

Organisation of palliative care

Recommendation no. R (03) 24
adopted by the Committee of Ministers
of the Council of Europe
on 12 November 2003
and explanatory memorandum

Contents

	Page
Preface	5
Introduction	10
Recommendation Rec(2003)24	11
Appendix to Recommendation Rec(2003)24	14
I. Guiding principles	15
II. Settings and services	16
III. Policy and organisation	18
IV. Quality and improvement research	19
V. Education and training	20
VI. The family	21
VII. Communication with patient and family	21
VIII. Teams, teamwork and care planning	22
IX. Bereavement	23
Explanatory Memorandum	25
Introduction	25

Brief Historical Overview	26
Some data on palliative care in European countries	30
Definitions and core principles	36
Settings and services	49
Policy and organisation	60
Quality improvement and research	65
Education and training of professionals and volunteers	71
Communication	73
Teams, teamwork and care planning	77
Volunteers	81
Bereavement	83
Glossary	87
References	92

PREFACE

In ageing European societies, a 20% increase in the need for palliative care is to be expected in the next 10 to 15 years, both for cancer and for non-cancer patients. The rough estimate of the need for palliative care beds is 50-100 per million inhabitants. This poses great challenges, both quantitative and qualitative, for all European countries.

The modern history of palliative care began in 1967, when St. Christopher's Hospice, a pioneer in this area, was founded by Dame Cicely Saunders in London. Since then palliative care has spread all over Europe, despite the challenges, which include scarce resources, poor availability of medical drugs and lack of understanding among the public and health professionals. The idea of palliative care may be new to many people, but it is perhaps one of the oldest medical specialties – care for the vulnerable was a primary task of medieval hospices, when cure was not available. The evidence base has grown, good practice models have been developed and time has come to consolidate the best experience available in Europe.

Inspired by the 1980 Report of the European Health Committee (CDSP) on "Problems related to death: care for the dying" and by the Parliamentary Assembly Recommendation 1418 (1999) on the protection of the human rights and dignity of the terminally-ill and the dying, in 2001 the European Health Committee decided to address the important issue of palliative care at a pan-European level by setting up a committee of experts which, over a two-year period, prepared European guidelines in this field. This was based on the premise that societies should be responsible for the quality of life of their citizens, including the last phase of it.



The committee of experts met four times - 6-7 March 2001, 18-19 October 2001, 26-27 February 2002 and 24-25 October 2002, in Strasbourg,

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I. Introduction

1. Recommendation Rec(2003)24, adopted by the Committee of Ministers on 12 November 2003 at the 860th meeting of the Ministers' Deputies, was prepared by the expert committee on the organisation of palliative care, set up under the authority of the European Health Committee (CDSP). The work of the expert committee was supported by representatives from the WHO, the European Association of Palliative Care and the Palliative Care in Eastern Europe (EAPC) Project
2. This publication contains the text of Recommendation Rec(2000)24 and its explanatory memorandum.
3. The recommendation is available on the Council of Europe site: <https://wcm.coe.int/ViewDoc.jsp?id=67075&Lang=en> (together with the explanatory memorandum) and on the Health Division site: http://www.coe.int/T/E/Social_Cohesion/Health/Recommendations/

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

(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.

EXPLANATORY MEMORANDUM

Introduction

1. Since the beginnings of time, societies have attempted to offer support and comfort to their ill and dying. Commonly, a tremendous reverence and mystique surrounds the dying person. The period following the death is usually characterised by strict adherence to established protocols and ritual. The need to grieve the loss of a loved one is recognised by most societies, although the manifestations of grief and the formal period of mourning will vary from one culture to another.

2. Illness and death are now, and always will be an inevitable and integral part of the human experience. The manner in which we seek to identify and respond to the unique and individual needs of the dying and their families as they cope with progressive loss is a sensitive index of our maturity as a society. Whenever possible, we must prevent illness. When illness develops, we must try to eradicate it or at least retard its progression. In parallel with these efforts, we must offer all patients an optimal level of pain and symptom control, in conjunction with psychological, emotional and spiritual support.

3. The last 2-3 decades, care at the end of life has started to receive the attention it deserves. Specific scientific journals have been started, organisations for both professionals and non-professionals have been set up (such as the European Association for Palliative Care), and national policy recommendations have been published, for instance by the Irish government (National Advisory Committee on Palliative Care 2001) and by the Institute of Medicine in the US (Field and Cassell 1997).

Brief Historical Overview

4. The interface between living and dying is a continuum that exists from birth to death. In living, we are dying; in dying, we have the opportunity for living. Health and social care programmes throughout the world are designed to support individuals, families and communities in achieving and maintaining an optimal quality of life. In the context of palliative care, where life expectancy is evidently limited, the issues become more urgent and immediate as we strive to make the best possible use of all available time.

5. Since the beginnings of time, societies have attempted to offer an appropriate level of care and support to their ill and dying members. However, until the middle of the last century, medical science had little to offer in terms of effective pain management and symptom control. Developments in drug therapies in the 1950s, combined with a greater understanding of the psychosocial and spiritual needs of dying patients, paved the way for the development of palliative care services. The principles of palliative care have become more widely understood and applied during the latter half of the 1900s.

6. In medieval times, the term "hospice" was used to describe a place of shelter for pilgrims and travellers. In Europe, the association between 'hospice' and the care offered to dying patients dates back to work of Mme. Jeanne Garnier in Lyon, France in 1842. In Ireland, the Irish Sisters of Charity, founded by Mother Mary Aikenhead, opened hospices in Dublin and Cork in the 1870's and subsequently in London in 1905. These institutions were closely associated with the care of patients suffering from advanced and incurable disease. However, efforts to control pain and other symptoms were hampered by a lack of

understanding of the nature of these symptoms and further compounded by a lack of effective medications.

7. The 1950's witnessed the introduction of a range of important drugs including psychotropic agents, phenothiazines, antidepressants and non-steroidal anti-inflammatory drugs. Around this time, there was a better understanding of the nature of cancer pain and of the role of opioids in controlling cancer pain. The availability of these new drugs created an opportunity to offer more effective pain and symptom management.

8. In terms of opioid use, there was enormous resistance arising from ill informed and unfounded fears concerning their use. Exaggerated concerns regarding such issues as dependence, addiction, tolerance and respiratory depression hampered their appropriate introduction to medical practice. These fears were shared equally between many members of the medical community and the general public. At governmental level, there often existed significant confusion between the beneficial therapeutic role of these agents and their potential for abuse. In some countries, opioid use was prohibited by legislation. In other countries, opioid use was legalised but their availability was hampered by excessive bureaucracy governing their prescription, storage and dispensing. It is vitally important that we learn from the mistakes of history. There must be no confusion between the appropriate, clinical use of opioid medications and their potential for abuse.

9. The evolution of modern hospice and palliative care owes much to the vision, courage and commitment of Dame Cicely Saunders. A nurse, social worker and physician, she is regarded and acclaimed as the pioneer of the modern hospice movement. Having worked for some years at St. Joseph's Hospice, Hackney, London, Dame Cicely opened St. Christopher's Hospice in

London in 1967. This was the first of the modern teaching and research hospice units. Dame Cicely has devoted her professional and personal life to the care and study of patients suffering from advanced and progressive disease. She identified and responded to an appalling deficit in terms of how we address the needs of dying patients and their families. She has always remained focused on the specific and unique needs of each individual patient and family. Dame Cicely Saunders has taught us about total patient care, family care, bereavement care and the need for true interdisciplinary teamwork. In a remarkably short period of time, she has transformed this area of health care and has challenged many of the established negative attitudes and biases. In brief, she has revolutionised the way in which we address the varied needs of dying patients and their families.

10. St. Christopher's Hospice has always sought to promote the principles of palliative care in all health care settings. This enthusiasm to disseminate knowledge and skills was not confined to the United Kingdom, but was also applied throughout the world. Health care professionals from all continents have studied at St. Christopher's and have applied their newly acquired knowledge and skills in their own countries. There is no one model of palliative care provision that is applicable in all situations. However, the core principles of palliative care, with emphasis on addressing the unique needs of each individual patient and family, are universal. The manner in which these objectives are met will vary from one country to another and even from one region to another.

11. When we examine the development of palliative care in various countries throughout the world, it is remarkable to see the impact that even one motivated person can have on affecting change. Typically, one individual who recognises that there is a better way to offer care, drives the initial stimulus for change.

Often, because of recent personal experience, this individual acts as a catalyst and inspires others to help bring about change. It is not possible or appropriate to catalogue the development of palliative care in each country. Suffice to say that palliative care services are now developing, albeit at different rates and to different degrees of sophistication, in all continents.

12. Palliative care does not just refer to institutional care. Rather, it is a philosophy of care that is applicable in all care settings. Commonly, we see the establishment of community-based teams, where care is brought to the patient's own home or to a nursing home. Equally, we see different models of palliative care provision within general hospitals. Ideally, patients will have a choice in respect of their preferred place of care i.e. home, hospice, and hospital. Where possible, patients should be able to avail of care in a range of settings, depending on their clinical needs and personal preferences.

13. Over time, the particular needs of hospice patients and their families are attracting increasing attention and discussion in health care programmes across all continents. Whilst the core principles underpinning palliative care provision are universally applicable, the methods necessary to achieve agreed objectives will vary from one country to another. It is the responsibility of health care planners in each country to assess their specific needs and to plan accordingly. In terms of planning palliative care services for the future, we can learn a very important lesson from the past. The focus of all efforts must remain directed towards achieving and maintaining an optimal quality of life for each individual patient and their family. Individual, institutional and group agendas must be subordinated to the needs of patients and families.

Some data on palliative care in European countries

14. Recently, a number of studies have provided data on similarities and differences in the development of palliative care in Europe. In a study of 28 countries in Eastern Europe and Central Asia, using an array of quantitative and qualitative methods, it became clear that there are at the same considerable differences in the extent to which palliative care is available to those who need it, and a remarkable similarity in the interest and the energy devoted to setting up comprehensive palliative care services (Clark & Wright 2002).

15. Poland and Russia have the largest number of palliative care services; some of the ex-Soviet republics have no recognisable services. In Eastern Europe, home care is the most common type of palliative care service, followed by in-patient palliative care; hospital teams, day care, and nursing home teams were found to be much less frequent. The study identified five so-called beacons (reference centres) in four countries (Romania, Hungary, Poland (2) and Russia); these are centres that have historically been crucial for the development of palliative care and that usually still play a role as a centre of expertise.

16. The study identified a number of important problems that the Eastern European countries share:

- lack of policy recognition, reimbursement and sustainability;
- insufficient availability of opioids;
- recruitment of workforce ;
- lack of medical and nursing equipment ;
- lack of research opportunities ;
- negative cultural stereotypes.

17. The "Pallium" study, funded by the European Commission, reviewed the concepts of palliative care and the related policies in seven Western European countries (Ten Have & Janssens 2002).

18. In the Netherlands, specific projects for palliative care had started from a pioneering nursing home in Rotterdam in the 1970s (comparable to the 'beacons' mentioned above); according to this study, the major part of palliative care in the Netherlands is home care, provided by conventional caregivers, and nursing home care. Hospices provide for a small proportion of palliative care; a distinction is made between low-care and high-care hospices, the former predominantly run by volunteers, the latter with a more substantial professional input.

19. In 1998 the government decided for a programme consisting Centres for the Development of Palliative Care in all academic medical centres. Policies in the Netherlands are directed toward the integration of hospices into regular health care system. As a part of this development, there are signs of increasing attention within medical schools: many postgraduate training programmes and programmes for Continuing Medical Education. Increasingly, nursing homes have started opening palliative care units inside their buildings or in specific buildings on their premises.

20. Because of a traditional focus on home care, much of the efforts in The Netherlands are directed toward the training and support of general practitioners. This has led, among others, to a network of mobile consult teams throughout the country. Since 2000, there is a government programme for support of volunteers, mainly concerning co-ordination and training.

21. The Pallium study found that in Belgium, the government has issued a series of Royal decrees specifying, among others, that every hospital and every rest- or nursing home should have a multi-professional palliative care team, further specifying the professions that need to be represented. On the other hand, professional organisations have worked together with regional and national governments to promote palliative care, with an emphasis on its integration into conventional health care, and with a focus on the home as the locus of care.

22. In Sweden, development in specialised palliative care started with a home-based hospice programme in the south of the country in 1977; this model spread over the country in the next decade. Sweden explicitly rejected, in a 1979 government report, the constitution of stand-alone institutions for the dying (see also Fürst 2000).

23. In Germany, the organisation of palliative care started, after a period of sensibilisation of German society, with the first palliative hospital ward established in 1983, followed by several hospice initiatives and a government initiative to establish 12 palliative care facilities.

24. In Spain, according to the Pallium study, developments in palliative care did not start as a grassroots hospice movement as in most other countries, but have been initiated from the national health care system; pioneering centres were located in tertiary hospitals. A 2000 National Plan for Palliative care mentions a number of 241 institutions for palliative care, half of them home care, caring for 23,000 patients every year. However, these institutions are unequally distributed over the country, no coverage of whole population.

25. The United Kingdom has been, to a large extent, the cradle of specific palliative care services in Europe. The English contributors to this study note that the strong British hospice movement has always remained outside of the National Health System, which has impaired its ability to 'evangelise' its approach throughout the system. Palliative medicine has been a recognised medical specialty for a number of years, and its academic status seems robust. However, as in most other countries, the majority of the funding of palliative care still comes from the private sector.

26. In Italy, there has been a development of palliative care since the beginning of the 1970s, leading to a large number of hospices all over the country; recently, the Italian government has given palliative care a prominent place within the "Piano sanitario nazionale".

27. By the end of 1999, the seven countries from the Pallium project showed the following picture:

	Belgium	Germany	Italy	Netherlands	Spain	Sweden	United Kingdom
Population (millions)	10.1	81.9	57.4	15.6	40	8.8	57.1
In-patient hospice	1	64	3	16	1	} 69	} 219
In-patient unit	49	50	0	2	23		
Hospital and nursing home teams	55	1	0	34	45	41	336
Home care	45	582	88	286	75	67	355
Day care	2	9	0	0	0	13	248

28. In Switzerland, the cantons have different accents in health care organisation; the government in French-speaking Switzerland is implied in palliative care, while in the German- or

Italian- speaking cantons, palliative care is an area for private initiative. As of 2000, the country had 9 hospital units, 6 hospices, 6 mobile home care teams and 5 mobile hospital teams (2 of which in a university hospital). According to a 2000 report of the Société de Médecine et des Soins Palliatifs palliative care training is very different according to nursing and medical schools; no more than one medical has specific palliative care training lasting a total of 8 hours; it is no examination subject; education is very variable.

29. The abovementioned Swiss report mentions a number of specific obstacles are, firstly, the federal structure of the country with deleterious effects on the distribution and co-ordination of development efforts; secondly, the absence of specialisation because, allegedly, "we all know what palliative care is". Thirdly, budget restrictions prevent the development of a new field of health care such as palliative care.

30. The specific issue of home care was addressed as following:

- the traditional family structure has changed in many regions; many elderly live alone and cannot rely on family support
- 50% of persons seriously ill would prefer to stay at home
- lack of financial resources is often a major obstacle

31. The report mentions a number of points of concern: after an initial period of success, the palliative care movement has blocked in Switzerland, probably because it had remained a personal activity of a few pioneers who have not provided for successors. However, in some cantons (Vaud, especially) palliative care develops on the basis of consensus among all

professionals involved, which, although difficult, was crucial. A last point of concern, which clearly is not specific for Switzerland is that up to now, the information of the public has been insufficient.

32. In Hungary, there have recently been important developments in palliative care. In 1997, the Health Care Act was made to contain explicit reference to palliative care, which formally entitles patients to symptom management and to live with their relatives; it states that home care should be offered when possible and that support for relatives and spiritual support of both family and relatives should be available to all.

33. The Ministry of Health Care and Hospice-Palliative Association have published and distributed professional guidelines, a comprehensive version having been published recently.

34. In September 2001, a one-year hospice nurse and coordinator education programme has started. As of 2001, the country disposed of 4 hospice units (a total of 55 beds); 14 home care teams; 2 day care centres; 2 mobile teams (Budapest); and units in 5 nursing homes.

35. Undergraduate training in medical school comprises about 10 hrs devoted to pain & symptom management, about 30 hrs to psychosocial issues. For nursing schools, there is a total of 80 hours of postgraduate nurses training; also postgraduate training for physicians.

36. In Austria, health care policy has taken up palliative care since 3 years and developed a plan specifying the number of palliative beds needed, 3/4 of which should be available by 2005.

37. Austria has no recognised specialty in palliative care and no recognisable specific expertise. There is a total of 8 hospices / units, a total of 100 beds (2001).

38. Training in palliative care is part of the nursing curriculum since 1998, and will be part of the medical curriculum from 2002; in specialist training programmes, very little, but growing attention for palliative care.

39. The financial support for both in-patient units and home care teams is a source of concern, because there is much dependency on relatively uncertain forms of private supplementary financing.

Definitions and core principles

40. As noted in the recommendation, these documents follow the definitions and descriptions of palliative care provided by the WHO in 1991 and 2002 and widely supported by the palliative care field.

41. Before discussing definitions and core principles, it is important to note that palliative care should not be regarded as essentially different from other forms or areas of health care. Such essential differences would make its integration into regular health care difficult if not impossible. Many of the crucial aspects of palliative care apply to curative medicine, as well; on the other hand, the development of palliative care could have a positive influence on other forms of health care by focussing on some underestimated elements such as spiritual problems.

Definitions

42. The definition of palliative care has evolved over the years, as the field has developed in various countries. Palliative care is defined not by reference to organ, age, disease type or pathology but rather by an assessment of the probable prognosis and with due regard to the specific needs of an individual patient and his/her family. Traditionally, palliative care was regarded as being applicable exclusively at the point when death was imminent. It is now accepted that palliative care has much to offer at a much earlier stage in the course of progressive disease.

43. The term palliative derives from the Latin *pallium* meaning 'mask' or 'cloak.' This etymology indicates what palliative care essentially is about: masking the effects of incurable disease, or providing a cloak for those who are left in the cold, because they cannot be helped by curative medicine.

44. Palliative care involves the use of all appropriate palliative interventions, which may include disease-modifying therapies such as surgery, radiotherapy, chemotherapy, hormonal manipulations etc. The ultimate objective of all of these interventions is to rehabilitate the patient to the greatest possible extent, and to achieve the best possible quality of life. Hence, it is vitally important that palliative care programmes are fully integrated into established health care programmes in hospital and community settings. The relative merits of all approaches to care, both disease-modifying and symptomatic, must be assessed on an individual basis and at frequent intervals, so that appropriate treatment schedules may be implemented.

45. The World Health Organisation has defined palliative care as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other

symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families." (World Health Organisation, 1990)

46. This definition is commendable to the extent that it is patient-focused, emphasises the multi-faceted nature of the human condition and identifies quality of life as its ultimate objective. However, the use of the word "curative" is unhelpful, as many chronic conditions cannot be cured, yet may be compatible with a life expectancy over many decades.

47. Doyle clarified the situation when he wrote 'palliative' care focuses on those last years or months of life when death is foreseeable rather than merely a possibility, looking at the pattern of physical, emotional, social and spiritual suffering which may be present, and which should and can be relieved.

48. A more recent WHO definition of palliative care put more emphasis on the prevention of suffering:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".

Principles of Palliative Care

49. As an appendix to its most recent definition, WHO set out the following core principle, according to which palliative care:

- provides relief from pain and other symptoms;
- affirms life, and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with a range of other therapies that are intended to prolong life, such as chemotherapy, radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

50. It is useful to further elaborate on these core principles of palliative care.

- Palliative care places great importance on achieving and maintaining an optimal level of pain and symptom management. This will require a detailed assessment of each individual patient, involving a detailed history, physical examination and investigations as appropriate. Patients must have ready access to all necessary medications, including a variety of opioids in a range of formulations. Disease modifying therapies may also offer

useful symptomatic benefit and should be available as required.

- Palliative care affirms life and regards dying as a normal process. This core principle seeks to address some of the attitudinal difficulties associated with palliative care. Essentially, the one thing that we all share in common is the inescapable reality of our death. Patients requiring palliative care must not be regarded as medical failures. Palliative care seeks to ensure that patients are enabled and encouraged to live their life in a useful, productive and fulfilling manner right up to the moment of their death. The importance of rehabilitation, in terms of physical, psychological and spiritual well-being, cannot be overstated.
- Palliative care intends neither to hasten nor postpone death. Palliative care interventions are not and should not be designed to end life prematurely. Equally, it is important that the technologies available in modern medical practice are not applied to prolonging life unnaturally. Doctors are not obliged to continue treatments that are patently futile and excessively burdensome to the patient. Equally, patients are entitled to refuse medical treatments. In palliative care, the objective is to ensure that patients have the highest possible quality of life. At the point when the disease process is bringing that life to a natural end, patients must be able to receive every possible measure of physical, emotional and spiritual comfort. Specifically, attention is drawn to the fact that euthanasia and physician assisted suicide are not included in any definition of palliative care; for that reason, the committee does not take a stand on these issues. See chapter VIII.

- Palliative care integrates the psychological and spiritual aspects of patient care. A high standard of physical care is of course vitally important, but in itself, is not enough. We must not reduce the human person to a simple biological entity.
- Palliative care offers a support system to help patients live as actively as possible until death. In this regard, it is important to note that the patient sets the goals and priorities. The role of the health care professional is to enable and assist a patient in achieving his/her identified goal. It is evident that the priorities for an individual patient may shift quite dramatically over time. Health care professionals must be aware of this shift and respond accordingly.
- Palliative care helps the family to cope during the patient's illness and in bereavement. In palliative care, the family is the unit of care. In this regard, family members will have their own particular issues and difficulties and these must be identified and addressed. The work of bereavement care does not wait until after the patient has died. See chapter VIII.
- Palliative care requires a coordinated team approach. It will be evident from the above, that usually no one individual, and no one discipline, can adequately address the range and complexity of issues that arise during the palliative care period. Although often a core team consisting of a physician, a nurse and a social worker can provide the necessary care, it is often the case that input is required from a broad range of medical, nursing and allied health care professionals. For such a team to work

cohesively, it is critically important that there are shared goals and objectives and also that there are effective and rapid means of communication. See chapter VII.

- Palliative care seeks to improve quality of life. The issue of 'quality of life' has attracted much research interest in recent years. It is important to recognise that this is not simply a measure of physical comfort or of functional capacity. Rather, it is something that may only be defined by the individual patient and it is something that may alter quite significantly over time.
- Palliative care is applicable early in the course of illness, in conjunction with disease modifying and life prolonging therapies. Historically, palliative care was associated with the care offered to cancer patients as they approached death. It is recognised that palliative care has much to offer to patients and families at an earlier stage in the course of disease, at least from the moment where the stage of advanced disease is reached and progression cannot durably be avoided. This requires that palliative care services be closely integrated with a full range of health care services in hospital and community settings.

51. As is evident from the above definitions, palliative care is not defined by any particular illness or disease type. Potentially, it is applicable to patients of all ages, based on an assessment of their likely prognosis and of their particular needs.

52. Terminal care is a continuum of palliative care and describes the management of patients during that period when death is imminent, and likely to occur within a few hours or at most, some days. The use of this term to describe all elements of palliative care is inappropriate and unhelpful.

53. Palliative medicine is the appropriate medical care of patients with active, progressive and advanced disease, for whom the prognosis is limited, and the focus of care is the quality of life. Palliative Medicine includes consideration of the families needs before and after the patient's death.

Palliative care approach. All health care professionals should be familiar with the essential principles of palliative care and must apply these principles appropriately in their practice.

General palliative care. It is recognised that some health care professionals, although not engaged exclusively in the practice of palliative care, might have additional training and expertise in the field of palliative care. The term “general palliative care” is used to describe the activities of such personnel.

Specialised palliative care. Specialised palliative care services are those services whose core activity is limited to the provision of palliative care. These services are typically involved in the care of patients with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources.

54. Even when so-called active, disease-modifying treatments are no longer appropriate, palliative care is a very active form of care, which in some instances may be tantamount to intensive care, though different from what is seen in an intensive care unit. Active interventions such as medical treatment of hypercalcaemia, radiation therapy for pain, bleeding or spinal cord compression, chemotherapy for incipient superior vena caval obstruction and surgery for fractures or intestinal obstruction are common. Also, working with patients and families who are experiencing the intense and at times overwhelming suffering

associated with progressive loss is an intensely active undertaking. Rehabilitation is generally recognised as an important form of active palliative care.(Doyle, Hanks, and MacDonald 1998)

55. However, palliative care is not only active but also proactive: it intends to foresee, if possible prevent, but always to take into account possible new problems in the disease process.

56. The core principles underpinning all palliative care services are focused on achieving the best possible quality of life for each patient and their family. This will involve strict attention to symptom control; a holistic approach that takes into account the person's life experience and current situation; care that encompasses both the dying person and those who matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues.

57. In Ireland, the Department of Health published a cancer strategy in 1996. this document identified the following principles that should be adopted in developing palliative care services:

- Patients should be enabled and encouraged to express their preference about where they wish to be cared for and where they wish to spend the last period of their life.
- Services should be sufficiently flexible and integrated so as to allow movement of patients from one care setting to another, depending on their clinical situation and personal preferences.
- The ultimate aim should be for all patients to have access to specialised palliative care services where these are required.

58. Palliative care is an area where ethical issues abound; most of them are similar to those that may be raised in other areas of health care. However, some issues, such as end-of-life issues, are clearly more prominent.

59. Consideration of the ethical principles involved in palliative care is based on recognition of the fact that the incurable and/or terminally ill patient is not a biological residue for whom nothing more can be done, a being in need of anaesthesia, whose life must not be prolonged unnecessarily, but a person and, as such, capable to the very end, if integrated into a relationship, of making life an experience of growth and achievement.

60. Professionals should recognise the limits of medicine and refrain from overtreatment. It is important to challenge the illusion that there is only one way of dealing with pain and suffering: eliminating them. It should also be remembered that total pain (fear of death, separation anxiety, loneliness, existential issues, the perception of being a burden on others, etc) cannot be treated by medical means only. It follows that, in the case of total pain, the effectiveness of analgesics is related to the possibility of including medicinal treatment within a significant relationship.

61. Following the four principles determined by Beauchamp and Childress (Beauchamp and Childress 1994) (respect for autonomy, beneficence, non-maleficence, and justice) as in all other areas of medical care, physicians and other caregivers should demonstrate respect for the patient's autonomy by agreeing about priorities and goals of care with the patients and carers, by not withholding information desired by the patient and by respecting the patient's wish not to receive treatment.

62. Caregivers should carefully balance the benefits and burdens of treatment ('beneficence') and assess the risks versus the benefits of each clinical decision ('non-maleficence'), in order to avoid futile treatment, which serves none of purposes of prevention, cure, care, rehabilitation and pain relief. And also to avoid interventions which, although they may achieve partial results, are detrimental to the patient's general well-being.

63. However, the usual rule-based approach to medical ethics as exemplified by the four principles just mentioned, may be insufficient in this area. Recently developed approaches such as the ethics of care (Tronto 1993) and virtue ethics (MacIntyre 1995), seem particularly appropriate for palliative care. The ethics of care stresses the essentially vulnerable and dependent nature of human beings. Therefore, it states that ethics should not only regard decision making, but also the quality of relationships, such as continuity, openness, trust and reliability.

64. Virtue ethics criticises the ethical focus on decisions from the standpoint of character: it stresses the importance of an enduring tendency to act in a virtuous manner.

65. Patients with advanced disease and dying patients have essentially the same rights as other patients, such as a right to receive medical care and personal support (for instance by having a close relative stay by the bed), a right to be informed, but also a right to decline information and/or diagnostic procedures and/ or treatment. Refusal of treatment must be safeguarded especially when appropriate medical treatment will do nothing to forestall death; treatment refusal may in no way influence the quality of palliative care. Most importantly, patients in palliative care have a right to the maximum attainable human dignity, to the best available pain relief and reduction of suffering.

66. As an example, we give the ethical principles of palliative care as formulated by the Hungarian hospice and palliative care association (Hegedüs 2000):

1. Palliative care team-members demonstrate respect for the patient's autonomy by agreeing priorities and goals with the patients and careers, discussing treatment options with the patient and jointly formulating care plans, not withholding information desired by the patient, fulfilling the patient's need for information about any treatment and respecting the patient's wish to decline treatment.
2. Palliative care team-members should weigh up the benefits and burdens of treatment ('beneficence'), assess the risks versus the benefits of each clinical decision ('non-maleficence'), understand the right of the individual patient to the highest standard of care within the resource available and understand decisions involved in the allocation and use of resources.
3. The basic rights of dying patients are the following: right to receive medical care, right to human dignity, right to personal support, right to pain relief and reduction of suffering, right to be informed, right of self-determination and right to refuse treatment.
4. The patient is entitled to receive detailed information on his or her state of health including any medical evaluation; examination and interventions proposed; potential advantages and

risks of performing or not performing the examination and intervention; the planned date for the examinations and intervention; the patient's rights to decide on the examination and interventions; any alternative procedure and methods; the process of the treatment and the expected results.

5. Patients have the right to participate in decisions affecting examination or treatment. It is a precondition of any medical intervention that the informed consent of the patient is obtained.
6. The right to refuse treatment: if the patient suffers from a serious illness, which, according to the current state of medical knowledge, will lead to death within a short period of time even with appropriate medical treatment, life-supporting or life-saving interventions may be refused, allowing the illness to proceed in a natural way. A person capable to act - with regard to his or her later state of incapacity, can refuse, in a public instrument (e.g. living will) certain life-supporting or life-saving treatments in a future situation of suffering an illness with no cure; being incapable of psychical self-care due to the illness, or having pain that cannot be relieved with appropriate treatment. The patient is entitled to name another person to exercise this right in case of the patient's incapacity. The declaration can be withdrawn at any time. Patients refusing treatment are fully entitled to pain relief and the easing of suffering.

7. Each act and decisions should be documented in written form.

Settings and services

Settings

67. Palliative care takes place in the following settings:

- home
- nursing home
- home for the elderly
- hospital
- hospice

68. By far the largest quantity of palliative care is given in the home; even if patients eventually die in an institution, they usually have spent a large period of palliative care in the home. This has important consequences for palliative care services that will be addressed below.

69. Over the past two decades, a number of reports from the United Kingdom have influenced the development of palliative care services. These reports have identified the following principles of care:

It is an essential principle of palliative care that patients should be able to access care at a time and in a setting consistent with their clinical needs and personal preferences. In essence, palliative care should be available to all patients wherever they may happen to be. As stated in the chapter on definitions, it is the responsibility of all health care professionals to familiarise themselves with the basic principles of palliative care. In order to achieve

this objective, it will be necessary to include palliative care as part of the basic curriculum for medical and allied professionals. Also, health care professionals must have an opportunity to update their skills and knowledge by means of continuing professional development programmes. Thus, if a patient consults a health care professional in a hospital clinic, a general practitioner's surgery, nursing home or any other setting, they should be assured that they will be offered a basic level of palliative care consistent with their needs.

70. It is also recognised that some care settings, although not engaged exclusively in the profession of palliative care services, will attract a higher proportion of patients who require palliative care support. In this regard, it is evident that some nursing homes, elderly care settings and services with a significant oncology workload will have a higher demand for palliative care expertise. At least some health care professionals working in these settings should have the opportunity to pursue additional training and gain additional expertise in palliative care. Also, it is expected that they would develop close professional links with specialised palliative care providers. The overall objective of such stratification is to ensure that patients may engage with a level of expertise consistent with their particular needs at any point in time.

Services

71. A distinction is useful between non-specialist and specialist palliative care services. Non-specialist or conventional services provide palliative care without making this into their core business. They include: district nursing services, general practitioners, home care teams, general internal medicine wards, and nursing homes.

72. The large majority of palliative care is, and will probably always be, provided by non-specialist services. In many cases, non-specialised professionals provide the care without the intervention of specialists; in many other cases, specialised intervention may be needed in the context of non-specialist care, while in a small proportion of the cases, specialists will need to take over the care entirely.

73. Non-specialised services also include services that are involved only incidentally, such as radiology and radiotherapy departments, surgery. Such services sometimes have waiting lists that may be especially detrimental to palliative care patients because of their short remaining life span in which they could benefit from the treatment. Therefore, the concept of a "palliative bus lane", involving preferential access for palliative patients, has been proposed.

74. A specific area where the concept of palliative care has received increased attention over the last years, is the intensive care unit.

75. Non-specialists may build up sufficient experience in relatively uncomplicated palliative care but, due to the limited number of palliative patients they see (in the Netherlands, for example, general practitioners on average see between 2-6 palliative care patients per year), the experience with complex palliative care cannot be acquired. Experiments with easily accessible consultation services show good possibilities of support for non-specialised professionals while the patient can remain within their care.

76. Specialised services denote services fully devoted to palliative care, whose teams are specially trained in this area of

care. Such services do not take the place of the care provided by front-line professionals (home care, hospital or rehabilitation facilities), but support and complement such care according to the needs identified and the complexity of the situation. Wherever they are, patients must be able, if necessary, to access such services at all times and without delay.

77. The most common services are specialist in-patient units, hospital palliative care teams, home care teams, day care facilities, hospitalisation at the home, and out patient clinics.

78. There is very little good evidence as to what type of palliative care services are preferred by patients. In a review, Wilkinson et al noticed a trend toward greater satisfaction with specialised services, both in hospitals and in the community, as compared to general hospitals (Wilkinson et al. 1999). Again, these results should be interpreted with caution.

79. Non-specialist services include the following:

- informal caregivers;
- volunteers;
- district nurses;
- general practitioners;
- non-palliative care specialists.

80. Specialist palliative care services are those services with palliative care as their core activity. They will require a higher level of professional skills from trained staff and a high staff/patient ratio. Such services should be available in all care settings and should be able to support a patient wherever the patient may be: at home, in hospital, in residential care, in nursing home, in day centres, in out-patients or in a specialist palliative care unit. Specialised palliative care services also have an

important role in supporting other health care professionals in the delivery of palliative care services at hospital and community level. All health care professionals should be able to access, advise and support from specialised palliative care providers when required.

81. The key characteristics of a specialist palliative care services have been described by the National Council for Hospice and Specialist Palliative Care Services in the United Kingdom and are endorsed by the National Advisory Committee on Palliative Care (Ireland). These are summarised as follows:

- the provision of physical, psychological, social and spiritual support, with a mix of skills delivered through a multi-professional, collaborative team approach;
- at least the lead person in each professional group within the multi-professional team should be a trained and acknowledged specialist in palliative care ;
- patients and families are supported and involved in management plans ;
- patients are encouraged to express their preference about where they wish to be cared for and where they wish to die;
- carers and families are supported through the illness into bereavement, and the needs of the bereaved are recognised and addressed ;
- there is cooperation and collaboration with primary health care professionals, hospital and home care services to support patients wherever they might be ;
- the contribution of volunteers is recognised and valued ;

- the service has either indirectly or directly a recognised academic external educational role and in-service education provision ;
- standards are set for the education and training provided ;
- quality assurance programmes are in place and are constantly used to review practice;
- clinical audit and research programmes exist to evaluate treatment and outcome ;
- staff support arrangements exist which are appropriate to meet the needs of those working in specialist palliative care, whether fulltime or part-time.

Staffing Requirements of a Specialist Palliative Care Service

82. It is recognised that palliative care is at varying stages of development across Europe. A range of factors, including economic considerations will influence the range and level of staffing that is available. However, all specialist palliative care services should have medical and nursing staff with recognised training and expertise in palliative care.

83. In the UK, the National Council for Hospice and Specialist Palliative Care Services has recommended that the following staff should also be available either full-time, part-time or with regular sessions:

- physiotherapy ;
- occupational therapy ;
- social work ;
- staff specifically trained to meet the psychosocial needs of the patient, family and carers ;

- staff with responsibility for bereavement services ;
- coordinator of spiritual care ;
- speech and language therapist ;
- dietician/Clinical Nutritionist ;
- pharmacist ;
- complimentary therapist;
- volunteer coordinator;
- educational personnel;
- librarian;
- appropriate level of administrative, secretarial and general support staff.

84. Not all specialist palliative care services will be in a position to satisfy all of the above recommendations.

Policy

85. Specialist palliative care services should provide care options in a broad range of settings. Services should be structured so that patients may move readily from one care setting to another depending on their clinical needs and personal preference. The following are the various settings in which specialised palliative care may be provided. These are not isolated entities but rather function as a coordinated, integrated and cohesive unit.

Palliative Care In-patient Unit

86. In this setting, dedicated beds are provided for palliative care purposes. Such units will require a highly trained interdisciplinary team and are designed to care for patients and families with more complex physical, psychosocial and/or spiritual needs. These units will be closely integrated with the range of hospital-based and community-based services.

Frequently, they are located on the grounds of or adjacent to a general hospital setting.

Hospital-based Palliative Care Team

87. This term describes a situation whereby a specialist palliative care team functions in an advisory and supportive capacity within a general hospital. The patients' care remains the primary responsibility of the physician or surgeon but they are supported and advised by specialist palliative care personnel. This model serves to disseminate palliative care principles amongst other medical colleagues in the hospital setting.

Community-based Palliative Care Team

88. Many patients will express the wish to have their care undertaken in their own home or in a place that has become their home i.e. nursing home, residential care setting etc. The specialist palliative care team will visit patients in this setting and advise on their management. Some patients may require a short admission to the specialist palliative care in-patient unit so that particularly complex problems may be addressed. However, it is anticipated that they will then be in a position to return back to their original home.

Day Care Facilities

89. Day care is may be provided by a palliative care in-patient unit, but also to a nursing home or other institution. Patients may attend on one or more days each week. Services offered may be considered as medical (blood transfusions, review of pain and symptom management etc), social (shower/bath), rehabilitative (physiotherapy/occupational therapy), relaxational (massage) or

diversional (art & crafts). Also, they serve to give the main carer an opportunity to have some free time.

Out-Patient Clinics

90. The provision of an out-patient assessment clinic is a valuable element of a palliative care programme.

[Wilkinson EK § Col. Patients and carer preferences for, and satisfaction with, specialist models of palliative care: a systematic literature review. *Palliat Med* 1999;13:197-216]

91. Specialist in-patient units usually have a capacity of 10 to 15 beds, admit patients whose degree of suffering (physical/psychological/social) calls for specialised interdisciplinary palliative care, either on a temporary basis or until they die. They also have a training and research function. They may be located within a hospital, thus receiving input from other specialists and deriving benefit from the available medical technology, or they may be totally independent. In the latter case, close links with a hospital possessing appropriate technology are desirable.

92. The occupancy rate of a specialist in-patient unit must be such as to permit the admission of patients without delay at all times, particularly those previously cared for at home. Until recently, the need in terms of palliative care beds for cancer patients was estimated at around 50 for every million inhabitants. However, this figure, which takes into account neither the needs of patients suffering from non-oncological diseases nor the increasing prevalence of chronic diseases related to the ageing of the European population, probably underestimates the real need by half. Generally speaking, the number of beds in a given region will depend on the demographic and socio-economic context and

on the availability or unavailability of other specialist palliative care services (respite beds, hospitalisation at home, etc).

93. Hospital palliative care teams, which usually comprise at least one physician and one nurse specialising in palliative care, but often include other professionals too (social worker, psychologist, chaplain, etc), act as consultants at the request of care staff, the hospitalised patient and his or her relatives. They co-operate closely with various other specialists (referring doctors, oncologists, radiotherapists, etc) and other health care professionals such as social workers, psychologists and chaplains. They also perform a training function.

94. The functions and mode of operation of home care teams are similar to those of hospital teams. They assist patients living at home, in a nursing home or in any other community setting, at the request of the primary care providers.

95. Several studies have described the many organisational, functional and financial obstacles facing isolated hospital and home care teams. It is essential that these teams be attached, or at least have close links, with an in-patient unit. As well as ensuring that teams receive support and continuing training, such links, whether formal or informal, lead to increased continuity in the care of patients.

96. Day hospitals offer day care, one or more days a week, for patients living at home. Facilities of this kind have so far developed mainly in the United Kingdom. The available data shows a great variety in their functions and modes of operation. The purpose of a day hospital may be to evaluate symptoms; to administer various forms of treatment in a convivial setting; to offer respite to patients, relatives and the primary care team, thus making it easier to keep patients at home and avoid unnecessary

hospitalisation; to provide psychological support; and to pursue any other complementary approach (music therapy, etc) aimed at improving quality of life for patients and their relatives.

97. In some countries, France or Finland for instance, a service called "hospitalisation at home" or "home hospital" involves increased provision of medical and nursing care in order to ensure that patients who would otherwise have to be hospitalised are kept at home. It involves more hospital-like care than home care teams usually are prepared to provide. There are different organisational models, ranging from an upgrading of existing resources within the home to the provision of a specialist team attending to all needs.

98. Out-patient clinics tend to be situated in an acute care hospital and consultations are generally performed by the hospital's mobile team, who provide counselling on an ad hoc basis for patients living at home who are able to attend the clinic.

99. A telephone helpline provides advice to professionals on caring for palliative patients and facilitates access to services specialising in palliative care, such as mobile teams or in-patient units. Through the formal links, which it maintains with other professional and voluntary workers, it also offers assistance in the form of advice and referral geared to each specific situation. Helplines of this kind are usually the result of co-operation between several specialised services within the same region.

100. The quality of the care provided in a given region depends not only on the quality of the care provided by each individual service, but also on co-ordination of services and the co-ordination existing between specialised services and primary care providers. The organisation of services into a co-ordinated regional network improves access to palliative care and enhances

the quality and continuity of care.(Elsey and McIntyre 1996; Mitchell and Price 2001; Schroder and Seely 1998)

101. The operation of such a network calls for a co-ordinating body or person (this function can be performed by an interdisciplinary group of professionals representing the various services involved in the network, or by the in-patient unit), a range of facilities corresponding to the different levels of care required by patients (in-patient unit, respite beds, home, hospitalisation at home, day hospital, long-stay hospital, acute care hospital), and liaison services (mobile hospital and home teams).(Zalot 1989) A network of this kind serves several different purposes: as well as co-ordinating care, it can evaluate its results (audit) and co-ordinate training and research.

102. The ingredients of a smoothly functioning network are:

- joint setting of objectives and quality standards,
- the application of admission and release criteria known to all, for each level of care,
- the use of common evaluation methods,
- the implementation of common therapeutic strategies, based, whenever possible, on the findings of clinical research.

Policy and organisation

103. Various member states of the COE have developed, in the last decades, comprehensive national plans for the development and maintenance of palliative care as an integral part of the health care system.

104. By way of examples and without suggesting to be complete, we will mention three such states. See also the chapter on general considerations.

105. Spain has developed a palliative care plan, which has been adopted by the interregional council of the national health care system, the Plan Nacional de Cuidados Paliativos; Bases Para Su Desarrollo (18 December 2000). The plan intends to offer palliative care according to need, preferably publicly financed, to encourage the co-ordination of the levels of health care provision, to ensure equity, to stimulate quality, effectiveness and efficiency, and to ensure satisfaction among patients, families and professionals. More specifically, the plan aims to facilitate interdisciplinarity and co-ordination with other (non-health care) sectors involved, to direct the attention to the home as the most appropriate place for palliative care, to ensure the development of guidelines and standards, and to stimulate the education of professionals and families. With regard to education, the plan distinguishes between a basic, an intermediary, and an advanced level of expertise. The Spanish plan contains an elaborate description of the way it will be evaluated.

106. In Hungary, the 1997 Health Care Act contains explicit reference to palliative care, which formally entitles patients to symptom management, to live with their relatives; home care should be offered when possible; support for relatives and spiritual support of both family and relatives is specified in the Act. The Hungarian Ministry of Health Care and Hospice-Palliative Association published and distributed professional guidelines.

107. In Ireland in 1999, to take a last example, the Minister for Health and Children established a National Advisory Committee on Palliative Care, which published an advice encompassing all

aspects of palliative care policies, also regarding organisation and financing, in which it was proposed that palliative care should be a separate area of government funding.(National Advisory Committee on Palliative Care 2001)

108. In most documents concerning national and regional policies, great importance is attached to public opinion and the role of governments, professional groups and non-governmental organisations in promoting an adequate image of death and dying and the care for patients with advanced incurable disease. An example of such policies outside Europe has been the "Death in America" project, funded by the Soros Foundation, in which death and dying was put on the public agenda through all kinds of means, ranging from public debate to theatre plays.

109. The basis of palliative care policies, both national and regional, is knowledge about the needs of patients. In order to develop and monitor national strategies concerning palliative care, countries will need the continuous gathering of basic data, a Minimal Data Set (MDS), which will, for example, involve epidemiological data, data about the use of palliative care services, specified according to groups, and data about the availability of such services in different regions; the content of an MDS partly depends on the specific information needs of different countries.

110. Some member states have performed a needs assessment study. In the example of the Netherlands, a government-sponsored study was undertaken in which an attempt is made to establish the actual and future needs of patients with advance disease; on that basis, the types and quantities of necessary care facilities are being established. Experiences with a so-called Minimum Data Set defining the data minimally needed to do and

monitor such needs assessments are encouraging.(National Advisory Committee on Palliative Care 2001)

111. Although data on the extent to which underprivileged members of society can access palliative care are scarce, there is a feeling in the committee that homeless people, those with a cognitive handicap, refugees and others may experience difficulties in accessing the palliative care they need. There are indications that people from ethnic minorities are underrepresented among patients receiving palliative care. This may be due to a lack of "feeling" for the culturally specific demands of these patients with regard to end-of-life care.

112. Children with an incurable and life-threatening disease pose particular challenges to the delivery of palliative care, which will most often be delivered in the home; however, the scarce data suggest that palliative care is insufficiently available for children (Clark 2002; Mabrouk 2001). Children require special services, delivered by the personnel with pedagogic training, particularly the nurses. It should be followed by the home care, offering support to children and their family.

113. In many countries, palliative care is either unknown to the general public or suffers from negative connotations such as fatalism. This may lead to a lack of public attention, which, in turn, may lead to insufficient interest, for instance in joining volunteer organisations. A lack of public interest may also lead to a continuing marginalisation of death and dying.

114. There are data suggesting that access to palliative care is dependent upon the type of disease patients have (cancer patients enjoying greater access), and also on socio-economic factors. Furthermore, in some countries the availability of intensive terminal care is restricted to patients having a limited prognosis,

for instance 3 months. This restriction almost always causes great problems when patients live beyond their original prognosis, but remain in need of high-quality palliative care.

115. Pharmacological interventions form the basis for symptom control. Other dimensions of suffering such as the social transitions linked to severe disease and dying as well as the spiritual needs are much easier to alleviate if adequate medical treatment has been given. However, in some countries there may be problems concerning production and logistics on the level of the local health care units. Also the economical support that may be needed to give appropriate pharmacological treatment has to be dealt with on a national and local level.

116. The availability of narcotic drugs is a specific concern since availability is often insufficient due to legal restrictions, both in terms of the variety of opioids available and different dose regimens. Morphine is the most commonly used opioid drug. Most cancer related pain is opioid responsive but contrary to most other analgesic drugs the effect is dose related, which means that there cannot be a fixed dosage for everybody but may need to differ between ten and several thousand mg per day.(Foley 1995; Foley 1996) Different opioid drugs have to be available since the individual response in terms of effect and side effects may require a change from one drug to another.(Indelicato and Portenoy 2002)

117. When the opioid drugs are used appropriately for the treatment of pain there is no evidence for drug abuse being any problem. The WHO and the European Association for Palliative Care (EAPC) have published guidelines for the management and treatment of pain.(Hanks et al. 2001; World Health Organisation. 1990)

118. Within federal, national or regional plans, particular attention should be given to minority categories of patients, such as institutionalised disabled persons, children, prisoners, etc. These persons should have immediate access, at all times and on a non-means-tested basis, to the services provided by the various special facilities and receive care tailored to their specific needs.

Quality improvement and research

Quality improvement

119. Generally speaking, quality improvement in palliative care is no different from quality improvement in health care as it has been described in Council Of Europe recommendation R(97) 17 and its appendices.

120. However, some of the specific dimensions of palliative care (the overriding importance of patient preferences, the family as the unit of care, the importance of spiritual and existential issues, and the involvement of non-professionals; see chapter 1) make for specific aspects of quality improvement and maintenance in palliative care.

121. In the medical profession as a whole, the development of evidence-based clinical guidelines has been one of the major innovations. Although guidelines for palliative care have been developed in many countries, the relatively weak evidence base of many common interventions in palliative care has been an obstacle to the development of strong guidelines. Fortunately, the Cochrane collaboration, the most important international body promoting evidence-based guidelines, has a section on palliative care.

122. Continuous improvement of the quality of care may be defined as a systematic process of evaluation and improvement of the quality of the services provided.

123. Procedures for evaluating the quality of care are, however, still lacking in many institutions specialising in palliative care. For this reason, the literature on this field still provides incomplete data.

124. There are many reasons for this inadequacy of quality evaluation. Among other things, quality evaluation calls for methodological skills and logistic resources, which are not always available to institutions that are usually small in size. The implementation of an evaluation procedure calls for the prior definition of quality standards, the use of evaluation methods suited to the palliative care context, such as multidisciplinary audits, and appropriate tools for measuring the results.

125. The measurements performed may simply involve collecting demographic, administrative and diagnostic data, which will provide standardised information on the type of patients cared for. They may represent performance indicators such as a service's response time or the proportion of non-cancer patients cared for, which will provide an estimation of the extent to which the goals set have been achieved. They may also be more complex measurements making use of tools for evaluating various quality dimensions. Among those currently available, some have been developed specifically and validated in the field of palliative care, such as the Support Team Assessment Schedule (STAS), the Edmonton Symptom Assessment System (ESAS) or the Palliative Care Outcome Scale (POS), for example. (Bruera et al. 1991; Hearn and Higginson 1999; Higginson and McCarthy 1993)

126. They are useful not only for a quality evaluation process but also in everyday clinical practice. It is advisable to use tools that have been validated rather than to develop new ones.

127. It is essential to develop quality standards and disseminate them among all institutions specialising in palliative care. Many clinical and service evaluation audits depend on the existence of such standards, in the light of which it will be possible to evaluate practice. A standard is the identification of a 'good practice' in a specific area of care.

128. Standards may be developed at national and regional/local level. The national level makes for a coherent development and monitoring strategy, as well as saving time and energy; the regional/local level allows for adaptation of national standards to the specific characteristics of a region or a given institution. The best approach seems to be a combination of the two.

129. The introduction of quality standards must be preceded by the widest possible consultation of all the partners involved, to ensure validity and relevance. Several countries have developed quality standards that can be used as a basis for discussion by those which do not yet have them.

130. As has been shown in the work of Higginson and others, the audit technique is particularly useful method of evaluation in the area of palliative care, specifically for specialist multidisciplinary teams.(Higginson 1993) It takes the form of a systematic evaluation of a given activity in the form of a continuous cyclical procedure involving the setting of objectives or standards, observation of actual practice over a given period, analysis of the latter in the light of the objectives or standards set and the introduction of potential corrective measures.

131. This method centring on patients and their relatives makes it possible to evaluate all aspects of a service's activities, clinical and non-clinical alike. Its aims include not only constant quality improvement but also the training of professionals involved in the analysis process.

Research in palliative care

132. Since research has (or should have) as its primary goal to improve the quality of care for patients, we discuss it under the heading of quality rather than devoting a separate chapter to it.

133. Since the early years, research has formed an integral part of the development of palliative medicine and care and has been regarded as a priority. Palliative medicine is, or should be, no less evidence-based than other areas of medicine.

134. Thanks to research findings, significant progress has been made in the field of pain and symptom management. Research is rapidly developing in other areas of both medical and health services research; however, it still needs further development in most of the other areas, in relation to current and future needs. Many palliative practices are based on anecdotal and/or historic evidence and, in many cases, are not based on a scientific method or scientific evidence. Without wanting to underestimate the value of creativity and the use of unconventional treatment methods, the committee feels there is still much research to be done to separate the useful from the useless.

135. The relative lack of scientific research in palliative care may be explained, *inter alia*, by factors, which limit research work in this group of patients. We will address logistic and demographic factors, academic factors, and specific ethical problems associated with palliative care research.

136. The recruitment of patients for a given study is difficult and time-consuming owing to the very nature of palliative care. As far as research is performed within in-patient units and hospices, the small size of these facilities may hamper research. Furthermore, the patients who are considered sufficiently stable to take part in a study rarely stay for long in these units, and the patients who are sufficiently ill to stay there are seldom able to bear the additional burden which the study represents. As a result, few individual units have a level of recruitment sufficient to carry out a study within a reasonable time.

137. In addition to this, there are specific clinical features, which further complicate research in this field. The patients are often elderly persons suffering from a condition affecting many systems in the body, and not just one organ, which is usually severe and accompanied by many concurrent symptoms. The disease is progressive and its symptoms can change very quickly, particularly in the terminal stages. Survival time is limited and multiple medication use is common.

138. These various factors call for a sound research methodology, so that the design best suited to the goal set can be chosen. The design may be qualitative as well as quantitative in nature; because of the importance in palliative care of issues of meaning and of psychosocial and emotional problems, a qualitative approach may often be suitable. Fortunately, qualitative research methods are increasingly being accepted in medical science. However, methodological knowledge is not enough to face up to such a challenge.

139. In many countries, palliative medicine and care are not yet recognised as a separate discipline, but more as a philosophy of care that emphasises the human dimension. There are few links

with academic bodies, and there is little recognition by academic bodies of palliative care as a public health priority, in the same way as other areas of medicine. For this reason, most national research funds either do not regard palliative care as a separate area of research or do not regard it as a priority, and therefore do not make the necessary funding available.

140. Other possible obstacles in the development of a research culture in palliative care include the following: a lack of common evaluation procedures and under-use of such procedures; imprecise definition of palliative care; a lack of interest from pharmaceutical companies, except in a few profit-promising sectors, such as analgesia; and a lack of co-ordination between palliative care centres involved in research.

141. Research on the terminally ill has been questioned by some on ethical grounds, especially the particular vulnerability of this group of patients and their inability to take part in decision-making (high incidence of cognitive disorders) and/or to give free and informed consent (dependence on the institution in which they are being cared for, feelings of gratitude, etc). (Grande and Todd 2000; Hardy 1997; Kaasa and De Conno 2001) However, the great majority take the view that these challenges are not specific to palliative care and are to be found in other areas of medicine (geriatrics, intensive care, etc). Consequently, there is no reason to place palliative care patients in a special category and to apply to them an ethical code other than that contained in the Helsinki Declaration. (Crigger 2000) Research in the field of palliative care must, then, comply with the ethical principles governing all clinical research involving patients and be validated by an independent regional or institutional ethics committee.

142. However, particular attention must be paid to evaluation of the risks and benefits of a given research project, whose

interpretation may differ greatly according to the stage reached in the progression of the disease. The objectives of care usually change in the terminal stages, with quality of life becoming the priority over survival. It is therefore important to take account of the factors, which in many cases are non-biological, likely to modify the perceptions of patients, in terms of risks and benefits.

143. Even though the EAPC has done its best to encourage co-operation, there is, up to now, a relative lack of co-operation between researchers in palliative care from different European countries. If only because of the frequent difficulties in recruiting patients for clinical trials in palliative care, multi-national collaboration seems inevitable in this area.

Education and training of professionals and volunteers

144. Education of professionals and of the public is absolutely crucial to the development of palliative care everywhere. In many countries, three levels of education have been specified: a basic level, to be taught to all health care professionals, an intermediate level, to be taught to those within a profession who want to acquire specific expertise in palliative care without wanting to become palliative care specialists, and an advanced level, intended to those who do want to become specialists in palliative care.

145. The undergraduate curriculum for professionals is the first period in which students may be taught about palliative care. Many professional organisations such as the Royal College of Physicians in the UK, the European Association of Palliative Care have developed curriculum proposals. (Time for education in palliative care 1997; Barzansky et al. 1999; Billings and Block 1997; Mularski, Bascom, and Osborne 2001; Seely, Scott, and Mount 1997) Experience with undergraduate training for doctors,

even though limited, shows that it is feasible to teach the essential aspects of palliative care to undergraduates. Less is known about the effectiveness and feasibility of undergraduate teaching programmes for the nursing professions and for other non-medical professions.

146. In all palliative care education programmes and curricula, an important place is given to ethical dilemmas and to the way caregivers, both professionals and non-professionals, can deal with such problems. In such programmes, attention is paid to the awareness a student has of her/his personal values, for instance with regard to end-of-life issues, and the impact these may have on the care situation. Openness about these aspects is encouraged.

147. Important psychological aspects to be addressed in education comprise breaking bad news, the diagnosis and treatment of psychological disturbances such as anxiety, depression, and confusion. Also, the recognition of an altered cognitive state is an important part of the curriculum. The same applies to the support needed by patient and family.

148. Social aspects, such as the living conditions of the patient and his or her family, and the presence or absence of social and practical support are important issues in education.

149. One of the most typical subjects for palliative care education is the attention for spiritual and cultural aspects. Students should learn to understand the importance of such issues for patients in the last phase of their lives, to recognise the needs, and to organise the help needed.

150. Organisational aspects that are taught concern knowledge of the health care system and of the services available, recognising the statutory requirements, and the opportunities and

limits of teamwork. Undergraduate curriculum should contain all aspects above. Most of them can be integrated to the other ongoing education in medical school (seminars, training).

151. In many countries, palliative care is addressed in the framework of continuing medical education (CME) at the basic level. Some of the national medical associations provide or support such courses intended for the regular physician.

152. Over and above such regular CME-programmes, some countries have developed education at a more advanced level, but still for non-specialists (the intermediate level). An example of this is the distant learning course in palliative care developed at the University of Wales, or the training course for expert general practitioners developed by the Dutch College of General Practitioners. The aim of such courses is to give participants an opportunity to become experts in palliative care, whilst continuing to perform in their original specialty. Another example of higher-level university education is the inter-university diploma (DES) in Belgium, initiated by the Universite Libre de Bruxelles. Emphasis is on continuity of care, without a dogmatic border between curative and palliative care.

153. At a still more advanced level, there is the training programme for palliative care specialists, which is mainly developed in the European countries where palliative medicine is recognised as a independent speciality.

Communication

154. Good communication skills are an essential part in all areas of health care, and as such, are not specific to palliative care. Complaints regarding substandard care are often caused by ineffective communication rather than by inappropriate care.

Communication involves much more than the delivery of information. It is a process involving many people where the objectives include information exchange, mutual understanding and support, addressing difficult and sometimes painful issues and dealing with the emotional distress associated with such issues. It involves time, commitment and a genuine wish to hear and understand the concerns of another. In part, it is about providing answers; in greater part, it is about staying with the person when there are no answers and trying to empathise with their pain. It is not an 'optional extra', but a vital, inherent and necessary component of health care. Traditionally, many undergraduate health care curricula did not address the issue of communication. This deficit is now recognised and most curricula are now addressing the issue of communication.

155. Communication does not just involve the health care professional and the patient. It involves communication between health care professionals and family, patients and their family, (or those significant to the patient), and communication between various health care professionals in a range of settings. In order to facilitate prompt and effective communication between all parties, the following elements are required:

- education and training for all health care professionals in communication skills;
- hospitals and clinics should provide convenient and suitable space where private meetings may be held with patients and families;
- health care professionals must schedule time each week for meetings with patients and families, and also to communicate with other health care professionals ;
- health care professionals should have access to modern information technology facilities.

Communication between patient and health care professional

156. Patients will encounter a variety of health care professionals during the course of a typical illness. Each encounter provides an opportunity for communication. Some of what we communicate is by means of language; much of what we communicate is non-verbal. In general, patients will require honest, accurate, accessible and consistent information regarding their disease and its implications. Not infrequently, health care professionals and family members will feel the need to mislead patients because of a desire to maintain hope. This well-intentioned strategy may well lead to great difficulties as the disease process progresses. Bad news is always bad news, yet the manner in which it is delivered, and the extent to which patients feel supported, accepted and understood, will have a significant impact on their ability to cope with their new reality.

157. Moreover, there are clear emotional psychological limitations in the amount of threatening information which people may take up in one conversation: as soon as the bad news has been broken, further information usually is not heard at all in the blow of the real bad news. Therefore, spacing of information and giving patients and families the time to take in the bad news has proven to be essential. Existing step-protocols for breaking bad news (e.g. Buckman in 3) have proven to be very effective.

158. As a general rule patients should be offered such information about their disease, treatment options or prognosis, in a sensitive, supportive and honest fashion. In terms of patient autonomy and respect for patient choice, it is vitally important that patients have the necessary information so that they may make an informed choice. Cultural influences may well influence this process in the sense that some patients may attach less

importance to complete information than others and may more easily leave important decisions to others.

159. Cognitive impairment may make communication especially difficult in palliative care. It is important to take into account a possibly variable, cognitive impairment and to check regularly the extent to which it is understood.

Communication between patient and family members

160. In the palliative care setting, patients and families are often under stress. Not infrequently, there is little if any communication between the various parties involved. In such circumstances, there is enormous scope for misunderstanding and resentment. Individuals may feel that they are carrying an unfair burden of care. Old rivalries and jealousies may surface, and the entire process may rapidly spin out of control.

161. Health care professionals have a duty of care to identify and respond to this phenomenon. At least, they can model the fact that information may be shared and that people may be honest with themselves and with others about their feelings and emotions. A single family meeting can bring about a great deal of change and serve to rescue a situation that otherwise would rapidly degenerating into a cauldron of anger, bitterness and resentment.

162. Attention must be paid to the particular needs of children and adolescents. In very tense family situations, children are sometimes excluded from the process in a well-intentioned but misguided attempt to 'protect' them. Like adults, children need an opportunity to be heard and understood and should be integrated into the core family group to the greatest possible extent. Whilst needing a great deal of support and explanation,

children may also be a source of great comfort and support to their parents and to other adults.

Communication between health care professionals

163. A large number of health care professionals, drawn from a variety of disciplines and working in a diverse array of settings, may be involved in the care of a single patient. Consequently, it is absolutely necessary that facilities are in place for the rapid exchange of accurate, current and relevant information. Common problems in communication, apart from time constraints, include role definition, boundaries, and different philosophies of care. Like in families, the issue is not simply one of information exchange. Rather, it is necessary to understand another's point of view, particularly when there are differences of opinion regarding appropriate treatment strategies. In such circumstances, a 'case conference' may provide an opportunity for mutual understanding, with the expectation of arriving at an agreed position to offer a patient. It is advisable to have an opportunity for open exchange of opinions, preferably with an outside facilitator. For further information, see the next chapter.

Teams, teamwork and care planning

164. Because of the often complicated nature of the problems facing patients in advanced disease and their families, both generalist and specialist care mostly need to be delivered by an interdisciplinary team that is set to provide physical, psychological, social and spiritual support, with a mix of skills, delivered through an interdisciplinary, collaborative team approach. This is not specific for palliative care: all forms of complex care, both acute and chronic, demand multidisciplinary team work. However, team work in palliative care has a few specific characteristics: the involvement of non-professionals

such as volunteers and family members, the need of care for the carers, and the importance of emotional and spiritual issues (Cummings 1998). Although the evidence is still incomplete, there are sufficient indications that working in teams benefits patients in palliative care.

165. The extension of the team is flexible and determined by the needs of the patient; thus a minimum variety may consist of a family physician and a community nurse, but teams usually also involve social workers, psychologists, and volunteers. There is hardly any discussion that all those professionals and volunteers involved should have an opportunity to participate in team decision making; however, it is still a matter of debate whether the family should be considered members of the palliative care team. The fact that the family are often the most continuously involved caregivers would plead in favour of participation, but the fact that they are at the same time the "unit of care" pleads against.

166. A distinction is often made between interdisciplinary and multidisciplinary teams. The former attaches less importance to professional distinctions than the latter - essentially, the care is provided by the whole team, so that tasks are not always distributed according to the profession. The leadership of the interdisciplinary team is dependent on the task at hand, not on professional hierarchy, as is the case with multidisciplinary teams. Some authors have a clear preference for inter- instead of multidisciplinary teams. The committee has no general preference and believes that the type of team should be decided on the basis of the local situation and the problem at hand.

167. Although no research has been done into the differences between physician-led teams and others, it is the feeling of the committee that within specialist teams, at least the lead person in

each professional group should be a trained and acknowledged specialist in palliative care.

168. Since it is clear that, for patients, it is crucial to receive the same messages from different team members, communication is an important facet of team work. Teams establish transparent channels of communication so as to ensure that all team members have an opportunity to contribute to the care process and are informed of developments at the earliest opportunity.

Care planning and advance directives

169. Palliative care improves importantly when it is planned in an anticipatory manner.(Cummings 1998) Care plans address important symptoms and symptoms to be expected, but also actual and future psychosocial and spiritual problems. If that is done in a systematic and continuous manner, it may be possible to avoid unnecessary crises and hospital admissions.

170. Advance care planning usually involves discussing advance directives concerning medical decisions around the end of life, such as abandoning medically futile treatment, possibly life-shortening pain and symptom management, and sedation at the end of life; to the extent to which patients bring up the issue, physicians should be prepared to explain their views on physician-assisted death (assisted suicide and euthanasia). For a detailed discussion and a Council of Europe recommendation on the issue, the reader may be referred to the Council of Europe document 8421, date 21 May 1999, Protection of the human rights and dignity of the terminally ill and the dying.

171. In the context of this memorandum, it may suffice to emphasise that even though the ethical assessment of such decisions varies between physicians, there is a common view that

professional caregivers need to be capable of an open discussion with their patients(Quill 1996). Such openness may, in some cases, even obviate the demand for physician-assisted death. It is important that professionals receive sufficient training in the ethical dilemmas associated with caring for patients at the end of their lives to be able to develop a well-considered view on these issues and to discuss that view in an appropriate manner with patients and families. Ethical dilemmas may notably occur when a patient persistently wishes to die, even if there still are further palliative options available. More frequently however, dilemmas occur outside the area of physician-assisted death, for instance when palliative treatment, such as pain treatment with high dosages of morphine, may have or may be supposed to have undesired life-shortening (or life-prolonging!) effects.

172. Apart from the obvious ethical advantages of involving patients and families in establishing and monitoring management plans, there is some evidence suggesting that this also contributes to the perceived quality of care.

173. Since many caregivers, both professional and non-professional, regard providing palliative care as both rewarding and demanding, in varying ratios, it comes as no surprise that considerable attention is given, in the literature, to the theme of "caring for the carers". Although, again, evidence has not yet been established as to what is the best modality for such care, from an occupational health point of view, there is little doubt that some form of attention for the caregivers is useful. During team meetings the issue of caregiver burden can be addressed systematically so as to prevent breakdowns. This applies strongly to the burden of family members, as well for whom care is a mixture of occupational health care and regular care. Family meetings in the presence of the patient and one or two professional caregivers can be useful for the maintenance of a

strong family support and for the prevention of avoidable crisis situations.

174. Cummings describes an important, and often forgotten aspect of teamwork: that teams have to be built and maintained (Cummings 1998). Teams, especially palliative care teams, are said to have a life cycle, somewhat akin to individuals' life cycles: a first phase of idealistic enthusiasm, characterised by co-operation and charismatic leadership; a second phase with a strengthening of the management component, where the initiators may have increasing difficulty recognising themselves in the team, and a third phase where there is a combination of idealism with pragmatism.

Volunteers

175. It may be useful, in this memorandum, to pay specific attention to a category of caregivers, which is rather, although, not entirely, specific for palliative care: volunteers. Volunteers have an important, if often underestimated role in palliative care. They can offer the patient a readiness to listen. Because they have no professional obligations they can devote themselves fully to the patient, who often needs time to talk about his or her suffering. The presence of a third party (in whom it is easier to confide) enables the patient to feel on equal terms with someone and be recognised as a living person who is still part of society.

176. Another important task of volunteers may be to enable family members to take time off from attending to the sick person (which often eases their feelings of guilt), but also to express their emotions, and, after the death of the patient, receive support in their bereavement.

177. Volunteers may have an important function for professional caregivers, as well, because they may enable them to enlist the support of liaison persons, and also because voluntary helpers are there to give professional caregivers the time needed to go about their tasks. Professional caregivers may, through the volunteer, receive fresh information on the patient.

178. To be credible partners, voluntary helpers must be trained, closely monitored and approved by an association. Training is essential and must be preceded by careful selection. Willingness to help is not enough.

179. Voluntary helpers form a team working under the responsibility of a co-ordinator, who serves as a link between the voluntary helpers and the carers, and between the hospital and the association. They are supervised within the context of a support group.

180. Voluntary associations provide the structure needed for the introduction of voluntary helpers in hospitals. They are also essential for the provision of voluntary help at home.

181. In the interdisciplinary team, volunteers take nobody's place; they complement the work of others and do not encroach on it. They simply make their own specific contribution. Their role and the tasks, which they will perform, should be clearly defined. Professional caregivers and administrators must be perfectly comfortable with the presence of these non-health professionals.

182. In Belgium, the Royal decree from 1991 allowed financial support to different organisations and associations of palliative care, which are active both in institutions and at home.

183. In an age when the subject of death is taboo, the presence of voluntary helpers alongside professional caregivers also has an important symbolic value. Above and beyond their personal commitment, they represent society around the dying person. Their work evokes the neighbourly solidarity of the past, when people died at home. They 'resocialise' death and show that it is not only a matter for health professionals, but also a problem for society as a whole.

Bereavement

184. Bereavement support is regarded in the literature as an essential part of palliative care programmes and as a service that should be available in all settings where palliative care is offered: specialist palliative care units, general hospital, community hospitals and within the home care setting. The reason for this is twofold. Firstly, bereavement usually starts before the actual demise of the patient, because the palliative phase of disease is essentially a period of increasing loss, both to the patient and the family. Secondly, professionals in palliative care regard the family (not necessarily consisting of blood relatives) as the 'unit of care'. This makes it logical to continue, as far as necessary, the caring relationship with the family after the death of the patient (Doyle, Hanks, and MacDonald 1998).

185. Bereavement services are provided to help patients and families cope with the multitude of losses that occur during the illness and after the patient's death. Bereavement services should be offered based on a number of factors, including individual assessment, intensity of grief, coping ability of the survivors and their needs as perceived by each family. The effectiveness of bereavement support has been demonstrated by various research studies on professional bereavement services and professionally supported voluntary services. On examining these studies Parkes

concluded that bereavement services "are capable of reducing the risk of psychiatric and psychosomatic disorders resulting from bereavement" (Parkes 1980).

186. Addressing issues related to loss, grief and bereavement should begin as soon as palliative care begins, with the initial assessment and continue throughout the course of care. A family member who feels that their loved one was well cared for and who had an opportunity to express their concerns and to receive support, is well placed to conduct the difficult work of grieving. Equally, a family member who has serious misgivings about the quality of care offered to their loved one and to themselves, is more likely to experience complex grief reactions and to have a prolonged period of bereavement morbidity.

187. Support for families comprises help during the course of the disease and help during bereavement. These two forms of help are in fact closely linked: everything that has been experienced positively prior to the loved one's death will help in coping afterwards. Preparation for loss is already part of the grieving process. Bereavement support can therefore be provided before, during and after the loved one's death. It is an overall process. It may last a few hours or several months. Professional caregivers can help in many ways: they can help the family members to identify and communicate their feelings and emotions more clearly (ambivalence, guilt, frustration etc). By doing so, the team may help to resolve unresolved or conflict situations. Also, the health care team can play a role in helping with funeral arrangements and legal formalities relating to the deceased's will, etc.

188. Looking ahead to and preparing for the period after the relative's death can be regarded as an anticipatory bereavement process.

189. If emotions are repressed, the grieving process promises to be difficult; providing an outlet for them makes the grieving process easier. It is essential to provide a time and a place for this.

190. The image, which relatives will take away with them, plays an important role in the grieving process. After death, when there is often a great feeling of emptiness, the bereaved person feels isolated, vulnerable and incapable of coping with the new situation. Family and friends offer little support; the social fabric no longer offers the support that it once did. Bereavement support, as provided for in palliative care, fills this gap: memorial ceremonies, exchanges of correspondence, telephone helplines, individual discussions and support groups are as many expressions of a new form of bereavement care. Bereavement services should be particularly attentive to the needs of children and adolescents, whose way of understanding and coping with grief may be quite different to that of adults. Bereavement services should also recognise cultural differences.

191. There is a lack of systematic evidence of the effectiveness of different forms of bereavement support. Bereavement services are managed and co-ordinated by qualified, professional staff with degrees and training appropriate to their responsibilities. Volunteers who are trained in bereavement care provide bereavement support and are supervised by professionals.

Levels of bereavement support

192. Bereavement support may be divided into three levels (Worden 1999).

The **first level** is general bereavement support. This can be provided by well-trained staff and supervised volunteers. It is not counselling, although trained bereavement support volunteers will draw on appropriate counselling skills. It may be particularly valuable to those who lack social support or feel isolated from potential sources of support. This level would adequately meet the needs of the vast majority of those who require bereavement support.

The **second level** is bereavement counselling, which should be provided by suitably qualified staff attached to a specialist palliative care service or in the community. This counselling would be appropriate for those whose loss is more complicated, perhaps by the presence of additional stressors in their lives or inadequate coping mechanism.

The **third level** involves more intensive psychotherapy, requiring referral to specialist health professionals. This may occur in situations where a loss triggers an underlying layer of dysfunctional behaviour or a more pervasive emotional crisis.

193. Implicit in these three levels of support is the use of risk assessment, which can be used to guide discussions with individuals or families about the level of bereavement care that might be most suitable for them.

Glossary

Care for the caregivers indicates an activity in palliative care that explicitly addresses the difficulties and burdens for caregivers that can be associated with caring for a dying person. It may also involve bereavement care. It is an important element in the prevention of caregiver burnout.

Care plan: a document dressed up by the palliative care team with the patient and the family, and regularly revised, which specifies the needs and preferences of the patient and the family, the developments to be expected, and the tasks of the various professional and non-professional caregivers involved; a care plan is, as much as possible, anticipatory and focuses on the prevention of crisis situations.

Day care facilities are usually attached to specialist palliative care in-patient units. Patients may attend on one or more days each week. Services offered may be considered as medical (blood transfusions, review of pain and symptom management etc), social (shower/bath), rehabilitative (physiotherapy/occupational therapy), relaxational (massage) or diversional (art & crafts). Also, they serve to give the main carer an opportunity to have some free time.

Family: in the context of palliative care, the family comprises all non-professionals who, on the basis of a pre-existent affective relationship, are involved in the care for the patient. The family is often referred to as ‘the unit of care’; even though this may not literally be true (the patient should and does remain at the centre), it confirms the importance of the family both as providers and as in need of care.

Futility is a much-debated concept indicating the use of health care interventions that do not have any substantial benefit for the patient, in terms of prevention, diagnosis or treatment. It is related to the French notion of ‘acharnement thérapeutique’ (therapeutical fury), which is used mainly for curative or life-prolonging treatment.

Hospice care: there is no entirely satisfactory definition of hospice care. Originally, the concept referred to a form of care, developed in contrast to mainstream health care, where much of the work was done by volunteers, and where there was a strong focus on comfort care and spirituality. Nowadays, in many countries, hospice care is used synonymously with palliative care.

Hospice may mean an institution or a home care service. A distinction is sometimes made by low-care and high-care hospices.

Individual care plan: see under ‘care plan’.

Interdisciplinary refers to a type of teamwork, where care is given by the team as a whole; borders between disciplines and their competencies are seen as less important than in teams that work in a multidisciplinary manner.

Multiprofessional refers to the presence of more than one profession in a team. A multiprofessional team may consist of physicians and nurses and an array of other health care workers; it may work either in an interdisciplinary or in a multidisciplinary way.

National / regional palliative care plan: a strategy developed by policymakers, professionals, and patients the aims and principles of which are to achieve coverage, equity, and quality

(effectiveness, efficiency, and satisfaction) in the provision of palliative care. The common elements of a rational plan include the evaluation of needs, the definition of clear aims, the implementation of specific services, the measures on general/conventional services (very specially those with high prevalence of advanced patients and the based in the community), education and training, promotion of opioid availability, specific legislation, financing, elaboration of standards, and systematic evaluation of the outcomes.

Palliative care: there are various definitions of palliative care. This recommendation and explanatory memorandum uses a slightly revised version of the definition formulated by the WHO in 1990 and revised in 2002: The active total care of patients with advanced, progressive disease. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families.

Palliative medicine is the specific medical care of patients with active, progressive and advanced disease for whom the prognosis is limited, and the focus of care is the quality of life. It is part of palliative care.

Quality of life: the core aim of palliative care is optimal quality of life. This concept, however, has remained elusive and is difficult to measure in patients with advanced diseases. Measurement tools developed for trials in disease-modifying treatment mostly cannot be used in palliative care, especially the lack of attention for spiritual issues at the end of life. Quality of life measures based on the preferences of patients seem appropriate for palliative care.

Rehabilitation is the restoration, as much as possible, of functionality in patients with advanced disease in order to allow them to be as active as possible and to have an optimal quality of life. It may involve the work of physiotherapists and occupational therapists.

Respite care indicates a form of care intended to temporarily relieve family members of the care of a patient; this may be necessary, for instance, to allow for medical treatment of a partner, or for a holiday. Respite care may be provided in hospitals, nursing homes, homes for the elderly, or hospice. The limits between respite care, day care, and temporary hospital admissions for medical reasons can sometimes be unclear.

Specialised palliative care services are those services with palliative care as their core specialty and which are provided by an inter-disciplinary team, under the direction of a suitably trained and experienced palliative care professional.

Spiritual care focuses on issues of meaning and on existential and religious questions that often come up in patients and families facing an advanced, progressive disease. It is not restricted to patients with a religion, but addresses all, both a-religious and religious patients and their families, both before and after death.

Terminal care is a continuum of palliative care and usually refers to the management of patients during the final hours or days of life.

Volunteers are those caregivers who devote a part of their time to the palliative care of patients without being remunerated and without a pre-existent affective relationship to the patient. They

usually are co-ordinated and trained by a volunteer organisation.
Health care professionals may also act as volunteers.

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