In institutionalised palliative care, Jozefa de Buysscher, better known as Sister Leontine, founded, in 1990, the first palliative care unit. It was a residential unit of 12 beds at the St Jan Hospital in Brussels. Others would soon follow.

Setting up palliative care networks

In 1991, the Belgian federal government decided to recognise and subsidise certain palliative care initiatives. In 1996, 25 pluralist palliative care networks covering the whole of Belgium were recognised and funded by the regional and federal governments. The aim of these networks is to support the development of palliative care in their geographic areas. This is translated by these governments into a set of concrete tasks.

A palliative care network has to:

- Inform the public on what palliative care is and what it can offer
- Cooperate with the different palliative care partners in its area and promote co-operation between them
- Educate and train healthcare professionals
- Organise and support volunteer work
- Collect facts and figures regarding palliative care in its area.

Setting up these networks was a major step in palliative care development in Flanders (and in Belgium as a whole), as they helped bring together and co-ordinate separate initiatives.

This article focuses on palliative care in Flanders, the Dutch-speaking, northern part of Belgium. The history, developments and challenges described partly apply to the rest of the country as well, certainly to the Brussels region. As far as the relationship between palliative care and euthanasia is concerned, the article does probably not apply to the same extent to Wallonia, the southern, French-speaking part of Belgium.

The early years

Palliative care in Flanders started in the 1980s when volunteers initiated palliative care projects, both in home care and institutionalised care.1

One of the home care pioneers was Lisette Custermans, who founded Omega, a not-for-profit organisation with the aim of providing care and support to patients at home. Arsène Mullie, former anaesthesiologist at the AZ St Jan Hospital in Bruges and Honorary President of the Federatie Palliatieve Zorg Vlaanderen (Federation of Palliative Care Flanders [FPCF]) also played an important role; in 1987, in the north of Flanders, he created a team providing what was, in those days, called ‘intensive care’ (and later became ‘palliative care’) delivered in patients’ homes. These pioneers, inspired by the work of Dame Cicely Saunders in England, were driven by the fact that roughly 70% of palliative patients died in an institution even though most wanted to die at home.

In 2010, Belgium was rated fifth best country worldwide regarding the ‘quality of death’. So has palliative care attained all its goals? Not quite. In Flanders, like in other parts of the country, many challenges remain. The Federation of Palliative Care Flanders tells us more.
**Important legislative changes**

In 2002, the Belgian parliament passed a law which states that palliative care should be equally accessible to all patients who need it, and formalises the government’s responsibility in providing the necessary funds to make this possible. Another law passed in 2002, concerning the rights of patients in general, has important implications for the way healthcare professionals work: it defines patient rights such as the right to information concerning one’s health status, the right to consent to or refuse an operation or treatment, and the right not to be informed. This law enables patients to actively participate in their own care.

These two laws coincided in time with the moment when the idea of advance care planning (ACP) reached Flanders via the Anglo-Saxon literature. In 2009, the FPCF took the initiative of integrating ACP into the region’s palliative care services. It organised a conference bringing together all ACP initiatives in Flanders (the conference was entitled ‘Giving the end of life back to people – On the advance planning of care’). It also launched a website dedicated to ACP, which offers downloadable brochures and documents.

The 2005 law on volunteer work is worth mentioning as well, since volunteers have always played (and still play) an important role in palliative care. This law provides volunteers and volunteer organisations with a clear legal status.

**The 2002 law on euthanasia**

In 2002, a law decriminalising euthanasia was passed in Belgium. It defines euthanasia as ‘the intentional termination of the life of another person at his/her request’.³

At first a substantial part of the Belgian palliative care community was extremely reticent to become involved in euthanasia. Vanden Berghe et al mention two important reasons for this.⁴

First, there is the radical nature of the act of euthanasia, which is (or was) considered contrary to the inspiration and mission of healthcare professionals. Second, the widespread opinion at the time was that optimal palliative care, including a thorough clarification of patients’ requests, eliminates the reasons patients may have for requesting euthanasia.

Today the situation is quite different: palliative care professionals in Flanders are now practising ‘euthanasia accompaniment’, supporting people who request euthanasia in all aspects of care. This includes ‘clarification of the request, communication with the family, consideration of other possibilities, medical and other assistance if euthanasia is performed, and support of the team afterwards’.⁴ Recent research shows that, in the first half of 2013, palliative care services were involved in 73.7% of all cases of euthanasia. It is important to stress that, with regards to euthanasia accompaniment, each professional’s personal decision regarding their degree of involvement is respected.

From the start, the FPCF has played a major role in the reflection on how the palliative care movement should or could relate to euthanasia. For a more detailed discussion on how euthanasia became ‘embedded’ in Flemish palliative care and the questions this raises, we refer to Vanden Berghe et al.⁴

**Where are we today?**

A data collection supervised by the Flemish government revealed that one in two people who died of non-sudden death in Flanders during the period 2008–2012 received support from specialist palliative care professionals.⁶ These professionals can be located in mobile teams providing care at home, palliative support teams in hospitals (there is one in every hospital), palliative care units, or palliative services in homes for the elderly. Palliative care services have been established in most settings, and are formally recognised and funded by the Flemish and/or Belgian government.

In 2010, Belgium took fifth place worldwide in the quality of death index of the Economist Intelligence Unit.⁷ So is our mission accomplished? Not quite … Despite all the efforts and good intentions of both formal and informal carers, there is still a lot of inappropriate care, and too many patients in the last phase of life do not get the support they need. We as a society can do better. The FPCF is playing its part in reflecting on the challenges ahead, and has issued a ‘vision statement’ outlining six areas where we would like to have improved palliative care in Flanders by 2020.⁸
The challenges ahead

Palliative care for all who need it

Palliative care should not be limited to cancer patients. Patients with other diagnoses, such as heart or kidney failure, respiratory disease and neurological disorders, as well as frail and elderly patients, need it as well. Other groups also need support: patients with cognitive or other impairment, patients of non-European origin, psychiatric patients, deprived patients and, last but not least, children – children with a life-limiting illness and children confronted with death and dying. One of the challenges lying ahead of us will be to provide specialised palliative care to all those patient groups.

Connectedness

In a context of increasing specialisation, it is a challenge for palliative care professionals to stay connected with their own team members, members from other teams, and others who contribute to patient care (GPs, volunteers, informal carers and so on). Connectedness with a patient’s family and/or friends is also crucial. Finally, it is important to stay connected with oneself: more initiatives (for example, supervision or coaching) need to be taken in the different palliative care settings to support and inspire palliative care professionals.

Care in diversity

There is concern that the use of standardised instruments – such as declarations of will, pain scales and care pathways – can jeopardise a customised palliative care service. Palliative care should not adopt a ‘one size fits all’ approach but help the patient write a unique ending to a unique life story.

Continuity of care

The transmission of relevant information and sharing of knowledge, not only within one setting but also between settings, is crucial to continuity of care. This presents us with a challenge, in a healthcare system where patients are often being transferred between settings.

Professional anchoring

Further efforts are needed to make palliative care even more effective and efficient. In modern healthcare, effectiveness is guaranteed by research evidence, applied in daily practice through guidelines and pathways. Evidence-based palliative care is situated in a triangle between research, education and care. Each of these components needs to be reinforced and the interface between them needs to be enhanced. Of particular interest is the spiritual dimension of palliative care, a domain that remains poorly understood.

It is essential that palliative care is structurally embedded into existing services, that existing structures are reinforced and that new ones are created, if and only if, they are really necessary.

A changing ethical landscape

Since 2002, a considerable amount of discussion on ethical issues at the end of life has taken place at a broad societal level, with all actors of healthcare. However, many questions remain unanswered. How do we foster ethical sensitivity? How do we protect the core palliative care values in a rapidly changing ethical landscape?

Conclusion

Beyond the challenges described above, there is a more general financial concern. More and more people need palliative care, partly because the population is aging. The introduction of ACP and euthanasia accompaniment, the earlier detection of palliative care needs, and the extension of care to different patient groups have significantly increased the workload in all settings. If the government really wants palliative care to be equally accessible to all patients who need it, and for palliative care in Flanders to improve further, the funding mechanisms will need to be revised.

References

2. www.delaatstereis.be [in Dutch] (last accessed 26/05/2015)

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