioner. The care of terminal cancer patients requires approximately 45 minutes per working week from the general practitioner. The total amount of time that a general practitioner devotes to palliative care, in other words including the care of terminally ill patients who are dying from diseases other than cancer, will be greater than this. Dutch general practitioners are generalists who also provide care to other, non-terminally ill patients. Generally speaking general practitioners only deal with a few terminally ill patients per year. This is one of the reasons why it is important to have sufficient opportunities for acquiring skill in the area of palliative care. Additional opportunities have also been created for obtaining advice in regard to complex problems. In 2000, for example, the Dutch Association of General Practitioners set up a course on Palliative Care for General Practitioners with an Advisory Role (see 2.2). This course trains general practitioners to act as advisors for colleagues. The six Centres for the Development of Palliative Care (see 2.3) have set up specialist multidisciplinary consulting teams that can be consulted by general practitioners and others. These centres have also initiated peer groups for general practitioners in which general practitioners can discuss with colleagues the cases of terminally ill patients who are difficult to treat. Palliative care training courses for general practitioners are also organized by these centres on a large scale.

- Home care organizations
When caring for terminally ill patients who remain at home, a general practitioner will often work closely with professional home care workers (nurses, care workers and helpers). There are some 120 home care organizations in the Netherlands that are financed through the collective AWBZ (Exceptional Medical Expenses Act) insurance, which entails a small income-related contribution from patients (10). This home care usually concerns nursing, care and domestic help. The target group is made up of clients who live at home and it includes terminally ill patients and their immediate family. Some home care organizations have teams of district nurses who have specialized in the field of home care technology, such as drips and pain management pumps, which can be important in regard to terminally ill patients. Since 1997 home care organizations have also been providing ‘support for informal carers’. This is a distinct and specific product that relates to psychosocial counselling, advice, instruction and information for informal carers. An indication decision by one of the independent Regional Indication Organizations (RIOs) is necessary in order to be eligible for home care financed under the AWBZ.
Patients with sufficient financial resources of their own can, if they so wish, purchase home care services themselves from a commercial professional home care organization (11). People with a client-linked budget (PGB) also make relatively frequent use of the services of commercial home care organizations. The national client-linked budget scheme for nursing and care, which is financed under the AWBZ, has been in existence in the Netherlands since 1995. This scheme enables people who are sick to arrange for care and to pay for it as they choose using a budget for a care need that has been determined by a Regional Indication Organization.

• Nursing homes
Palliative care receives particular attention in Dutch nursing homes. Physical and psychosocial care for people who need help during the last phase of their lives has traditionally been one of the core tasks of nursing home staff. There are approximately 330 nursing homes in the Netherlands, with around 57,600 beds and capacity for 4600 outpatients (11). The most important target group of the nursing homes is made up of elderly people with somatic or psychogeriatric problems who need help. There are no precise data about how many residents of nursing homes receive palliative care. It can be assumed that the group concerned is large given the target group of nursing homes as described above. In addition to providing palliative care to their own residents, growing numbers of nursing homes are also admitting terminally ill patients from outside for brief periods. In July 2002 there were 37 Dutch nursing homes with a hospice unit for short-term palliative care (12). These units have a total capacity of about 152 beds. The number of beds per unit ranges from one to fourteen. Admission to these units is often linked to a time limit of between two and three months.
Efforts are made in the hospice units in nursing homes to create an environment that is geared to the needs of people in the last phase of their lives. In some cases these units, with individual rooms and accommodation for visitors, are in the nursing home itself and in some cases they are in a separate building on the same site. Professional care is provided in the units by nurses and care workers. The units can also call on the services of the nursing home’s general practitioner, clergy, psychologist, physiotherapist and other nursing home staff. Given these features, hospice units in nursing homes are suitable for patients who need complex palliative care and who cannot or do not wish to remain at home, in a hospital or in a care home (13).
As is the case with home care and care home care, nursing home care is largely funded under the AWBZ, with a relatively small personal contribution from patients. In principle, as with other forms of care funded under the AWBZ, everyone is entitled to this care provided that a Regional Indication Organization has made a positive indication decision in regard to the type of care concerned.
The Ministry of Health, Welfare and Sport recently committed additional funding (see 3.5) for the care in nursing homes and care homes of terminally ill patients with complex problems.

- Care homes

There are approximately 1365 care homes in the Netherlands, with a total of some 112,400 beds (11). Residents have a single room, or a double room in the case of married couples. In many cases care homes also provide external services to elderly people living at home, such as meals and connections to alarm systems.

As is the case with nursing homes, care homes also focus on old people who need help. Compared with residents of nursing homes, generally speaking the residents of care homes have less complex physical or psychogeriatric problems.

There are no precise figures about how many people receive palliative care from care home staff (primarily care workers). It is known, however, that the number is substantial because in all cases the residents are elderly and the policy is to care for these people until the end of their lives as much as possible in a care home.

In addition to providing palliative care to their own residents, there is an increasing trend for care homes to admit terminally ill patients for short-term care. These are primarily terminally ill patients who, for example, can no longer remain at home because of the absence of care by family members and who do not have complex care needs.

There are growing numbers of hospice units in care homes for the purposes of providing short-term care. In mid-2002 26 Dutch care homes had a hospice unit. Between them these units have a capacity of around 60 beds. The number of beds per unit ranges from one to seven (12). Professional care workers play a key role in these special units, often with support from volunteers. In most cases the patient’s own general practitioner provides the necessary medical care.

Usually the maximum length of care that applies to external terminally ill patients in a hospice unit in a care home is the same as in the hospice units in nursing homes, namely between two and three month.

A positive indication decision from a RIO is needed for admission to a care home. In principle normal admission to a care home is funded under the AWBZ, as is admission to a hospice unit. Care homes are also eligible for the additional funding referred to above that the Ministry of Health, Welfare and Sport has committed for the care of terminally ill patients (see 3.1).

In order to enhance the quality of palliative care in care homes, initiatives were recently undertaken in regard to improving the skills of care workers, formulating quality criteria and developing instruments and models for palliative care units (see also section 2.2).
Independent professionally staffed hospices and volunteer-run hospices

As we have seen in the preceding sections, there are many options in the Netherlands for outpatient palliative care, and nursing homes and care homes have traditionally provided palliative care in house. This is why the Netherlands has relatively few independent hospices and also why they appeared later – all after 1992 – than in such neighbouring countries as the United Kingdom, Germany and Belgium (14). Currently the number of Dutch people who die in an independent hospice is still relatively low (less than 1%) (4). In this context independent means that the hospice is not a part of, for example, a nursing home or care home. In the Netherlands a distinction is often made between professionally staffed hospices, which have their own nursing personnel, and volunteer-run hospices, which are staffed primarily by volunteers.

In mid-2002 there were 16 professionally staffed hospices with a combined capacity of about 85 beds. The number of beds per professionally staffed hospice ranges from four to ten (12). Dutch professionally staffed hospices have a homely atmosphere. The government and the organizations themselves consider hospices (including volunteer-run hospices) as a ‘relocated home environment’. Nurses make up the core team in a professionally staffed hospice, but they also work with volunteers. In some cases the medical responsibility is borne by the patient’s own general practitioner and in others by a hospice doctor or medical specialist associated with the hospice. Other disciplines are available in independent hospices on an on call basis or otherwise. These features make these hospices particularly suitable for looking after people who can no longer be cared for at home for medical reasons. Some professionally staffed hospices focus primarily on people with complex problems, while others are also open to people with less complex problems (13).

The core teams in the volunteer-run hospices are volunteers and not professionals. All the volunteer-run hospices are small scale – the number of beds per volunteer-run hospice ranges from one to six (12). There were 21 volunteer-run hospices in the Netherlands in July 2002 with a combined capacity of 61 beds. The volunteers work as much as possible with families in providing daily care services in the volunteer-run hospices. The patient’s own general practitioner is responsible for providing the medical care. Professional home care staff can also be called upon for nursing and care tasks when necessary. Volunteer-run hospices are suitable primarily for looking after terminally ill patients who can no longer be cared for at home for social reasons rather than exclusively medical reasons (7,13).
The vast majority of professionally staffed hospices and volunteer-run hospices apply specific admission requirements, such as expected duration of the care and the complexity of the care. Most of them also require a positive indication decision from a Regional Indication Organization.

A number of different services (such as general practitioner care, services from home care organizations and medicines) that are provided for terminally ill patients in professionally staffed hospices or volunteer-run hospices can be paid for by regular insurance of the patient or under the AWBZ (for which an indication for nursing and care from a Regional Indication Organization is necessary). Professionally staffed hospices and volunteer-run hospices are dependent on donations, charitable organizations, sponsors or local authorities for the costs of accommodation and maintenance.

- **Hospitals**

There are some 137 hospitals in the Netherlands, including eight university hospitals and two specialist oncology clinics. The total number of hospital beds is approximately 56,500 (11). Although the primary function of Dutch hospitals is curative, they devote explicit attention to palliative care. This can be seen, for example, in the way that hospitals often participate in regional palliative care networks (see 2.4). The university hospitals and specialist oncology clinics, in particular, also make an important contribution to the Centres for the Development of Palliative Care (see 2.3).

There are few hospice units in Dutch hospitals because they are concerned first and foremost with curative treatments. There are three hospitals in the Netherlands with a hospice unit. One of these units, containing seven beds, is located in an oncology clinic, namely the Dr. Daniël den Hoed Clinic in Rotterdam. This clinic specializes in terminally ill oncology patients with complex medical problems. The other two units, which have three and seven beds, are located in general hospitals in Rotterdam and Tiel. These two units do not focus solely on terminally ill cancer patients. They also admit other groups of terminally ill patients with complex medical problems.

- **Volunteers and volunteer organizations**

Volunteers in the Netherlands are called upon on a large scale to provide terminally ill patients and members of their families with practical and emotional support. For example, volunteers can sit up with the patient, and assist at mealtimes and when making the bed. They can also lend a sympathetic ear. Most of the organized volunteers in the terminal care sector work in organizations that are members of the National Association of Terminal Care Volunteers Trust (VTZ). A small proportion of volunteers are organized in buddy
projects (for AIDS patients) or through the Red Cross.
In 2002 there were over 170 local VTZ member organizations that direct the efforts of more than 4000 volunteers. The VTZ provides support to its member organizations and volunteers through information and training and through quality monitoring (15).
If volunteers from a VTZ member organization are assigned, it is not to replace professional staff but to support families. Besides helping people in their homes, VTZ volunteers are frequently to be found in hospice units, professionally staffed hospices and volunteer-run hospices.
Volunteers who are associated with the VTZ can only be called upon to help in the case of a patient who is in the terminal phase.
Although volunteers receive no payment for the work they do, there are costs that arise out of the coordination, transport, training and supervision of volunteers. The work of volunteers depends in part on a wide range of sponsors, donations and gifts. The coordination of volunteers in the terminal care sector is also financed by the Ministry of Health, Welfare and Sport through the Coordination of Voluntary Care and Home Care Grants Scheme (CVTM).

- Informal carers
Informal carers are people from a patient's immediate family or a patient's broader social network who carry out care tasks. Research has shown that over a three-year period, between 1997 and 1999, 6% of the Dutch population provided informal care to terminally ill people (11). This informal help primarily concerns domestic help, but it also relates to assistance for personal care and emotional support. On average Dutch terminally ill patients receive support from two informal carers – in many cases the partner or one or more children (16). Close relatives are usually very motivated to make a contribution to palliative care. The care of a terminally ill patient is a substantial burden for many informal carers. They can become physically and emotionally exhausted. Their problems can be made worse if others involved are only concerned with the terminally ill patient or if there is insufficient scope for fitting care tasks in with the normal pattern of their activities (16).
Extra care for volunteers may be necessary in such cases. As referred to above in the section on home care, informal carers can also obtain support from professional home care organizations in the form of psychosocial counselling, advice and information about palliative care.
The help that informal carers provide to terminally ill patients is unpaid in most cases (sometimes there is a possibility of paid care leave). However, patients can pay informal carers for their services when they have a client-linked budget (PGB), as described above.

2.1 GENERAL

There has always been concern about appropriate care for the dying. Nevertheless, during the nineteen-nineties social and political priority for the palliative care of terminally ill patients increased substantially. The example set by the hospice movement in the United Kingdom and the United States, the debate about euthanasia in regard to the quality of palliative care and the ageing of the population were factors in this. It is no coincidence that it was during this same period that the first hospice units, independent professionally staffed hospices and volunteer-run hospices appeared in the Netherlands.

The Minister of Health, Welfare and Sport initiated a stimulation programme during the second half of the nineteen-nineties based on the expectation that the need for palliative care will increase further in the coming decades and to support initiatives in the sector.

The principle underlying this stimulation programme was that palliative care should be provided as much as possible by doctors, nurses, care workers and other care providers who work in regular non-private facilities. In this way access to and the availability of palliative care would be improved.

The stimulation programme encompassed three specific separate programmes (19, 20, 21):

1 encouragement of research and innovative projects under a programme of the Health Research and Development Council/Medical Sciences (ZonMw);
2 promotion and guidance of palliative care by six university centres: the Centres for the Development of Palliative Care (COPZs);
3 stimulation of the integration of hospice facilities in regular health care by the Hospice Care Integration Project Group (PIH).
The programmes are discussed in greater detail in the following sections.

### 2.2 ZONMW PALLIATIVE CARE IN THE TERMINAL PHASE PROGRAMME

In many cases ministries in the Netherlands do not allocate grants directly to organizations that conduct research or innovate in the health care sector. Instead, the ministries work through intermediary organizations, such as the Health Research and Development Council/Medical Sciences (ZonMw). ZonMw is associated with approximately 40 programmes, one of which is the Palliative
Care in the Terminal Phase Programme (term 1997 to 2002). An inventory study – Palliative Care in the Netherlands – was carried out as part of the first, exploratory phase of this programme (23). This study revealed that the palliative care sector in the Netherlands was undergoing rapid change and that many new initiatives relating to palliative care and expertise enhancement were being undertaken. In many cases, however, it was found that there was little coordination and cooperation between these initiatives.

During the second phase of the programme a grant was allocated for a scenario study of trends in the demand for palliative care (4). One of the forecasts that came out of this study was that between 1997 and 2015 the number of Dutch residents dying annually from non-acute diseases will probably increase by 20% – from over 55,000 to more than 66,000. This suggests that the demand for palliative terminal care will also grow by some 20% between now and 2015.

In the third phase of the programme, which is still underway, ZonMw has allocated grants to a number of different projects and experiments that aim to improve palliative care for specific target groups, including children, ethnic minorities and patients with amyotrophic lateral sclerosis. Funding was also provided to the Dutch Association of General Practitioners for setting up and running a course on Palliative Care for General Practitioners with an Advisory Role, which trains general practitioners as advisors for colleagues.

The Prismant Institute is being financed by the ZonMw to implement a number of projects to improve the palliative care in care homes. There are programmes in a number of care homes to enhance the expertise of care workers, to develop quality criteria and instruments based on the perspective of the patient, and to devise models for palliative units in these care homes.

ZonMw has also provided financial resources to the National Association of Terminal Care Volunteers Trust (VTZ) for the implementation of a number of projects. The VTZ has invested this money in training volunteers, setting up a quality system, regional collaboration and creating greater awareness of palliative care provided by volunteers among potential new volunteers, patients, close relatives and professionals (24).

### 2.3 CENTRES FOR THE DEVELOPMENT OF PALLIATIVE CARE

- **General**

In 1997 the Minister of Health, Welfare and Sport decided that Centres for the Development of Palliative Care should be set up to develop and guide palliative care in the Netherlands. These centres were tasked with initiating projects in two main areas – ‘structural change and care coordination in the palliative care sector’ and ‘knowledge development and expertise enhancement in the palliative care sector’.
The COPZs officially started operating in 1998 and they are located in six cities in the Netherlands, i.e., Amsterdam, Groningen, Maastricht, Nijmegen, Rotterdam, and Utrecht. Each centre comprises an alliance containing at least a medical faculty and a university hospital, usually in collaboration with inpatient and outpatient care providers and a Comprehensive Cancer Centre (IKC) in the region concerned. The Ministry undertook to fund the centres for a period of six years (1998 to 2003) so that they could give palliative care in the Netherlands a powerful push as well as any guidance that was necessary. This funding takes the form of an annual fixed sum for coordination of the COPZs and project management. The COPZs moreover receive grants for implementing innovative or research projects that come within the scope of the main areas referred to above. The COPZs’ projects and the related project proposals are appraised by an independent COPZ Evaluation Committee that was set up by the Minister of Health, Welfare and Sport in 1998. The Evaluation Committee makes recommendations to the Minister about whether project proposals or projects should be eligible for initial or further grants.

- **Advice provided by COPZs**
  
  Many of the COPZs’ projects relate to specialist regional consulting teams (25). In mid-2002 there were ten regional consulting teams that were being directed by the COPZs. Care workers with specific palliative care expertise are part of these multidisciplinary consulting teams. Around 70% of team members are nurses. The other team members are generally medical specialists, general practitioners and psychologists with specific palliative care expertise. These consulting teams sometimes also include members of the clergy, social workers and pharmacists.

  The consulting teams have the capability of providing services, patient-related or otherwise, to those caring for terminally ill patients. These services include advice, information, support in the workplace, care coordination, skill-related training and expertise enhancement. None of these teams takes over ultimate responsibility for the care being provided. The consulting teams have been incorporated as far as possible in existing institutional structures and alliances.

  A peer group for general practitioners project was set by the COPZ in Amsterdam in 1999. This project gives general practitioners the opportunity to discuss with their peers cases from their own practices of terminally ill patients with complex problems. The peer groups are supervised by a doctor who is a specialist in palliative care.

  In 2000 the COPZ in Nijmegen initiated the home care nurses contact project. Through this project home care workers can consult a specialist palliative care nurse.

  In some cases there is a combination of consultation forms in the sense that
specialist care workers who can be consulted individually by colleagues are also part of multidisciplinary consulting teams.

In 2000 the COPZ Evaluation Committee (25) concluded that in principle the COPZs’ regional consulting teams were accessible to care workers providing care to 43% of the Dutch population. In 2000 there were over 22 FTE advisory staff available to do this, which works out at 0.32 FTE per 100,000 people. In other words the COPZs are working very hard to get the advisory function in the Netherlands off the ground. A number of organizations that are not associated with the COPZs are also actively involved in setting up consulting teams. This means that general practitioners, home care staff, professionals from inpatient facilities and others have been provided with many options for obtaining advice relating to complex problems affecting terminally ill patients.

It needs to be possible to compare the different consulting teams with one another and the teams need to record information in a uniform way in order to conduct a good evaluation. At the request of the Evaluation Committee a joint registration form was designed by the COPZs in 1999 to this end. In principle all the records of the COPZs’ consulting teams are stored in a joint database. The first evaluation report based on these joint records and databases was published in 2001-2002 (26). The report revealed, among other things, that during the year under evaluation there were 2357 consultations and on average there were 0.25 consultations per 1000 members of the population. Most consultations were conducted over the telephone. The patient was visited in 19% of the consultations. The telephone consultations were mostly initiated by general practitioners, whereas the bedside consultations were generally at the request of hospital nurses or medical specialists. A nurse was often the initial contact person from the team to talk to the person seeking advice, but in virtually all cases there was subsequently multidisciplinary discussion. Almost all the patients on whose behalf advice was requested had cancer. The questions were primarily related to pain and other physical complaints, pharmacological subjects, psychological problems or the organization of care.

• Training projects in the COPZs
The COPZs have also undertaken a number of initiatives relating to the training of professionals caring for terminally ill patients (25). In 1999 the COPZ Evaluation Committee had made a recommendation to the Minister of Health, Welfare and Sport prior to these initiatives. In the recommendation it was concluded, in part on the basis of an inventory of palliative care in the Netherlands (23), that a great deal had already been developed in regard to training but that there was little harmonization between existing courses. New
training projects would only make the diversity even greater. It was therefore agreed that each COPZ would be assigned an area of attention in the field of initial training, specialist training and in-service/refresher courses for doctors, nurses and care workers. These projects will be completed before the end of 2003 (when the government grants to the COPZs cease). Starting in 2004 the projects relating to the initial training of doctors, nurses and care workers have to be integrated into the basic curriculums of the courses concerned. The COPZs are currently also developing a database containing information about all existing in-service/refresher courses relating to palliative care. The goal of this database is to improve the dovetailing between the supply of in-service/refresher courses and the demand from care workers. This database can also provide insight into the content and national availability of in-service/refresher courses.

- Research by the COPZs

The COPZs have initiated sixteen research projects. Most of these projects concern epidemiology, ethics or informal care. The epidemiological projects are intended to generate more information about the problems and needs of the patients and the scope of palliative care. The ethics research projects are aimed at producing a better understanding of decisions in the palliative care sector. The research projects relating to volunteer care are useful for building up a clearer picture of the needs of informal carers and the occasions when intervention is necessary in the work of informal carers.

In principle the research projects also have to be completed before the end of 2003.

- The Evaluation Committee’s Advisory Report

Based in part on the experience with the different projects initiated by the COPZs, in mid-2001 the COPZ Evaluation Committee made recommendations about the future structure and substance of palliative care in the Netherlands. Among other things the case is put for palliative care departments in Comprehensive Cancer Centres that should take over the functions of the COPZs within a few years.

2.4 HOSPICE CARE INTEGRATION PROJECT GROUP

- Background and goals of the Hospice Care Integration Project Group

As discussed in section 1.3, there is a range of hospice facilities in the Netherlands – the independent professionally staffed hospices, the volunteer-run hospices and the hospice units in nursing homes, care homes and hospitals. During the second half of the nineteen-nineties the Ministry of Health, Welfare
and Sport stated repeatedly that it is desirable for hospice facilities to be integrated, or in any event to cooperate closely, with regular, non-private health care institutions. This improves access for terminally ill patients to hospice facilities and existing institutions can utilize one another’s skills and possibilities (19).

In 1999 the Minister of Health, Welfare and Sport set up the Hospice Care Integration Project Group (PIH) with the intention that it should operate until the end of 2001. This project group’s most important task was to investigate possible ways to stimulate the integration of professionally staffed hospices, volunteer-run hospices and hospice units into regular health care.

- Network model
During its first year the Hospice Care Integration Project Group had an inventory made of the number and nature of these hospice facilities. The inventory of hospice facilities was moreover used to devise a model in order to integrate hospice care (see model 1).

**Model 2  Network model**
The network model is based on the five places where terminally ill patients can stay. The arrows indicate the flows of patients, care workers, knowledge and resources between these places. The hospice facility has been positioned in the middle because it can perform a function for all the other places in the network as a location for the temporary accommodation of terminally ill patients. A network should feature very close collaboration and coordination between all the providers of palliative care in a particular region. In this way people complement one another and it becomes possible to improve the transfer of patients from one care location to another.

During the 2000-2001 period the feasibility of the network approach was evaluated in ten pilot networks. The evaluation of the pilot networks suggests that the cooperation between the providers of palliative care is indeed improving. The problem that was the underlying reason for setting up the Hospice Care Integration Project Group – the relatively detached operation of the hospice facilities in relation to the regular health care system – is being solved through the network approach. The evaluation moreover shows that the flexibility and availability of care improves if people collaborate in accordance with the network model. The continuity of the care – in other words the way the institutions work together in individual cases – is also improved. Another result from the evaluation is that a broad and varied range of palliative care can be provided in a network. Consequently the probability that palliative care is provided that dovetails with the specific wishes, needs and problems of patients increases. The network approach moreover leads to enhancement of the skills of care workers as a result of sharing experience, benchmarking, consultation and discussion with peers.

- Final recommendations of the Hospice Care Integration Project Group

At the end of 2001 the Hospice Care Integration Project Group formulated its final recommendations on the basis of its experience with the pilot networks. In its recommendations it advocates further government encouragement for the formation of regional networks of palliative care providers. The project group also identified a number of financial problems that would need government measures. For example, volunteer organizations, nursing homes, care homes and other organizations would need additional financing for their palliative care activities (16).

These recommendations, plus the recommendations of the COPZ Evaluation Committee (27), represented important building blocks for new policy measures. These policy measures, which were expanded on in 2001/2002, are discussed in the next chapter.
3 Government Policy 2001-2002

3.1 GENERAL

The positions that provide a framework for future government policy on palliative care were formulated at the end of 2001/beginning of 2002 (17, 18, 28). The underlying principle was a generalist, regular context. In other words palliative care has to be provided by generalist care professionals (including general practitioners, home care workers and nursing home staff) who are part of the regular health care system. However, these generalist care professionals need to have a large number of options for training and consultation in order to provide good quality palliative care.

A further underlying principle was that the initiatives undertaken and achievements made in the nineteen-nineties in Dutch palliative care have to be retained and further developed. The preceding years had been largely characterized by developments and improvements in palliative care. Awareness of the importance of good palliative care was also an important element of this. A great deal has happened and much has been developed in recent years. The important phase that has now started is one during which all these improvements are to be utilized and the basis for the care for people at the end of their lives is to be reinforced more systematically.

At the end of 2001/beginning of 2002 this resulted in policy positions with regard to:

a  The substance of palliative care
   In this regard the Minister referred, among other things, to current initiatives in the areas of quality policy and quality criteria that were developed and implemented in and by care institutions, volunteer organizations, alliances and patient organizations. The point of view of the patient is an important underlying principle in respect to these initiatives. Quality criteria that reflect the views of patients are important for moving away from a supply-driven system and the development a demand-driven health care system.
   The importance of continuing and using existing initiatives for enhancing expertise was also referred to in this context. The different education projects and products that are being developed by the COPZs (see 2.3) will probably be complete during the course of 2002 and 2003. Application of the products will benefit the substance of palliative care.

b  The organization of palliative care
   Measures have been announced that are aimed at:
• the ongoing creation of regional networks of palliative care providers;
• organizing palliative care departments in Comprehensive Cancer Centres, which among other things have to provide support to the regional networks that are to be created and to regional consultation teams dealing with palliative care;
• setting up a national palliative care support point that is to facilitate exchange and coordination between care providers.

c The financing of palliative care
The following financial measures have been announced:
• increasing the budget for the coordination of volunteers so that more volunteers can become active in terminal care;
• financing network coordinators, who have a coordinating role in networks made up of institutions and care providers in the palliative care sector;
• increasing the financial resources for palliative care in nursing homes and care homes;
• increasing the financial resources for the National Association of Terminal Care Volunteers.

In the following sections there is a detailed description of these new policy measures, which are related primarily to organization and financing (see b, c).

3.2 FURTHER NETWORK FORMATION

Following on from the experiences and the advisory report of the Hospice Care Integration Project Group, the Minister of Health, Welfare and Sport has decided that there need to be networks of palliative care providers throughout the Netherlands (17, 18, 28). The objectives underlying the encouragement of networks nationwide are:

a further integration of hospice facilities in the regular health care system;

b good cooperation and coordination between the different care providers;

c optimal utilization of one another’s expertise and possibilities leading ultimately to:

d good quality palliative care as demonstrated by good dovetailing of the demand for and supply of care, greater availability of care and continuity and flexibility in the provision of care.

The networks must incorporate all the institutions that provide palliative care in a region, town or city – hospice facilities, home care, hospitals, nursing homes and care homes. General practitioners who are involved in palliative care must also be part of the networks. It is important for the effective performance of a network that the network’s supply is close to the patient. Existing cooperative alliances also have an influence on the creation of networks. The Minister has therefore
stated that the optimal scale should be left up to people in the field. The Minister’s expectation is that between 50 and 60 networks will be formed in the Netherlands. Every network will have to appoint a network coordinator who will lead the network and who will have to be financed under the Coordination of Voluntary Care and Home Care Grants Scheme (CVTM, see 3.5).

3.3 ORGANIZING PALLIATIVE CARE DEPARTMENTS

The Minister of Health, Welfare and Sport has also implemented measures aimed at organizing palliative care departments in the nine Comprehensive Cancer Centres (IKCs) in the Netherlands (17, 18, 28). The IKCs have always been regional organizations that advise, support and train care providers (medical specialists, general practitioners, nursing home doctors, nurses and others) in regard to diagnosing, treating, counselling and caring for cancer patients. With regard to organizing palliative care departments, the IKCs have to extend their work area to incorporate care professionals who are providing care to inpatients and outpatients with diseases other than cancer, such as some terminal heart, lung and neurological disorders. The setting up of the palliative care departments is aimed at achieving the following objectives:

a systematic support of the regional networks of palliative care providers in all IKC regions;
b systematic support of regional specialist consultation teams in all IKC regions. In this regard all regional consultation teams should seek to link up with the IKCs in so far as this is not already the case;
c systematic enhancement in all IKC regions of the expertise of care providers in the field of palliative care;
d combining knowledge about quality improvement and research relating to palliative care.

The palliative care departments in the IKCs have to take over the tasks of supporting consultation teams, networks and care providers from the COPZs (see section 2.3). The COPZs have carried out a great deal of pioneering work on palliative care and on getting palliative care on the agenda of many institutions. However, the six COPZs do not cover the whole country. The COPZs are moreover strongly linked to medical faculties and university hospitals, and a university hospital is not independent and it is only one of the types of institution where a patient can die. If a COPZ were to continue to be connected too closely to a university centre, it could generate problems in regard to the development of palliative care in the region. Most of the COPZs have therefore sought to establish links with an IKC for the regional development of palliative care. In view of this trend the transfer of the support tasks of the COPZ is a logical step – it will
provide nationwide coverage because between them all IKC regions encompass
the Netherlands. At the same time the best possible use can be made of the
many years of experience that the IKCs have in such areas as consultation,
information and expertise enhancement.

The IKC palliative care departments will have supporting and facilitating tasks.
The IKC will not have a managerial role – the institutions and the alliances will
continue to bear responsibility for planning facilities and the associated patient
flows as well as for creating networks.

During the course of 2003 the Ministry of Health, Welfare and Sport will state
how the palliative care departments will be funded from 2004 onwards (when the
government grants to the COPZs have stopped).

3.4 NATIONAL SUPPORT POINT

The planned independent support point is intended for providers of palliative
care. This national support point should act as a sort of ‘marketplace’ where care
providers can learn more about important trends and initiatives relating to
palliative care. The national support point’s aims are to:

a bring about more interaction between care providers about care innovations,
expertise enhancement, quality projects etc. at a national level, which in turn
should result in:

b more coordination between care providers in regard to palliative care
initiatives;

c more information sharing with foreign organizations and care providers
about palliative care in the Netherlands and elsewhere.

The national support point should, for example, have the following specific
activities – organizing national meetings about such subjects as network
development and expertise enhancement, and maintaining a website with
information about palliative care initiatives. In the meantime the Agora Trust has
taken on the task of the national palliative care support point.

3.5 INCREASE OF FINANCIAL RESOURCES

• Increasing the budget for coordination of volunteers

In 2002 the Ministry of Health, Welfare and Sport increased the budget for the
Coordination of Voluntary Care and Home Care Grants Scheme (CVTM) (18, 28). The
increase in the CVTM budget was considered to be necessary in order to
cover the costs incurred by local volunteer organizations when coordinating their
volunteers. The continuing increase in the number of volunteers in the palliative care sector was one of the reasons for this. The increase in the CVTM budget was also deemed to be necessary in order to compensate for the cancellation with effect from 1-1-2002 of the Intensive Home Care Grants Scheme (ITZ). Up to and including 2001 grants were allocated under this scheme to a large number of local volunteer organizations, which used them as one of the sources for financing the coordination costs.

- Financing of network coordinators
  The CVTM has also been increased in order to make it possible to finance the coordinators of palliative care networks (see 3.2).
  In order to be eligible for the CVTM financing, the organizations concerned have to submit an application to a care office, or in other words the central care insurer in a region.

- Increasing financial resources for the National Association of Terminal Care Volunteers Trust (VTZ)
  In 2002 the Ministry of Health, Welfare and Sport also increased the funding for the VTZ (18, 28) in order to enable intensification of the trust's activities.
  This funding increase is a logical consequence of the growing use of volunteers.
  The VTZ will now be able to spend more time on such matters as training, setting up new facilities in the region, coordinating activities with other organizations involved and developing policy in the sector.

- Increasing financial resources for palliative care in nursing homes and care homes
  An increase in the financial resources of nursing homes and care homes (18, 28) is another recent financial measure. It was known from, among other things, the advisory report of the Hospice Care Integration Project Group (16) that nursing homes and care homes cannot finance the nursing and care of terminally ill patients with complex problems entirely from the current budgets that are set up under the collective AWBZ insurance. These people often need expensive medicines and intensive care. This is why the Minister has allocated additional financial resources.

3.6  MONITORING

The Ministry of Health, Welfare and Sport have stated that it is necessary to closely monitor the implementation and the consequences of the measures described above. The instrument for doing this is a monitoring investigation.

The most important objective is to acquire an understanding of the results of
these policy plans and of possible problems. In mid-2002 the Ministry was preparing a monitoring investigation that was to be contracted out to a research institute that had yet to be identified. Funding has also been reserved for monitoring.
4 Euthanasia policy

• General

In recent decades euthanasia has been the subject of wide ranging political and social debates in the Netherlands and other countries (29). It is often asserted in these debates that requests for euthanasia are virtually never forthcoming if high quality palliative care is being provided. On the other hand there are people who contend that even the best palliative care cannot always prevent a request for euthanasia. A moment can come when all options have been exhausted and there is unbearable and hopeless suffering.

Although the discussion about whether or not euthanasia can have a place in palliative care will continue in the years to come, it would appear prudent to devote attention in this booklet to Dutch government policy with regard to euthanasia.

In the Netherlands euthanasia is taken to mean the termination of life by a doctor at the request of a patient. This also includes doctor-assisted suicide. Euthanasia is not taken to mean abandoning treatment if (further) treatment is pointless. In such cases it is part and parcel of normal medical practice that the doctor abandons treatment and lets nature take its course. The same applies to administering large doses of opiates for pain relief whereby a side effect is that death occurs more quickly.

The main objective of Dutch government policy in regard to euthanasia is to employ regulations and uniform review in order to realize decision making about euthanasia as painstaking as possible and to develop a transparent procedure that can guarantee openness.

• Legislation

The Dutch law forbids killing someone, even if that person requests to be killed. However, in recent decades requirements of due care have been formulated through jurisprudence and the medical profession and these have been incorporated in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (30, 31, 32). This new euthanasia legislation, which came into force on 1 April 2002, lays down requirements and review procedures that have been applied in prior years in medical and legal practice. Grounds for exemption from criminal liability have been incorporated in the Dutch Penal Code that stipulate that the doctor who applies euthanasia is liable to punishment unless the doctor has complied with the requirements of due care demanded by the law and has reported the non-natural death to a ‘regional euthanasia review committee’. The requirements of due care mean that the doctor:
• must be convinced that there is a voluntary and carefully considered request
from the patient;
• must be convinced that the patient’s suffering is hopeless and unbearable;
• has to tell the patient about the patient’s situation and the patient’s prospects;
• has to consult at least one other independent doctor who sees the patient and gives his opinion in writing about the requirements of due care as referred to in the first four parts;
• has to implement the termination of life or assisted suicide with due medical care;
• has to become convinced together with the patient that there is no other reasonable solution for the situation that the patient is in. This last requirement of due care means that it has to be ascertained whether there are further possibilities in the area of palliative care to reduce the suffering.

A relationship based on trust is an important principle that underlies the euthanasia legislation. The doctor who turns to euthanasia in the case of a patient must be the doctor treating that patient. The doctor needs to know the patient well enough to be able to assess whether the request for euthanasia is made on the basis of the patient’s free will and that it has been carefully weighed up, and whether it is true to say that there is hopeless and unbearable suffering.

The Regional Euthanasia Review Committee reviews the medical actions of the doctor and the way in which decisions relating to euthanasia have been made. Each of the five review committees has three independent members – a lawyer/chair, a doctor and an ethicist. If, after studying the file, a review committee comes to the conclusion that the doctor acted with due care, the committee notifies the doctor of this. No further notification is sent to the Public Prosecution Service. This implies that prosecution cannot occur. The doctor is not liable to punishment. If, however, it appears that a doctor did not comply with the requirements of due care, the case is brought to the attention of the Public Prosecution Service and the Health Care Inspectorate. Both bodies then consider whether the doctor should be prosecuted.

Doctors who have practised due care in their decision making and actions in the specified way do not need to feel criminalized and can admit their actions openly and honestly. The consultation of another doctor prior to euthanasia and the review method afterwards are important guarantees of the protection of the patient who has made a voluntary request to have his life terminated. The doctor is under no obligation to respond to a request for euthanasia and a patient has no entitlement to euthanasia. Furthermore, other care providers, such as nurses and care workers, can never be compelled to assist the doctor in respect of euthanasia in any way whatsoever.
The option of rejecting a request for euthanasia or assisted suicide guarantees that the doctor never needs to act in conflict with his own standards and values. In other words euthanasia does not come under a doctor’s duty to provide care. In practice the option of euthanasia is moreover not available in all Dutch care institutions. For example, no cooperation in regard to euthanasia is provided in a number of hospices and some of the hospice units in nursing homes and care homes.

- Reports
Last year the five Regional Euthanasia Review Committees received 2054 reports of the termination of life on request and assisted suicide. Of these, 1819 retailed to euthanasia, 191 related to assisted suicide and 44 related to a combination of the two. These figures are taken from the 2001 annual report of the Regional Euthanasia Review Committees (33). The review committees concluded in almost all cases that the doctor had acted with due care. Doctors had to provide the committees with additional information in writing or verbally in a number of cases. The number of reports in 2001 was slightly lower than in 2000 (2123 reports). The reason for this decrease is not clear. An evaluation of the practice and reporting of euthanasia that is currently being carried out is expected to produce, among other things, a better understanding of the reasons for this. This evaluation, which is being conducted by the Free University Amsterdam and the Erasmus University, Rotterdam, on the instructions of the Ministry of Health, Welfare and Sport and the Ministry of Justice, will be completed in 2003. Similar studies were carried out in 1990/1991 and in 1995/1996 (34), and therefore there is the possibility of making comparisons with the situation before the new euthanasia legislation came into effect.

- Euthanasia policy in an international context
In common with virtually all other countries, in the Netherlands euthanasia comes under the Penal Code. According to the law it is forbidden to kill someone, even if that person expressly requests to be killed. The essence of Dutch euthanasia legislation is that there is an exception to this - doctors, and only doctors, may apply euthanasia provided that they comply with a number of requirements of due care stipulated by the law and openly admit that, and why, they acted on a request from a patient for euthanasia. The Netherlands has therefore opted for openness and providing for discussion about questions relating to the end of life, whereby the responsibility for terminating life is borne by the people concerned and the government has a supervisory role.
The Dutch government takes the view that the Termination of Life on Request and Assisted Suicide (Review Procedures) Act does not conflict with the obligation under international law to protect the right to life against its infringement by the government or citizens. This obligation is laid down in the United Nations International Covenant on Civil and Political Rights, the European Convention on Human Rights and elsewhere. The principle underlying the stipulation referred to above is respect for life. The covenants and conventions deprive the government and others of the right to take someone’s life against their will. However, the stipulations concerned are not aimed at maintaining hopeless and unbearable suffering. However, they provide individuals with protection against infringements of their right to life. There is no indication in the text or from legal history as to when an infringement is illegal. A general prohibition in regard to euthanasia cannot be derived from the covenants and conventions. However, the principle underlying the covenants and conventions is ‘respect for life’. Dutch euthanasia legislation is also based on this standard. The application of euthanasia at the voluntary request of a patient is not a form of intentionally taking someone’s life, as referred to in the aforementioned covenant or convention articles. Dutch euthanasia legislation therefore does not conflict with international covenants and conventions in which fundamental human rights are defined. The Dutch government endorses these rights fully, but it does not go so far as to not permit individuals to decide for themselves whether their lives are worth living (35).
5 Conclusions

There is currently a wide range of palliative care services available in the Netherlands. There are opportunities to receive palliative care at home, in nursing homes, care homes, hospitals, independent professionally staffed hospices and volunteer-run hospices. A striking feature of the situation in the Netherlands is that special facilities for terminally ill patients, such as hospices, have only appeared since the beginning of the nineteen-nineties, whereas neighbouring countries had them sooner. This is probably explained by the fact that in the Netherlands general practitioners, nursing home doctors, home care workers and others have always given high priority to care for the dying in addition to providing care for other patients. In the Netherlands there is therefore a relatively large number of options for nursing and care at home, and staff in nursing homes and care homes are becoming progressively better equipped for caring for the dying.

The provision of palliative care in the Netherlands underwent rapid change after 1995 and the range of care services for terminally ill patients expanded substantially. The Ministry of Health, Welfare and Sport initiated many policy measures in recent years in order to stimulate and guide the provision of palliative care in the Netherlands. First and foremost was the stimulation policy that was pursued between 1995 and 2000. It consisted of three mutually complementary trajectories:
1 the ZonMw Palliative Care in the Terminal Phase Programme;
2 the promotion of palliative care by six Centres for the Development of Palliative Care;
3 the encouragement of the integration of hospice facilities in regular health care by the Hospice Care Integration Project Group.

It can be concluded that the ZonMw programme referred to above has resulted in a better understanding of the nature and scale of palliative care and the needs of people in the terminal phase. The Centres for the Development of Palliative Care initiated many research projects and also important projects relating to consultation and training in the palliative care field. The Hospice Care Integration Project Group made a major contribution to cooperation, coordination and network creation between providers of palliative care.

Recent years have been largely characterized by developments and improvements in palliative care. The priority given to this type of care has increased significantly and, thanks in part to all sorts of stimulation measures taken by the Ministry of Health, Welfare and Sport, there have been many
developments and knowledge has increased. The principle underlying all these measures is that in principle good quality palliative care has to be accessible and available to every terminally ill patient and his family. Palliative care therefore should be provided as much as possible by regular generalist care providers, who need to have sufficient options for training and consultation.

Palliative care provision in the Netherlands is currently in a phase when all these improvements need to be given a systematic basis. The measures recently announced by the Ministry of Health, Welfare and Sport, aimed at further network creation, organizing palliative care departments in Comprehensive Cancer Centres and a national support point, are important building blocks for this basis.

This publication has also addressed the policy of the Dutch government on euthanasia. According to Dutch law it is forbidden to kill someone, even if that person requests to be killed. However, there is an exception to this. Doctors treating patients may apply euthanasia provided that they comply with a number of requirements of due care stipulated by law and they have their actions reviewed by a regional independent review committee. The new euthanasia legislation and the openness with which this difficult subject is discussed in the Netherlands are intended to encourage doctors and other care providers to take decisions associated with the end of life with due care.
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>AWBZ</td>
<td>Algemene Wet Bijzondere Ziektekosten [Exceptional Medical Expenses Act]</td>
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<td>CBS</td>
<td>Centraal Bureau voor de Statistiek [Statistics Netherlands]</td>
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<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
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<td>COPZ</td>
<td>Centrum voor Ontwikkeling van Palliatieve Zorg [Centre for the Development of Palliative Care]</td>
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<td>CVTM-regeling</td>
<td>subsidieregeling Coördinatie Vrijwillige Thuiszorg en Mantelzorg [Coordination of Voluntary Care and Home Care Grants Scheme]</td>
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<tr>
<td>IKC</td>
<td>Integraal KankerCentrum [Comprehensive Cancer Centre]</td>
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<td>NPTN</td>
<td>Netwerk Palliatieve Zorg voor Terminale patiënten in Nederland [Palliative Care for Terminal Patients in the Netherlands Network]</td>
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<td>PGB</td>
<td>PersoonsGebonden Budget [client-linked budget]</td>
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<td>PIH</td>
<td>Projectgroep Integratie Hospicezorg [Hospice Care Integration Project Group]</td>
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<td>RIO</td>
<td>Regionaal Indicatie Orgaan [regional indication organization]</td>
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<td>VTZ</td>
<td>Landelijke Stichting Vrijwilligers Terminale Zorg [National Association of Terminal Care Volunteers Trust]</td>
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<td>VWS</td>
<td>(Ministerie van) Volksgezondheid, Welzijn en Sport [(Ministry of) Health, Welfare and Sport]</td>
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<td>ZonMw</td>
<td>ZorgOnderzoek Nederland Medische Wetenschappen [Health Research and Development Council/Medical Sciences]</td>
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<td>Health Insurance in the Netherlands</td>
<td>1E</td>
</tr>
<tr>
<td>The medical Research Involving Human Subjects Act</td>
<td>2</td>
</tr>
<tr>
<td>The Organ Donation Act</td>
<td>3</td>
</tr>
<tr>
<td>Psychiatric Hospitals (Compulsory Admissions) Act</td>
<td>4</td>
</tr>
<tr>
<td>Sport for All Incentives in the Netherlands</td>
<td>5</td>
</tr>
<tr>
<td>Policy spearheads for 2001 and beyond</td>
<td>6</td>
</tr>
<tr>
<td>Health Care, Health Policies and Health Care Reforms in the Netherlands</td>
<td>7</td>
</tr>
<tr>
<td>The Application of Genetics in the Health Care Sector</td>
<td>8</td>
</tr>
<tr>
<td>Modernization of Curative Care, Deliberately and Cautiously Towards Demand-Oriented Care</td>
<td>9</td>
</tr>
<tr>
<td>The Individual Health Care Professions Act</td>
<td>10</td>
</tr>
<tr>
<td>Infectious Diseases Act</td>
<td>11</td>
</tr>
<tr>
<td>The Status of General and University Hospitals</td>
<td>12</td>
</tr>
<tr>
<td>Choosing with Care</td>
<td>13</td>
</tr>
<tr>
<td>The equipping of patients and consumers in a demand driven care sector</td>
<td></td>
</tr>
<tr>
<td>A Question of Demand Outlines of the reform of the health care system in the Netherlands</td>
<td>14E</td>
</tr>
<tr>
<td>Medicines policy in the Netherlands</td>
<td>15</td>
</tr>
<tr>
<td>Palliative care for terminally ill patients in the Netherlands</td>
<td>16</td>
</tr>
<tr>
<td>Medical Examinations in the Netherlands</td>
<td>17</td>
</tr>
<tr>
<td>Drug policy in the Netherlands, Basic principles and enforcement in practice</td>
<td>18</td>
</tr>
</tbody>
</table>
There is a broad range of palliative care available in the Netherlands. There are many options for obtaining palliative care at home. The care that terminally ill patients need can also be provided in nursing homes, care homes, hospitals and hospices. Government policy in this field is one of the reasons for rapid change in the palliative care sector in recent years. Since the middle of the nineteen-nineties the Dutch Ministry of Health, Welfare and Sport has initiated measures aimed at the stimulation and further development of palliative care. This publication gives an insight into these policy measures and their implications for care provision, training and research in the field of palliative care.