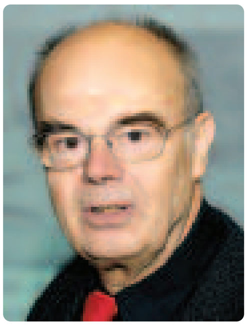
EUROPEAN *insight*

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

DGP: Germany aims to offer specialist palliative care to all who need it

Since 1994, when the Deutsche Gesellschaft für Palliativmedizin (DGP, the German Association for Palliative Medicine) was founded, palliative care in Germany has come a long way. It has overcome multiprofessional and interdisciplinary challenges and set priorities for care that offer an alternative to assisted suicide



Christof Müller-Busch, President, DGP

Palliative care in Germany got off to a rather difficult start. In 1971, when the film *16 Days Left. A Hospital for the Dying in London* (a documentary film about St Christopher's Hospice) was shown on German television, it led to many disputes and misunderstandings about the kind, and the setting, of end-of-life care. The health and social services as well as the churches were sceptical about palliative care and a public debate began about the ethical value of *Sterbekliniken* – the German translation of 'hospitals for the dying'. Opponents saw them as 'special ghettoes for the dying', while others recognised the need for more attention to be paid to people at the end of life. It was not until 1983 that the first inpatient palliative care unit opened, in Cologne, and it still took some time from then until palliative care was recognised as a specific discipline in healthcare – in 2003, by the German Medical Assembly.

Since 1994, when the Deutsche Gesellschaft für Palliativmedizin (DGP, the German Association for Palliative Medicine) was founded, palliative care has increasingly attracted professional and public attention. Initially, it was offered mainly to hospital inpatients suffering from cancer, but, over the past 15 years, it has been extended to outpatients and those with life-limiting diseases other than cancer. There are now more than 350 palliative care units and inpatient hospices in Germany, about 60 outpatient palliative care services, and 1,500 outpatient hospice services.[1] More than 10,000 nurses have had further training in palliative care and more than 3,000 physicians have achieved an additional qualification in it.[2] Five universities have established chairs for palliative medicine and, thanks to the support of Deutsche Krebshilfe (the non-profit organisation German Cancer Aid), at least four further chairs are to be created. In 2011, palliative care will become a compulsory part of medical education and will be included in the final exams.

Hospital care and hospice care

One of the characteristics of German palliative care is the differentiation beween inpatient care in hospitals and inpatient care in hospices.

Hospitals provide specialised care in palliative care units that is financed by state health insurance. Their aim is to discharge patients as soon as symptom control is achieved and social support is secured, thus enabling them to remain as long as possible in a different setting; for example, at home or in a care home.

Hospices have structures that are independent from hospitals and are financed by a mix of health

and long-term care insurance, donations and contributions from patients. Medical care in inpatient hospices is provided by GPs.

More than 60,000 voluntary hospice workers provide psychosocial support for terminally ill patients and their families. Their work has been important in raising public awareness of the problems in end-of-life care provision. Since 2001, voluntary hospice workers have been supported by qualified staff, who are paid by the state.

Debate around assisted suicide

There is still a long way to go before palliative care is available to all who need it, but the importance of a comprehensive palliative care system is now widely accepted by decision-makers, medical bodies, public organisations and the media.

The fact that it is now seen as a high priority is not only a result of demographic changes, but also a response to the increasing debate throughout Europe on euthanasia and assisted suicide. In Germany, the provision of good palliative care and social support is seen by many as an important step, both in decreasing intolerable suffering at the end of life and in offering alternatives to requests for the wilful causation of death by assisted suicide as part of the medical service.[3]

In 2002, the health ministers' conference of the federal Länder in Germany adopted a resolution on 'dying with dignity' that voiced concerns about euthanasia and contributed to greater public awareness of the debate around it. Its view was that hospice and palliative care should be provided nationwide as a humane alternative to euthanasia and assisted suicide, and that comprehensive palliative care services should be developed to meet the increasing demand of severely ill people who wish to stay at home in the final days of life.

A further milestone was reached in 2005 with the parliamentary report *Improvement of care of the dying by palliative medicine and hospice care*.[4] As a consequence of this report, a law was enacted in 2007 that entitles patients with advanced disease to receive specialised palliative care in an outpatient setting (*Spezielle Ambulante PalliativVersorgung*, SAPV). It has been estimated that 80,000–100,000 people (around 10–12% of the 840,000 who die each year in Germany) need such care because they suffer from terminal illness with complex medical and psychosocial problems.

SAPV will be offered by specialised, multiprofessional palliative care teams (PCTs). The cost for one of those PCTs is €250,000 million a year. This has been earmarked in addition to the regular health budget. In contrast to general

After successful pain therapy in palliative care, this patient, who had widespread prostate cancer, said: 'Before, I was prepared to commit suicide, but now waiting for death is donated time'

palliative care, provided by GPs, PCTs will offer services that range from partial to full specialised palliative care, including counselling, co-ordination and support care.

Several pilot projects of specialised, multiprofesssional PCTs have been launched over the past few years; this year, the first PCT became operational within the new SAPV framework. It is estimated that 330–350 PCTs will be required to cover the entire country.[5]

Apart from coverage, another important issue in palliative care is the development of a broadly accepted evaluation system for quality management. An evaluation system with different modules has been developed in Germany for the regular monitoring of structure, processes and outcomes in different care settings. More than 100 hospital and hospice palliative care units monitor a representative sample of patients every year. This provides general information on the delivery of palliative care and enables benchmarking of the participating institutions. To date, the evaluations cover more than 15,000 datasets of patients in different settings.

A 'Charter for terminally ill and dying patients in Germany'

There is still a need for greater recognition of palliative care. One of the goals of the future 'Charter for terminally ill and dying patients in Germany' will be to give it a higher priority on the health policy agenda. This charter will be the result of a consensus process initiated by the DGP in 2008, as part of the Budapest Commitments, in partnership with the German Union for Hospice and Palliative Care and the German Medical Assembly; 150 experts from more than 50 organisations have joined five working groups, each working on a different theme. These are:

- The challenges for society – ethics, law and public communication
- Unmet needs – consequences for healthcare structures
- Qualification of professionals and volunteers – training and education
- Future perspectives and research
- Learning from experience – the international dimension.

First results from the working groups will be presented at an international conference in autumn 2010. One of the challenges is what response will be given to demographic changes, as well as to the increased awareness of the palliative care needs of elderly and severely ill people (people with dementia, with chronic pulmonary or chronic heart disease, and so on). The DGP is convinced that a better quality of life can be achieved in all situations, without having to resort to 'society-compatible shortening of life' (as euthanasia or assisted suicide has been called by some in Germany in recent years – a term that has caused more controversy).

Palliative medicine in Germany is based on the idea that *aktive Sterbehilfe* (the German term for voluntary euthanasia or assisted suicide, which literally means proactively helping someone to die) becomes redundant if all efforts are concentrated on *aktive Lebenshilfe* (that is, proactively helping someone to live). Nevertheless, the terms *Sterbehilfe* and *Lebenshilfe* are rather unprecise and can lead to a misunderstanding of the kind of help that is needed – and morally acceptable – for patients with terminal illness nearing death. The DGP has clearly stated that palliative care will play no part in euthanasia or assisted suicide, because voluntarily causing death cannot be considered a therapeutic act.

Further integration of palliative care into the healthcare system (for example, by training GPs, extending the country's coverage by PCTs and counselling services, training nursing home staff, training volunteers, and especially developing networks that overcome boundaries and integrate different palliative care providers) is not only a challenge for health policy, but for society as a whole. The palliative care and hospice movement serves as an indicator of how society deals with death and dying, and of how much it values a healthcare system that cares for people at these important moments in their lives.

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