

Germany has adopted a charter for the care of the critically ill and the dying

BY FRIEDEMANN NAUCK, KARIN DLUBIS-MERTENS

In September 2008, the Deutsche Gesellschaft für Palliativmedizin (DGP – German association for palliative medicine), the Deutscher Hospiz- und Palliativverband (DHPV – German hospice and palliative association) and the Bundesärztekammer (BÄK – German medical association) jointly initiated a project focused on needs of the dying, which was funded by the Robert Bosch-Stiftung (Robert Bosch Foundation) and German cancer aid (Deutsche Krebshilfe e.V.).

Two years later, after an intensive work process, the *Charter for the care of the critically ill and the dying in Germany* was consensually approved, on 17 August 2010, by 50 relevant healthcare and sociopolitical institutions and organisations, and then made public in Berlin on 8 September 2010.^{1,2}

This charter is Germany's contribution to the Budapest Commitments, a European and international framework for palliative care development.^{3,4} The Budapest Commitments were launched at the 10th Congress of the European Association for Palliative Care in 2007 in Budapest. They provide a framework and incentive for countries who commit to foster palliative care at their national level. Twenty-one countries have signed up to the Budapest Commitments and/or have been taking action so far.³

The *Charter for the care of the critically ill and the dying in Germany* contains five key principles pertaining to the following areas:

- > Ethics, the law and public debate
- > Organisation of care/needs of patients and families
- > Training and education of professionals
- > Future development and research
- > European and international dimension.

The charter's five key principles are outlined in Box 1. They are much more extensively described in the actual charter itself, which comprises 27 pages in total and is structured around an analysis of the current situation and a definition of medium- and long-term objectives. The charter and the key principles stress the need for further research, and state that the care of the critically ill and the dying in Germany must match European standards and best practice.⁵⁻⁷



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Abstract

ANNAHME DER CHARTA FÜR SCHWERSTKRANKE UND STERBENDE MENSCHEN IN DEUTSCHLAND

Die »Charta zur Betreuung schwerstkranker und sterbender Menschen in Deutschland« wurde im Konsens von über 50 am Runden Tisch beteiligten Institutionen im Sommer 2010 verabschiedet und der Öffentlichkeit präsentiert. Die Bedürfnisse und Rechte schwerstkranker und sterbender Menschen standen im Mittelpunkt dieses intensiven Arbeitsprozesses, den die Deutsche Gesellschaft für Palliativmedizin (DGP), der Deutsche Hospiz- und Palliativverband (DHPV) und die Bundesärztekammer (BÄK) gemeinschaftlich im September 2008 in Gang gesetzt haben und – auch dank der Förderung der Robert Bosch Stiftung und der Deutschen Krebshilfe – im Zeitraum von zwei Jahren zum Konsens führen konnten.

In fünf Leitsätzen und deren Erläuterungen zeigt die Charta gesellschaftspolitische Herausforderungen auf, benennt Anforderungen an die Versorgungsstrukturen und die Aus-, Weiter- und Fortbildung, skizziert Entwicklungsperspektiven für die Forschung und misst den Stand der Betreuung schwerstkranker Menschen in Deutschland an europäischen Maßstäben. Die Bestandsaufnahme in allen fünf Bereichen wurde verknüpft mit der Definition der jeweiligen mittel- und langfristigen Ziele.

Die Charta stellt den deutschen Beitrag zu den beim Kongress der European Association for Palliative Care (EAPC) 2007 international vereinbarten Budapest Commitments dar, an der sich Anfang 2011 bereits 21 Länder beteiligten.



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BOX 1

The five key principles of the Charter for the care of the critically ill and the dying in Germany

1. ETHICS, THE LAW AND PUBLIC DEBATE

All human beings have a right to a dignified death. They must be sure that they will be respected in the last phase of life with regard to their preferences, wishes and values, and that all decisions will be made according to their wishes. Care by family, professionals and volunteers should work towards this goal.

Dying with dignity very much depends on the way humans live together. This is deeply influenced by societal values and social conditions, which are reflected in legal regulations.

We will take action to facilitate dying with dignity and to ensure that efforts to legalise assisted suicide are balanced by a perspective of care and support. Society must attach value to the idea that dying is part of life.

2. ORGANISATION OF CARE/NEEDS OF PATIENTS AND FAMILIES

All critically ill and dying people have a right to comprehensive medical, nursing, psychosocial and spiritual care that takes into account their individual situation and palliative/hospice care needs. Relatives and close friends are part of the unit of care. Care is given by professionals and volunteers for as long as possible in the patient's own home or other place of choice. To achieve this goal, all carers have to work closely together.

We will take action to further develop a high-quality network of healthcare structures. All patients in need, in-

dependent of their age or the nature of their disease, shall have access to the necessary structures.

All relevant healthcare structures must form a network in order to ensure continuity of care.

3. TRAINING AND EDUCATION OF PROFESSIONALS

All critically ill and dying people have a right to appropriate and qualified multiprofessional care, if required. To make this possible, all professionals involved in the care of the critically ill must have the possibility to participate in further training in order to obtain the necessary knowledge, skills and attitude. The latter includes the willingness to reflect on one's own mortality and on ethical and spiritual matters. Curricula must be regularly updated to reflect international advances in the field.

We will take action to ensure that care of the critically ill and the dying is integrated in all relevant curricula (in education, further education and continuing education) in a comprehensive and elaborate manner.

4. FUTURE DEVELOPMENT AND RESEARCH

All critically ill and dying people have a right to care based on best practice. To ensure this, new knowledge derived from research and innovative practice models must be shared and integrated into clinical routine, provided ethical and legal regulations are respected.

To achieve this aim, the general conditions under which research in this field can take place must be improved, in particular research structures and the funding of research and innovative practice models. Furthermore, topics of research need to be identified, and research methods and strategies relevant to the care of dying patients need to be further developed.

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DRAFTING AND ADOPTING THE CHARTER:**AN INTENSIVE WORK PROCESS**

At the start of the process, five workgroups were set up to deal with the five key principles. More than 150 experts, including two speakers, were involved in the workgroups for more than a year.

The work process comprised several meetings of the five workgroups, six roundtables, regular telephone conferences and steering groups sessions, as well as a one-day final conference of the editorial team.

The charter was based on the extensive production of the five workgroups and discussed at the final roundtable with representatives of 50 relevant healthcare and sociopolitical institutions and organisations; it was eventually adopted by consensus in August 2010.

The tight time schedule was a major challenge and the drafting and discussion process had to be extremely focused. The collaborative development of the charter demanded high levels of communication, cooperation, discipline and commitment from all those involved; that is, some 200 people in total.

SOME QUESTIONS THE PARTICIPANTS REFLECTED UPON

Some of the questions the participants reflected upon during the work process are outlined below.

What does end-of-life care require to allow a dignified death? How can we ensure that decisions regarding treatment and care respect a critically ill person's wishes and values?

Can every person with a life-limiting illness in Germany count on receiving comprehensive medical, nursing, psychosocial and spiritual care if they require it? How do we include family and friends?

We will take action to further develop interdisciplinary research and ensure that research results are integrated efficiently into clinical routine. By doing this, the care of the dying and their families will continuously be improved.

5. EUROPEAN AND INTERNATIONAL DIMENSION

All critically ill and dying people have a right to benefit from care that takes into account internationally recognised and adopted recommendations and standards regarding the delivery of palliative care. In this context, a national strategy is needed that must be worked out consensually and supported by all stakeholders.

We will take action to improve the international networking of all German clinical and research organisations in this field, and we will support a continuous and systematic exchange with other countries. We want to learn from their experience and exchange ideas and initiatives.

KEY POINTS

In September 2010, the *Charter for the care of the critically ill and the dying in Germany* was officially launched in Berlin. It is Germany's contribution to the Budapest Commitments.

The drafting and approval of the charter was an intensive process that involved 150 experts as well as representatives from 50 healthcare and sociopolitical organisations, and demanded high levels of commitment from all participants.

The charter contains five key principles pertaining to the areas of ethics, standards of care, training and education of professionals, research, and international networking.

It is hoped that the charter will be a starting point to a public debate on matters of death, dying and bereavement.

The professionals involved in the care of critically ill patients may not be able to cure, but they can provide relief of pain and of other distressing symptoms, nurse patients and support their families. How can we give them adequate education and training to ensure that they are able to provide the best possible care?

How can we ensure that every critically ill and dying person in Germany will be treated and cared for according to best practice in palliative care?

About half a year after the adoption of the charter, there is evidence that it has been successful in promoting the public debate on the care for the critically ill and the dying in Germany. In May 2011, 333 organisations and healthcare services, as well as numerous individuals, had signed the charter, thus stating that they will support its objectives and stand up for the rights of the critically ill and the dying.

About 25,000 copies of the charter have been ordered for display in healthcare services or during events, as educational material for palliative care courses or primary and secondary schools, and as an incentive for regional initiatives in the field of palliative care. The media coverage and the number of people visiting the charter's website reflect a broad public interest.

We think that the charter can be a starting point to talk about matters of death, dying and bereavement. Its opening sentence reads: 'Every human being has a right to die a dignified death'. Now that the charter has been adopted and distributed, and a comprehensive list of goals has been defined, the signatories must take concrete action to put it into practice.

For more information about the German charter, visit the website: www.charta-zur-betreuung-sterbender.de ■

Declaration of interest: The authors declare that there is no conflict of interest.

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