



In this new section, European palliative care organisations are invited to explain their goals, express their hopes and voice their concerns

## **NPTN: palliative care comes under the spotlight in the Netherlands**

Palliative and end-of-life care in the Netherlands has blossomed since the 1980s, and the Dutch government has drawn up a National Programme for Palliative Care for 2008–2010. Arianne Brinkman and Jaap Gootjes, from the Netherlands Palliative Care Network for Terminally Ill Patients (NPTN), explain the developments



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The development of palliative care in the Netherlands has boomed in the past 20 years, with the number of hospice facilities increasing from 38 in 1999 to 241 in 2008. The Dutch government has encouraged it through various programmes, and the Netherlands Palliative Care Network for Terminally Ill Patients (NPTN) has played an important role. In 2003, the 8th Congress of the European Association for Palliative Care (EAPC) took place in The Hague, further stimulating palliative care in this country.

### **The start of the hospice movement**

Until the 1980s, most people with severe illness were treated in hospitals and nursing homes. Around this time, Dutch healthcare workers came across the work of Dame Cicely Saunders and this led to the start of the country's hospice movement. The debate about the practice of euthanasia also played an important role. For the Dutch hospice pioneers, the most important motivation was to provide better care for the dying.

In the 1980s, the first 'nearly-home facility' was established in Nieuwkoop. The phrase 'nearly-home facility' refers to the role that the hospice was meant to play: a replacement home for the dying that could be just like their own home.

In a 'nearly-home facility', a doctor provides medical care and home-care nurses come once a day or more for short periods of time to provide nursing care. The 24-hour care is provided by the families and by volunteers. A national volunteer organisation known as the Volunteers Palliative Terminal Care (Vrijwilligers Palliatieve Terminale Zorg/VPTZ), was also set up in the 1980s. The VPTZ volunteers support patients and those close to them in their own homes.

Then, in 1992, two independent 'high-care' hospices opened: the Johannes Hospitium in Vleuten and Hospice Kuria in Amsterdam. They have their own nursing staff and doctors. Their patients often require more medical care than those in the nearly-home facilities. In 1993, the first specialised unit for palliative care in a nursing home, the Antonius IJsselmonde in Rotterdam, was set up. These organisations were unhappy with what they saw as excessive medical or technical dominance in the care of terminally ill patients. A new culture was created, in which dying was not labelled as the final failure of the healthcare system but seen as a normal part of life.

In 1996, the NPTN was founded. Its aim is to stimulate and develop palliative care for terminally ill patients in the Netherlands. From the start, the

**Headquarters of the Dutch parliament in The Hague. The Dutch government has shown increasing interest in palliative care**



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organisation included a number of members from the Dutch health service. This allowed for structural meetings to take place between the hospice organisations and those delivering mainstream healthcare. Since its foundation, the NPTN has been a forum for national support and has organised national exchanges of knowledge through ‘network days’. It is also influential in lobbying government.

## Initial government interest

In the 1990s, the Dutch government began to take an interest in palliative care and initiated:

- ‘Palliative Care in the Terminal Phase’, a programme developed by ZonMw, the Netherlands Organisation for Health Research and Development, which focused on the promotion of expertise, needs planning and structural change
- Centres for the development of palliative care
- The Hospice Care Integration Project group, whose main goal was the integration of hospice facilities into mainstream healthcare.

Based on these programmes, government guidelines were drawn up, which stated that:

- Palliative care should focus on achieving the best possible quality of life for patients, according to the WHO definition of palliative care
- Palliative care should remain, as much as possible, part of mainstream healthcare. General care providers should be supported by, and get advice from, specialised,

multidisciplinary consultation teams

- There should be co-operation within palliative care networks to ensure that care is organised as well as possible
- There should be support, on a national level, by the Agora Foundation (the national point of support for palliative care) and, on a regional level, by the palliative care departments in the Comprehensive Cancer Centres.

## Current government policy

Palliative care remains an important point of focus for government policy. Special attention is given to network development. The government also provides funds for, among other things, financing network co-ordinators, covering co-ordination costs for volunteers, and financing palliative units in nursing and care centres.

### A national programme

The current government gives palliative care a high priority. Together with the national umbrella organisations in palliative care (such as the NPTN, the VPTZ and the Association of High-Care Hospices) and the four academic centres for palliative care research, it has drawn up the National Programme for Palliative Care 2008–2010, which contains a policy framework for palliative care. The development of a national programme also fits in with the wish of the Committee of Ministers of the Council of Europe. The programme is a dynamic work document that offers the

possibility of a phased implementation. It has three themes: first, the organisation and financing of palliative care; second, the improvement of quality of palliative care and transparency; and third, education and advancement of professionalism.

In addition, the current Dutch Secretary of State for Health, Jet Bussemaker, now wants to see:

- A new care model, in which curative and palliative care are either organised simultaneously or interact more
- The strengthening of palliative care at primary care level, close to people in their own homes.

### Extra money made available

For 2008–2010, an extra sum of almost €10 million a year has been made available for palliative care. These funds are meant to subsidise terminal palliative care, to pay for the accommodation costs in nearly-home facilities and high-care hospices, and to improve the quality of palliative care.

### The role of the NPTN

Today, the NPTN has more than 100 members and hopes to contribute to the further development of palliative care in the Netherlands. In addition, it is the point of reference for the government. The NPTN works together with the Agora Foundation, the national point of support for palliative terminal care.

### Putting palliative care in the spotlight

The original aim of the NPTN, to ‘put palliative care in the spotlight’, has been achieved. At local level, palliative care networks have been set up

throughout the country. At regional level, there are now palliative care departments in all the Comprehensive Cancer Centres. At national level, we have the Agora Foundation, the national institute for information and stimulation of palliative care, which was formerly part of the NPTN but now functions separately.

It is of great importance that, at a national level, the common interests of palliative care are represented, with the aim of promoting the position of palliative terminal care within the general healthcare framework.

### Four projects to go ahead

As part of the National Programme for Palliative Care drawn up by the Department of Health, the NPTN has put forward four proposals for projects aiming to:

- Investigate the public’s familiarity with palliative care, as part of an international day of palliative care
- Support carers
- Promote the early detection of palliative patients in the home setting
- Promote bereavement care.

All four proposals have been accepted.

The NPTN is pleased that palliative care remains an important spearhead of government policy and will continue to devote itself to the improvement of palliative care in the Netherlands.

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Hospice Kuria in Amsterdam, one of the two independent ‘high-care’ hospices that opened in 1992