Council of Europe

Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care,

Adopted by the Committee of Ministers on 12 November 2003

at the 860th meeting of the Ministers' Deputies

The Committee of Ministers, under the terms of Article 15.*b* of the Statute of the Council of Europe,

Considering that the aim of the Council of Europe is to achieve greater unity between its members and that this aim may be pursued, *inter alia*, by the adoption of common rules in the health field;

Recalling Article 11 of the European Social Charter on the right to health protection, and recalling that Article 3 of the Convention on Human Rights and Biomedicine (ETS No.164) requires that contracting parties provide equitable access to health care of appropriate quality, that Article 4 requests that any intervention in the health field, including research, must be carried out in accordance with relevant professional obligations and standards, and that Article 10 emphasises the right of everyone to know any information about his or her health;

Recognising that a health care system should be patient-oriented and that citizens should necessarily participate in decisions regarding their health care;

Recalling in this context the recommendation of the Committee of Ministers to member states, Recommendation No. R (2000) 5 on the development of structures for citizen and patient participation in the decision-making process affecting health care;

Convinced that the respect and protection of the dignity of a terminally ill or a dying person implies above all the provision of appropriate care in a suitable environment, enabling him or her to die with dignity;

Recalling in this context Recommendation 1418 (1999) of the Parliamentary Assembly on protection of the human rights and dignity of the terminally ill and the dying;

Further recalling Recommendation No. R (89) 13, on the organisation of multidisciplinary care for cancer patients;

Recognising that palliative care needs to be further developed in European countries;

Recalling in this respect the 1998 Poznan Declaration on palliative care in Eastern Europe;

Recognising that the right to health care is aimed at the patient's enjoyment of the highest attainable sense of well-being, irrespective of age, ethnicity, economic or social status, and the nature of any disease or infirmity;

Considering that there is a growing number of people in need of palliative care;

Considering that the differences in the availability and quality of palliative care throughout Europe need to be addressed through increased co-operation between countries;

Conscious that palliative care is the active, total care of patients with advanced, progressive diseases, aiming at the control of pain and other symptoms, and offering psychological, social, and spiritual support;

Aware that the goal of palliative care is the achievement of the best possible quality of life for patients and their families;

Aware that palliative care aims to help men, women and children with advanced, progressive diseases to enjoy the best possible quality of life until the end, and intends neither to hasten nor postpone death;

Considering that palliative care affirms life and regards dying as a normal process, and is not guided by hopelessness or fatalism;

Considering that palliative care is an integral part of the health care system and an inalienable element of a citizen's right to health care, and that therefore it is a responsibility of the government to guarantee that palliative care is available to all who need it;

Considering that it is necessary to pursue the development of quality care, carried out humanely, in order to make it an essential part of health care for patients near the end of life;

Recognising that all people near the end of life desire to be treated as valued persons by health care professionals and to have skilled attention directed at maintaining dignity and fostering independence, relieving symptoms and maximising comfort;

Recognising that palliative care, like all medical care, should be patient-oriented, guided by the needs of the patient, taking into account his or her values and preferences, and that dignity and autonomy are central issues for patients in need of palliative care,

Recommends that the governments of member states:

1. adopt policies, legislative and other measures necessary for a coherent and comprehensive national policy framework for palliative care;
2. take to this end, whenever feasible, the measures presented in the appendix to this recommendation, taking account of their respective national circumstances;
3. promote international networking between organisations, research institutions and other agencies that are active in the palliative care field;
4. support an active, targeted dissemination of this recommendation and its explanatory memorandum, where appropriate accompanied by a translation.

Appendix to Recommendation Rec(2003)24

General considerations

While in many countries the greater part of health care budgets is spent on people in their final years of life, they do not always receive the care that is most appropriate to their needs.

Palliative care does not address a specific disease and spans the period from the diagnosis of advanced disease until the end of bereavement; this may vary from years to weeks or (rarely) days. It is not synonymous with terminal care, but encompasses it.

The creation, in member states, of a climate in which the importance of palliative care is recognised is crucial.

The public, including patients and their families, needs to be educated regarding the importance of palliative care, and of what it can offer.

Several recent studies, providing data in a total of thirty-five countries across Europe, have pointed out differences between countries with regard to palliative care, among which are variations in reimbursement (where applicable), in health care system organisation and in the place of palliative care within it; differing ethical and cultural factors; the role of national organisations, and international collaboration in palliative care development; opioid availability; and questions of workforce training and development.

I. Guiding principles

Palliative care policies should be based on values propounded by the Council of Europe: human rights and patients' rights, human dignity, social cohesion, democracy, equity, solidarity, equal gender opportunities, participation and freedom of choice.

Palliative care has the following core dimensions:

- symptom control;
- psychological, spiritual, and emotional support;
- support for the family;
- bereavement support.

The following principles underpin the recommendation:

1. Palliative care is a vital and integral part of health services. Provisions for its development and functional integration should be incorporated into national health strategies.
2. Any person who is in need of palliative care should be able to access it without undue delay, in a setting which is, as far as reasonably feasible, consistent with his or her needs and preferences.
3. Palliative care has as its objective the achievement and maintenance of the best possible quality of life for patients.
4. Palliative care seeks to address physical, psychological and spiritual issues associated with advanced disease. Therefore, it requires a co-ordinated input from a highly-skilled and adequately resourced interdisciplinary and multi-professional team.

5. Acute intervening problems should be treated if the patient so wishes, but should be left untreated, while the best palliative care continues to be provided, if the patient prefers.
6. Access to palliative care should be based on need, and must not be influenced by disease type, geographical location, socio-economic status or other such factors.
7. Programmes of palliative care education should be incorporated into the training of all concerned health care professionals.
8. Research aimed at improving the quality of care should be undertaken. All palliative care interventions should be supported to the greatest possible extent by relevant research data.
9. Palliative care should receive an adequate and equitable level of funding.
10. As in all sectors of medical care, health care providers involved in palliative care should fully respect patients' rights, comply with professional obligations and standards, and, in that context, act in the best interest of the patients.

II. Settings and services

1. Palliative care is an interdisciplinary and multi-professional undertaking which attends to the needs of the patient, while not neglecting the informal caregivers, such as family members.
2. Palliative care services and policies must offer a wide range of resources, such as home care, in-patient care in specific or conventional units, day hospital and out-patient clinics, emergency call-out and respite care facilities. These should be comprehensive and appropriate to the health care system and culture, and should focus on the changing needs and wishes of patients.
3. Informal caregivers should be supported in their caregiving, and should not incur major social setbacks, such as job loss, as a consequence of caregiving. A formal right to "care leave" may be desirable.
4. All professionals involved in the care of patients with advanced, progressive disease should have easy access to specific expertise if and when they need it.
5. Specialist palliative care should be available for all patients when they need it, at any time and in any situation.
6. It should be ensured that there is leadership in the development of palliative care at national level and proper co-ordination of services with a clear allocation of responsibilities. The formation of regional networks is recommended as a good means to reach this goal.
7. Patients should be guaranteed access to palliative care without undue financial barriers. Financial and other arrangements should be such that continuity in palliative care is guaranteed, and is adapted to the needs of the patient.
8. There should be sufficient respite care facilities to offer temporary relief when caregivers in the home become overburdened.

III. Policy and organisation

1. Palliative care must be an integral part of a country's health care system, and as such it must be an element of comprehensive health care plans, and of specific programmes concerning, for instance, cancer, Aids or geriatrics.
2. Governments should have a needs assessment study performed that addresses the need for services, for personnel of different levels of expertise, and for training of different professions (including volunteers).
3. On the basis of a needs assessment, national or regional governments need to design and implement comprehensive rational palliative care strategies in close collaboration with professionals and patients and families, or their representatives.
4. As part of such strategies, governments should identify legal, social, economic, cultural, administrative and/or physical barriers in access to palliative care services. Initiatives and programmes should be implemented in order to reduce such barriers, which often lead to inequalities.
5. Legislation should make opioids and other drugs accessible in a range of formulations and dosages for medical use. The fear of abuse should not hinder access to necessary and effective medication. Countries may wish to consider whether this will require new legislation or an amendment to existing legislation.
6. It is recommended that, both at national and at regional and local level, interdisciplinary focal groups or councils devoted to palliative care involving patients, families and others be constituted in order to maintain political and social attention. Preferably, such groups co-operate with governments and other bodies in putting in place the necessary policies.
7. In order to facilitate the monitoring of the quality of palliative care, the constitution of a uniform "minimum data set" (MDS) is necessary, at least at national level.
8. Because of the importance of equity, special attention should be paid to palliative care for underprivileged groups (for instance, prisoners those with learning disabilities, the homeless, refugees) and to cultural and ethnic differences related to the needs of patients. Equally importantly, special attention should be paid to palliative care for children.
9. Professional caregivers are entitled to a fair remuneration, and to recognition for the work they do and for their competence.
10. A national annual report on organisation and functioning of palliative care should be published.

IV. Quality improvement and research

1. The definition and adoption of indicators of good palliative care assessing all dimensions of care from the perspective of the patient should be encouraged.
2. Clinical practice guidelines for palliative care, based on the best available evidence, should be developed in a systematic way, with the participation of patients.
3. Continuous feedback on practices in the form of an audit is essential to quality control.

4. Even though scientific research in palliative care may pose specifically pressing ethical problems, care services and medical intervention should be evaluated using proven scientific methods, both qualitative and quantitative in nature. The focus of such studies should be patient-related.
5. Collaborative research, both at national and at European level, should be encouraged.
6. An observatory should be set up at national and regional level to collect, process and disseminate reliable information on developments in and quality of palliative care.

V. Education and training

1. Both for research and for education, academic recognition of palliative care is important.
2. Palliative care should be included in all undergraduate training of doctors and nurses. Standard curricula should be established, as well as postgraduate training and education, and there should be training programmes for experts in palliative care.
3. International co-operation on education should be encouraged, for example by establishing a directory of palliative care units wishing to participate in twinning programmes.
4. All professionals and non-professionals involved in palliative care should be trained appropriately for their task; they should receive at all levels of training concrete, insightful and culturally sensitive instruction in palliative care.
5. Education in palliative care should be both monodisciplinary and interdisciplinary.
6. Education in palliative care should be regularly followed up, for instance in the form of supervision.
7. Centres of reference should be set up in each country for teaching and training in palliative care.
8. Ideally, there should be the following three levels of (continuing) education for professionals: basic, intermediary and advanced education.
9. It is recommended that countries devote specific attention to educating the general public about all relevant aspects of palliative care.
10. The unjustified negative images concerning opioids among patients, families, professionals and the public should be corrected, with the essential differences between the clinical applications and the potential for abuse being stressed, both in public campaigns and professional education.

VI. The family

1. The aim and the principle, in helping those close to patients (principally family members), are to put to good use and to develop their ability to bring emotional and practical support to patients, to adapt to the process, and to cope with grief and loss. Particular attention must be paid to the prevention of and the treatment of depression from exhaustion.

VII. Communicating with patient and family

1. Palliative care demands a climate, an attitude and a caregiver-patient relationship which encourage openness in information to patients and families.
2. Professionals should take into account the extent to which patients wish to be informed about their situation; in this regard, attention should be paid to cultural differences.
3. Professionals should adapt the way in which they give information to patients to the emotional or cognitive barriers that are often associated with having an advanced and progressive illness.
4. Where children are involved, either because of their own illness or because of the illness of a parent, communication should be adapted to their needs.

VIII. Teams, teamwork and care planning

1. Palliative care is an interdisciplinary and multiprofessional undertaking, most often involving a physician and a nurse and other health care workers who have the expertise needed to respond to the physical, psychological, and spiritual needs of the patient and the family. The functioning of such teams should be facilitated.
2. Decision-making, especially the making, monitoring and regular reviewing of individual anticipatory care plans, should be shared between the patient, the family and the team, whenever this is appropriate, and complies fully with the patients' wishes. Appropriate communication between the various services involved (curative and palliative) should be ensured.
3. Volunteers can be an important part of the team. They do not take over the work of professionals, but have their own contribution and expertise. The setting-up of volunteer services, and the process of becoming a volunteer, should be facilitated.
4. All team members should be competent in their roles and aware of the possibilities and limitations of both their own role and that of the other members.
5. Receiving coherent messages from different care providers is crucial for the patient and the family. Therefore, optimal information flows between care providers are essential in order to avoid misunderstandings or discrepancies. It is advisable to establish a leading co-ordinator, preferably, depending on circumstances, the primary physician.
6. All communication between professionals concerning patients and families is subject to professional secrecy, fully respecting the patient's right to medical secrecy and the families' right to privacy.
7. Palliative care is usually very rewarding, but equally it can be very demanding. Therefore, caring for the caregivers is an essential part of palliative care, and the occupational health of those working in palliative care should be a focus of policies.

IX. Bereavement

1. Bereavement care services should be offered to those who are in need of support.
2. All professional workers in palliative care should be attentive to signs of complicated or disturbed bereavement.