NORWEGIAN ASSOCIATION FOR PALLIATIVE MEDICINE

STANDARD FOR PALLIATIVE CARE

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Introduction

Background

Palliative care is undertaken in all areas and at all levels of patient care. Palliative medicine is a natural part of most clinical specialties but also has characteristic features not covered by any existing specialty. Palliative medicine is developing into an independent field of specialization.

During the past 10 to 15 years, a variety of palliative care services have been established in Norway. In 2003, a DRG billing code was instituted specifically for palliative treatment.

Developments such as these led the Norwegian Association for Palliative Medicine to meet with the Specialist Council of the Norwegian Medical Association in order to discuss recruitment and training in the field of palliative medicine. The meeting, held in September 2002, concluded with the Specialist Council encouraging the Association for Palliative Medicine to develop a standard for the field. At the annual meeting of the Association for Palliative Medicine in November of 2002 a workgroup was established specifically for this task. The following document defines the standard for palliative care and the organization of palliative care services in Norway in the coming years.

When setting up the workgroup, geographic spread and representation from different medical fields were emphasized.

The workgroup consisted of:

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Dagny Faksvåg Haugen and Ørnulf Paulsen have served as secretaries for the group.

The group has had 5 meetings and 7 telephone meetings. The work was otherwise carried out via email and telephone. This project was financed by Quality Assurance Fund II.

The group has based its work on public surveys and other relevant reports and plans. In addition, the group members have contributed their own expertise and experience from this type of work.

The document was discussed in an open multidisciplinary workshop arranged by the Norwegian Association for Palliative Medicine on May 9-10, 2003. There were 34 participants with a broad range of experience from palliative care in Norway. The document was reviewed by the participants in autumn 2003, and their comments were considered in later stages of the process.

The group completed its work in November 2003, and the document was submitted to the Norwegian Medical Association the following December. The Norwegian Medical Association submitted the Standard for review within and outside the Medical Association in the spring of 2004. Commentary from this review has been incorporated into the document as it appears today. The workgroup collectively supports the recommendations made in the document.

The workgroup would like to note that a standard does not provide detailed guidelines for local application. The basic principles for organization are presented on page 16.

Palliative care is fundamentally a multidisciplinary field. Recommendations for organization pertain to the field in general. The portion of the document that deals with expertise naturally reflects the fact that it is published by the Norwegian Medical Association.

The field of palliative medicine is new and under rapid development. The workgroup considers that the document should be revised in three years' time.

Standards, Quality

QUALITY

A standard is a defined level of quality. By following standards in a professional area, quality is assured to be at least at a predetermined minimum. To set standards for palliative care and its organization will mean that more patients can receive effective palliative care. The use of quality standards in health care policy and prioritizing clarifies direction and therefore encourages better results.

To enforce a standard is only meaningful if quality can be measured and documented. This can, in turn, create a basis for evaluating a service. Questionnaires may be a burden for seriously ill patients. Thus, the value of such documentation and evaluation must be weighed against the potential burden for patients.

Health care professionals have a long tradition of focusing on the quality of treatment of the individual patient. Only recently have quality measurements been adopted as guiding indicators for hospitals and health care administrations. National standards for minimum quality within a field, with field-specific indicators to measure quality, might be used both in national policy-making and as a means to ensure best possible quality of care throughout the country.

The group suggests several indicators for surveillance of the quality of palliative care and its organization.

QUALITY INDICATORS

Quality measurements can be linked to structure, process, and results within a given area of health care, as shown in the example below.

Quality measurement for:

1. **Structure**
   The department has implemented the use of ESAS (Edmonton Symptom Assessment System, see attached) as a standardized method to evaluate symptom control (yes/no).
2. **Process**
   The number of patients to whom the ESAS is actually administered (percent of total patients in the department).
3. **Results**
   How many patients achieve a significant improvement of the defined symptoms as measured by the ESAS (percent of total patients in the department).

The workgroup's suggestion for quality indicators can be found in the chapter regarding basic palliative care, page 15.

NATIONAL ACTIVITY REGISTRATION

A common national registry for palliative care activity should be established. This will ease the work of reporting and evaluating. It will also serve as an important tool for leadership at all levels and assure the best possible quality of service throughout the entire country. Reports, including data from the registry, must be developed at a regional and national level. The Norwegian Patient Registry is the logical body to undertake this responsibility. A common national registry for palliative care will become easier when non-surgical procedure codes are complete.

GUIDELINES AND PROCEDURES

General clinical *guidelines* for palliative treatment should as far as possible be national. Further development of guidelines is a task for the Norwegian Association for Palliative Medicine in conjunction with the regional centres of excellence for palliative care.

Implementation of common *procedures* at all Norwegian health care institutions can be difficult due to varied local conditions. Specific procedures must therefore be developed locally or regionally. Through the development of manuals the different parties secure ownership of the methods, which eases their implementation and benefits patients.

All palliative teams and units in hospitals and nursing homes should have a manual with guidelines and procedures for quality palliative care. These should define availability, responsibility, and routines. Manuals must have predetermined expiration dates and a system for updating.

The specific content of guidelines and procedures falls outside the framework of this standard.

Definitions

WHAT IS PALLIATIVE CARE?

Palliative care is 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. Palliative care affirms life and regards dying as a normal process, and neither hastens nor postpones death.
- European Association for Palliative Care (EAPC) / World Health Organization (WHO)

Palliative care has its roots in the hospice movement, and the definition is founded on hospice philosophy. Palliative care as a specific medical field is characterized by the following:

- Relief of pain and other distressing symptoms. Physical, psychological, social, and spiritual/existential aspects are central.

- The patient and family require a comprehensive approach from many professional groups. The roles of physician and nurse are foremost, but chaplain, physiotherapist, social worker, dietician, occupational therapist, and psychologist can all play important roles in the treatment team.
- Close proximity to the home is central in planning treatment and care.
- Palliative medicine is scientifically based, just as other medical areas. There is a great need for research and development in this patient group.

TODAY'S PALLIATIVE CARE POPULATION

- The number of cancer cases is on the rise because of the expected increase in the absolute incidence of cancer and because the number of elderly persons is growing.
- Around 15,000 cancer patients in Norway today require qualified treatment for pain and other distressing symptoms.
- At least 15% of these patients have such complicated pain and symptom complexes as to require expertise which today is not sufficiently available in primary or secondary health care.

Patients with incurable, progressive disease often have reduced functional status and a need for polypharmacy and complicated and distressing examinations and treatments.

- In Norway, at least 95% of patients treated at palliative care centres are cancer patients with advanced, incurable disease.
- Patients with neurological disease largely comprise the remainder of this group.
- In countries with high incidence of AIDS, these patients dominate.
- There is an international initiative to extend palliative care to include other areas like advanced heart and lung disease.

In some earlier recommendations, the population of palliative care patients has been restricted to those with a life expectancy of less than 9-12 months. In reality, the palliative phase starts when the disease is classified as incurable and ends when the patient dies. Palliative care also includes grief therapy and bereavement care.

PALLIATIVE MEDICAL TREATMENT

Tumour-specific Treatment

Tumour-specific treatment consists of surgery and oncological treatment.
Oncological treatment includes:

- chemotherapy
- hormone therapy
- immune therapy
- radiation therapy

alone, or in combination.

Reduction in the size of a tumour is often the most effective method to prevent and palliate symptoms. In addition, modern oncological treatment has a documented life-prolonging effect in a large number of patients.

Up to 2/3 of oncological treatment in Norway are given to patients who cannot be cured of their disease. Oncological treatment is often divided according to treatment intention:

- curative
- life-prolonging
- palliative, symptom-preventing
- palliative, symptom-alleviating

It is primarily patients who receive treatment in the last two groups that are candidates for palliative care. Some palliative care patients may be offered treatment that both prolongs life and prevents symptoms, but the primary goal will be symptom relief (e.g., radiotherapy for bronchial obstruction). It is important that patients who require palliative follow-up are referred for such treatment as soon as the need arises.

Non-tumour-specific Treatment

Non-tumour-specific medical treatment is aimed at relieving distressing symptoms without reducing tumour size or cancer cell number. Such treatment can be divided into:

- pharmacological treatment
- non-pharmacological treatment

Non-tumour-specific treatment can in some cases have a life-prolonging or symptom-preventing effect (e.g., antibiotics for infection, fluids for disorientation, stenting of the bile duct for icterus).

The goal of palliative care is to give the patient and the family the best possible quality of life in the patient's remaining time. This is achieved through prevention and management of physical symptoms, as well as through the provision of information and interventions aimed at psychological, social, and spiritual/existential problems.

HOSPICE

The term hospice in Norway is not uniform in meaning and is not used in this document. The term is used to describe various services, which may include one or more of the following elements: palliative care team, palliative care unit, palliative care day centre, or palliative care outpatient clinic. The term hospice is also used nationally and internationally to describe a direction in medicine and a treatment philosophy.

The description and requirements of a palliative care team and unit as described below should also apply to those units using the term hospice.

National and International Surveys

The workgroup considers Nordic surveys most relevant for the development of a Norwegian standard. The surveys are based largely on experience from other countries in Europe, the USA, and Canada. Organizational recommendations are, on the other hand, dependent on the political framework in which the model is implemented. International programs primarily serve as clinical guidelines.

Two Norwegian reports have been central in the work:

- NOU 1997:20 " Omsorg og kunnskap! Norsk kreftplan" (Care and knowledge! Norwegian Cancer Plan)
- NOU1999:2 "Livshjelp. Behandling, pleie og omsorg for uhelbredelig syke og døende". (Life-help. Care for the incurably ill and the dying)

The Norwegian Cancer Plan includes recommendations for palliative care as a part of the total treatment and care offered to cancer patients. In the Life-help report these recommendations are further developed. A principle message is that palliative care is an integral part of the public health care system.

The Life-help Report offers recommendations for the organization of palliative care at all levels of health care:

- **Primary care:** Strengthened home care services and dedicated beds in nursing homes. At least one physician and one nurse in each municipality with expertise in palliative care to guide care providers.
- **2nd line care:** Dedicated units, outpatient clinics, and palliative care teams at larger hospitals.
- **Tertiary care:** Regional centres of excellence and departments/divisions for palliative medicine at university hospitals in all regions.

There are additional national and regional reports focusing on palliative care and its organization (see p. 45).

In broad terms, the recommendations from the national and regional reports are consistent:

- The primary care physician is primarily responsible for the patient in the home.
- The primary care physician and municipal health care services are linked to specialist care through a network consisting of a regional palliative care centre and one or more hospital-based palliative care centres.

Basic Palliative Care

This chapter describes principles for palliative care and defines standards for basic palliative care. These standards apply to all health care workers practising palliative care, regardless of field or treatment level.

The palliative care culture is characterized by:

- a holistic approach to the seriously ill and dying and their close ones
- respect for patients, their close ones, and colleagues, with a focus on the patient's best interests. This involves approaching the patient and the family with an understanding of their unique situation and circumstances.
- an active and goal-oriented approach to diagnostics and prevention and palliation of symptoms
- foresight and planning with regard to complications and needs that may arise
- a focus on open lines of communication and flow of information
- multidisciplinary collaboration
- coordinated services and systematic cooperation across service levels
- systematic cooperation with other medical specialty areas

Basic palliative care comprises:

– Assessment of Symptoms and Problems

Routine use of assessment tools: ESAS (TPAT, see attachment), pain chart, and MMSE (Mini Mental State Examination).

– Symptom Management

All departments offering palliative care should develop guidelines and procedures for symptom management that at the very least describe:

- general treatment principles
- treatment of
    - urgent conditions such as
        - acute severe symptoms: pain, nausea etc
        - spinal cord compression
        - superior vena cava obstruction
    - pain
    - other commonly encountered symptoms and conditions such as
        - gastrointestinal disorders
        - dyspnoea
        - anxiety and depression
        - symptomatic intracranial metastases

- INFORMATION

Systematic work to ensure that patients are informed about their situation and that they have understood the information they have been given.

- FAMILY MEMBERS

Routines for inclusion and systematic follow-up of family members, including children.

- TERMINAL CARE

All efforts should be made to permit the patient to die where he or she wishes, and to ensure dignity at the end of life.

The WHO has defined criteria for terminal care as follows:
The patient shall

- be informed about his or her situation
- have a private room
- not have to be alone
- be relieved of pain and other symptoms
- be given the opportunity to talk about existential and spiritual issues

This may entail the patient receiving medications subcutaneously (for example as a continuous infusion), and that important drugs like analgesics, anxiolytics, and antiemetics be readily available.

- GRIEF THERAPY AND BEREAVEMENT CARE

- Guidelines for grief therapy with general support, guidance and availability of professional help
- Predefined services for the bereaved, including counselling

- DOCUMENTATION AND COMMUNICATION BETWEEN INVOLVED PARTIES

Confidentiality and legal aspects

It is important that the form of cooperation does not neglect the requirement of confidentiality as described in the Health care Professional Law, Paragraph 25 (information to cooperating personnel). Informed consent (written) is preferred, but not always required, as stated in the Health care Professional Law, Paragraphs 25 and 45 (transfer of, distribution of and access to medical records). Informed consent is required to create an individual plan (see Instructions for the development of individual plans, Department of Health and Social Welfare, 2001). If the patient does not give informed consent, this should be documented.

Shared-access medical record / "home-based" medical record

Documentation that can be used by all involved parties must be a primary goal. The following are minimum requirements for documentation that should be available to both patient and health care professionals:

- list of contacts, including primary care physician, responsible hospital physician, and telephone number for home care nurse
- current medication list
- discharge summary from latest hospital admission
- ESAS form

Admission/Discharge

Standardized referral forms for palliative treatment / palliative care unit should be used. This should include:

- current problem
- list of medications
- contact nurse (including telephone number) in home care
- primary care physician (including telephone number)
- recent ESAS form
- planned follow-up

Discharge from hospital should be announced in a timely fashion. Discharge of complex patients should not occur just before the weekend. A discharge summary should accompany the patient and should include:

- events and status
- current medication list
- ESAS profile
- name of the person(s) responsible for follow-up and when this is planned
- advice regarding expected development and possible complications

Individual plan

Patients requiring coordinated care should have a plan that incorporates the specific areas as outlined in the Regulations for individual plans. The individual plan shall include

- a coordinator, for example a nurse from the municipal home care service
- shared-access documentation
- a responsible person for each service area
- a list of contacts and assigned responsibility, including during specific periods such as evenings, nights, and weekends
- follow-up
- clear guidelines for where and how admissions should be arranged. In cases of "open admission", this term should be clearly defined.

Common meeting places / Interactions

Joint meetings to plan ahead are useful, especially in cases of complex problems and when home care is planned. The involved care providers should be represented. The

initiative may come from the primary care providers, the hospital department, or the palliative care team.

Availability by telephone is important for home care nurses, primary care physicians, and hospital departments. Dialogue is especially important in the early phase of cooperation and when the patient is unstable, as is often the case toward the end of life.

Network collaboration

Certain routines should be recorded either in the manual or in written agreements, for example, routines regarding admission (to hospital and nursing home), individual plans, and routines/checklists at discharge.

Quality Indicators

Regular recording and reporting on the following indicators should be performed as part of the process to improve the quality of palliative care services. It is recommended that a selection of these be registered in the Norwegian Patient Registry's database.

Structure/Organization

Municipality / local authority:

- palliative care unit within nursing home* (yes/no)
- 24-hour availability of home-care nursing (yes/no)

Health care administration / hospital:

- palliative care team within hospital (yes/no)
- palliative care unit in hospital (yes/no)
- 24-hour accessibility to health care professionals (yes/no)

Process

Hospital:

- proportion of patients with skeletal metastases who have used the symptom registration form (ESAS) (percent)

Palliative care centre:

- Lapsed time (number of workdays) from received referral to commencement of investigation/treatment (number)
- proportion of patients who leave the hospital with a written discharge report (percent)

Results

Hospital:

- proportion of patients with primary diagnosis cancer having an NRS-score (Numerical Rating Scale, refer to ESAS) for pain at rest less than or equal to three at time of discharge. (percent)

*for small municipalities shared facilities may be more practical

Organization

Levels of Expertise and Treatment

The *palliative phase* is characterized by:

- complex symptoms that vary over time and often change quickly
- significantly reduced physical function and extensive, often continuous care needs
- simultaneous contributions from relatives and multiple professionals and levels of health care services (primary care physician, home care nurse, oncological outpatient clinic, hospital department etc)

Principles of Organization

- Palliative care shall be integrated in the public health care system.
- Basic palliative care shall be carried out in all hospital departments as well as in primary care services.
- All levels of the health care system shall have a service with special responsibility for and expertise in palliative care (palliative care team, palliative care unit).
- Palliative care needs to be flexible, dynamic, and easily accessible, with a clear delegation of responsibility.
- Organization of palliative care services requires holistic thinking and flexible systems incorporating home-care as well as hospital and nursing home care.
- Planning must take into consideration the size and constituents of the population and the geographic conditions.
- The organization must be open for local adjustments within each health care region.
- The principles of equal access to health care for the population and treatment at the lowest effective care level also apply to palliative care.

It is important to emphasize that through **close cooperation** across levels, optimal treatment with appropriate expertise at any given time can be achieved.

The workgroup is committed to an organizational model based on professional networks within each health care region, administrative area, and municipality. However, the responsibility for the organization and function of the individual services will naturally lie with the leaders at the different organizational levels.

Cooperation

The organization of palliative care should ensure that patients experience a *continuous treatment chain*. This can be enabled by:

- *Joint meetings* prior to discharge from hospital or nursing home, where the responsible physicians, nurses and other health care professionals meet with the patient and family in order to decide and arrange further follow-up, treatment, and a clear delegation of responsibility.

- Use of an *individual plan* in which the involved parties, with the patient's informed consent, share information and plan further follow-up and delegation of responsibility. It may be natural for the palliative care team to take the initiative to establish such a plan. Primary care physician, coordinator (home care nurse / resource nurse), responsible hospital physician, and, if appropriate, hospital nurse in charge of the patient should be named, with unambiguous assignment of responsibility (see below).

- *Easy transfer* of the patient between departments and levels within the health care system and by *exchange of expertise* between involved persons. Hospital staff must, for example, have the opportunity to visit the patient's home and to give instruction to municipal health care workers. Through close cooperation and delegation of responsibility, health care workers can be active participants in a network.

- *The palliative care team* functioning as a pivotal link between hospital and primary care, where the primary care physician has the overall responsibility.

- Palliative care units in hospitals and nursing homes providing *advice and guidance* concerning all aspects of palliative care, at least during regular working hours. The regional palliative care centre should provide this type of advice on a 24-hour basis.

- *Palliative care units* in hospitals and nursing homes taking urgent admissions.

- A *network of resource nurses* with common professional cultures, common routines and a common educational program.

Levels of Expertise

International experience suggests that the majority of patients with advanced, incurable disease benefit from, and therefore should have, an evaluation by a palliative care team. Patients with particular needs require admission to a palliative care hospital unit or nursing home unit (alternatively, a day ward). The particular treatment, nursing, and care needs determine the range of treatment options. Admission to palliative care hospital and nursing home units should preferably be short-term and goal oriented.

Through close cooperation between institutions in the region, patients with especially complicated symptoms and problems can also be offered the necessary treatment. Any expertise that a treatment team does not have can be obtained via the regional palliative care centre or other contacts within the network.

Tertiary care is assumed to have the highest level of expertise. The regional health care administration should delegate responsibility for follow-up on the organization of the palliative care services in the region to the centre of excellence within the regional palliative care centre. Responsibilities should include clinical services, professional networking, education and training, research, and development of the field. The centre of excellence should oversee a clear distribution of responsibilities and functions among all the relevant institutions in the region. This will in essence also include oversight of regular clinical hospital departments, outpatient clinics, and primary care services.

Responsibility

The concept of an individual physician overseeing a patient's management *(responsible physician)* is characterized by the physician's active role in both treatment and follow-up of that patient, including where legal aspects are concerned.

The primary care physician (GP)

- has the overall coordinating responsibility for treatment and care.
- "…shall be responsible for the patients on his/her list having access to primary care services, including consultations, home visits, and urgent care" (The Norwegian Medical Association's KS-agreement).
- should take leadership by actively initiating, prioritizing, coordinating, and following up the required diagnostics and treatment in cooperation with the specialist services. This also includes soliciting support from other professionals when necessary (e.g., home care physiotherapist, community chaplain, social worker) in order to ensure a holistic approach to the patient's problems and needs.

The responsible hospital physician

- is responsible for care and treatment of the patient as long as he or she is an inpatient, in accordance with Patient responsible physician regulations (Forskrift om pasientansvarleg lege m.m.).
- shall be clearly defined for the patient and documented in medical records.
- shall maintain the continuity and holistic nature of care, and address the patient's need for information; and should therefore, as far as is practical, be the same person – also in the event that the patient is moved between units in the hospital.
- shall attend to the patient's best interests, particularly at times of important changes of treatment regimens and strategies, such as consideration of the appropriateness of an operative procedure, fluid treatment, or termination of treatment.
- is responsible for bringing in other professionals when necessary in order to ensure a holistic approach to the patient's problems and needs.
- should make important decisions in cooperation with the patient's primary care physician.

The treatment-responsible physician

- is any physician who initiates, changes or terminates a treatment regimen.
- is responsible for his or her orders.
- should make any changes in cooperation with the patient’s primary care physician or responsible hospital physician, as far as this is possible.

The physician at the palliative care centre

- usually has a consultative role in relation to the primary care physician or responsible hospital physician.
- can also be the treatment-responsible physician. In this case, he/she will have responsibility for a specific treatment in a defined timeframe, for example, all analgesic medication in the period from 'day X' to 'day Y'. Such a temporal treatment responsibility can be useful to ensure good quality of the care.
- will, as a general rule, have treatment responsibility for patients admitted to the palliative care unit. In order to assure continuity of care, it is important to have close

cooperation with the responsible hospital physician at the patient's principal hospital unit.

The two first points also apply to *the physician at the pain clinic.*

The physician at nursing home, infirmary, and rural health clinic

- has treatment responsibility for patients admitted to the institution.
- should have close cooperation with the patient's primary care physician and responsible hospital physician.

The physician at the palliative care unit in these institutions will, in a similar manner, have treatment responsibility for the patients admitted to the unit.

The resource nurse

- can have a defined authority to maintain professional development and maintain procedures and guidelines within palliative nursing.

A nurse

- can in large degree have authority to
  - carry out practical procedures
  - follow up defined treatment regimens, for example, invasive pain treatment.

This often improves both continuity and quality. The responsible physician should define dosage limits for drug ordinations.

- shall be certified to carry out such procedures.

Other professionals in the palliative care team

- will in most cases have a consultative role in relation to the responsible physician and the remaining team members inside or outside the hospital.

System responsibility

- lies with the leaders at the various organizational levels.
- includes accountability for overall results; comprising responsibility for organization, collaboration, activities, and finances, in addition to fulfilling the defined professional standard.

The regional health care administration

- has responsibility for establishing the centre of excellence and the palliative care network at the regional level as described below, and for follow-up and quality assurance. This is enabled through prioritizing of economic funding and sufficient physician positions, follow-up of the quality indicators in 'NPR', and other factors.

Organizational Units

Hospital Departments

Tasks

All departments having cancer patients or other patients with a need for palliative care shall provide good pain and symptom management and competent terminal care.

Clinical Services

- The department shall be able to provide basic palliative care (pp. 12-15).
- The department shall know which patients should be referred to the palliative care centre, department of oncology, and pain clinic.

Organization

- There shall be a clear delegation of responsibility between the department and the palliative care centre/team with regard to shared patients. The palliative care team will normally have a consultative function.
- All departments (or wards) that have palliative care patients shall have a resource nurse who is part of the competence network in the region (p. 34).
- Staff should be offered guidance and supervision.

Personnel

- At least one physician in a permanent position should have expertise in palliative care (level B) (p. 38).
- All wards treating cancer patients should employ an oncology nurse specialist.
- The department shall have access to physiotherapist, chaplain, and social worker.

Facilities and Equipment

- Private rooms for seriously ill patients and terminal care.
- Meeting room.
- Facilities for families.

Departments of Oncology

Tasks

Palliative care is a large portion of the activity at a department of oncology. The department of oncology shall give good pain and symptom management, and has specific responsibility for the tumour-specific treatment given to palliative patients (see p. 9).

Clinical Services

The department shall be able to provide basic palliative care (pp. 12-15). Beyond this, there are three central modalities:

1. Pharmacological pain and symptom control

- Knowledge and skills should be sufficient as to offer the majority of patients optimal symptom management.
- At the same time it is important that patients in need of referral be identified quickly and referred promptly.

2. Radiation therapy

Palliative radiotherapy is especially important in the following conditions:

- pain due to skeletal metastases or tumour growth into nerve plexi. Effective pain control can be achieved in 50-80% of such cases.
- symptomatic cerebral metastases.
- spinal cord compression due to vertebral metastases.
- haemorrhage from the urinary tract.
- haemoptysis, dyspnoea, and cough due to tumours in the large airways.

3. Chemotherapy

- Palliative chemotherapy constitutes a central part of available treatment at a department of oncology.
- Generally, the reduction in tumour size caused by chemotherapy will also lead to a reduction in symptoms or delay of onset of symptoms.
- The oncological milieu is responsible for the use of effective chemotherapy.
- The profession also has a great responsibility to ensure that chemotherapy is *not* used when it is not effective or when the expectation of effect is very low.
- Improvement in quality of life shall be the goal of treatment.
- Toxicity resulting from ineffective chemotherapy is unacceptable.

Organization

- The department of oncology shall have organized cooperation with the hospital's palliative care centre. The cooperation shall include both research and development, and clinical services. There shall be a clear delegation of responsibility for shared patients.
- The department (wards) shall have resource nurses who are a part of the competence network within the health care region (p. 34).
- Continuing education of the staff must be prioritized.
- The staff shall be offered guidance and supervision.

Personnel

- The physicians shall have expertise in palliative care (minimum level B) (p. 38).
- The department should have a high percentage of oncology nurse specialists with expertise in palliative care.
- The department shall have a physiotherapist, chaplain, and social worker.
- The department should maintain cooperation with a dietician and a psychologist. Collaboration with a psychiatrist may also be warranted.

Facilities and Equipment

- Private rooms for seriously ill patients and terminal care.
- Facilities for families with the possibility of overnight stay.
- Meeting rooms.

Oncology Outpatient Clinics in Small Hospitals

Tasks

Small hospitals often do not have a palliative care centre or a department of oncology. The oncology outpatient clinic under these circumstances will have responsibility for palliative care at the hospital, with the potential for collaboration with a pain management outpatient clinic (NOU 1999:2).

Clinical Services

- The outpatient clinic shall be able to provide basic palliative care (pp. 12-15).
- The personnel shall know which patients should be referred to departments/teams with expertise in oncology or palliative care beyond that which is available at the outpatient clinic.
- The personnel have a consultative function for the other departments within the hospital and for the primary health care services.

Organization

- The outpatient clinic shall have organized cooperation with the departments within the hospital that treat cancer patients, with the nearest department of oncology, and with the palliative care centre in the same administrative area.
- At least one nurse at the outpatient clinic should function as a resource nurse and be a part of the competence network in the region (p. 34).

Personnel

- The outpatient clinic should employ an oncology nurse specialist.
- At least one physician and one nurse should have expertise in palliative care (level B for the physician, p. 38).
- The outpatient clinic should have access to a chaplain, social worker, and physiotherapist.

Facilities and Equipment

- Sufficient number of examination and treatment rooms.
- Meeting rooms.

The Hospital Pain Clinic

Definition

The pain clinics are consultative units for evaluation of problematic pain conditions. Services include:

- pain management outpatient clinics at small hospitals.
- pain management clinics at larger hospitals.
- multidisciplinary pain management clinics at university hospitals.

Tasks

All units shall attend to all types of difficult pain, including cancer pain among inpatients and outpatients.

Clinical Services/Organization/Personnel/Facilities

Refer to Department of Health Investigation series no. 2 1988: Smerteklinikkvirksomhet i Norge (Pain clinic services in Norway) (IK-2264) and Retningslinjer for smertebehandling i Norge, Den norske lægeforening 2004 (Guidelines for pain management in Norway, The Norwegian Medical Association, 2004).

The units shall have special expertise in the treatment of complex cancer pain and be able to provide the most common invasive and neurolytic treatment methods.
The pain clinic shall maintain organized cooperation with the palliative care centre (at the regional hospital: Regional palliative care centre). The pain clinic physician should be part of the palliative care team. The pain clinic and the palliative care centre should be colocated.

Regional Palliative Care Centre

Definition

The regional palliative care centre is the regional centre of excellence for palliative care. The centre consists of:

- a clinical division
- a centre of excellence

The centre shall strengthen and disseminate palliative care expertise within the region. It shall be an active catalyst for, and supporter of, the establishment and maintenance of the organized palliative care network within the region. The clinical division of the regional palliative care centre will also function as a hospital-based palliative care centre inside the catchment area of the hospital (see p. 25).

Tasks

1. Clinical Division

Functions as a hospital-based palliative care centre (p. 25) for the area in which the regional hospital acts as local and central hospital, as well as for the other departments within the hospital.

Regional functions as reference department for hospital-based palliative care centres in the region:

- Advice and guidance
- Admission of patients with especially complicated problems and symptoms. This also includes psychological, social, and spiritual/existential matters.
- Admission of patients in need of diagnostics, assessment, or treatment at the tertiary care level.
- Observation and teaching practice for health care professionals and students.
- Base for clinical trials and other research.

2. Research and Development / Centre of Excellence

- University unit with full time position in palliative medicine, professor and/or assistant professor (refer to NOU 1999:2).
- Undergraduate and postgraduate education for professionals involved in palliative care teams.
- Courses and seminars for primary care services and hospitals.
- Research and development, see page 42.
- Development of procedures and guidelines for its own administrative area, including the network of resource nurses, refer to hospital-based palliative care centre (p. 27). National cooperation regarding national guidelines.
- Support for planning the organization and expansion of palliative care services in the region.

Clinical Services

Refer to page 26 (Hospital-based palliative care centre).

Organization

- The regional palliative care centre may be organized in different ways. The centre may be a unit within another hospital department; however, in this instance it should remain physically distinguishable. The centre might also form its own administrative unit, divided into a centre of excellence and a clinical division.
- The centre of excellence should be a formal unit of the university's medical faculty.
- The centre shall have its own director, who will be accountable for results.
- Medical responsibility shall lie with the attending physician. The physician should have expertise in palliative medicine corresponding to level C (pp. 38-40).
- The regional palliative care centre shall cooperate with hospital-based palliative care centres in the region and with the other regional centres.
- The centre shall cooperate with palliative care units in nursing homes within its catchment area.
- The regional palliative care centre is responsible for the network of resource nurses within its catchment area.

- The centre shall work in cooperation with colleges of nursing and related institutions.
- The centre of excellence should be based throughout the health care region, for example, by way of decentralized positions or cooperative agreements.
- The regional palliative care centre shall have structured cooperation with the regional department of oncology and with the multidisciplinary pain management clinic at the university hospital. The palliative care centre and the pain clinic should be colocated.
- The centre's obligations within teaching, research, and development should be considered when staffing the regional palliative care centre. Due to greater obligations in these areas, staffing at the regional centre should exceed that of the other hospital-based palliative care centres. This applies to team members from all professional groups.
- Time and personell shall be allocated to research and development.
- The regional palliative care centre shall respond to inquiries from health care professionals. 24-hour availability should be sought.
- The number of beds must be determined according to both local and regional hospital functions. Bed number must be consistent with population size and practicality.
- Staff should have individualized plans for professional development and education. Continuing education must be adapted and prioritized. Staff shall be offered guidance and supervision.

Personnel

Refer to p. 28 (hospital-based palliative care centre).

Facilities

- Separate, appropriate facilities for the clinical division and the centre of excellence.

Hospital-based Palliative Care Centre

Definition

1. Consists of a multidisciplinary treatment team *(palliative care team)* with ambulant function for home visits and consultative work within the hospital departments. The team members have broad expertise in palliative care.
2. The centre can also include beds *(palliative care unit)*. These are acute care beds with focus on problem solving with active diagnostics and treatment. Short length of stay is intended.
   A palliative care unit with 2-6 beds should be able to serve a population of 150-200,000.
3. The centre is responsible for the competence network of resource nurses in the administrative region.

1. The Palliative Care Team

Tasks

- Ambulant service to patients' homes and nursing homes
- Outpatient consultations
- Consultative work in other hospital departments

- Assessment and planning prior to admission to the palliative care unit
- Pain and symptom management in the palliative care unit
- Assessment, advice, and efforts in relation to social and spiritual/existential needs

The palliative care team shall have a broad base of expertise in acute palliative care. The team is a central link between primary and secondary health care services. The team shall have weekly meetings where patients are discussed.

Any expertise that the palliative care team lacks should be accessed through contacts in the hospital, other areas of the health care region, or from outside of the region when no other options are available.

2. The Palliative Care Unit

Tasks

- Acute care beds with emphasis on problem solving. Short duration of stay is a goal (e.g., 5-7 days).
- Active diagnostics and treatment in relation to symptom management and rehabilitation.
- Planning of patients' future follow-up.
- Possibility for stay during terminal phase.

Clinical Services

- Assessment, evaluation, and efforts in relation to
  - physical
  - psychological
  - social
  - spiritual/existential

  symptoms and needs
- Advanced procedures for pain and symptom management such as
  - subcutaneous and intravenous infusion of medications
  - fluid and nutrition therapy
  - opioid switch
  - epidural and spinal catheters for pain treatment
  - neurolytic blockade, minimum coeliac blockade
  - potential for terminal sedation to the dying (possibly in cooperation with the ICU)
- Assessment and provision of relevant oncological treatment, possibly through further referral
- Unhindered access to laboratory services, radiology (CT and MRI), isotope studies, treatment rooms for invasive procedures
- Systematic support for families
- Systematic grief therapy and bereavement care
- Systematic use of individual plans
- Ready accessibility for cooperative partners. In urgent cases, same or next day consultation.

Research and Development

Research and development are principal functions of the palliative care centre. Together with the regional palliative care centre, these functions should include:

- development of procedures and guidelines for the local health care administration, including the network of resource nurses
- teaching: thematic in-service training days, courses, and seminars for primary and secondary care staff
- observation and teaching practice for different professional groups
- systematic teaching and/or observation for those receiving training at the hospital
- participation in research and development projects

Organization

- The palliative care centre may be organized as a unit within another hospital department; however, in this instance it should remain physically distinguishable.
- The centre should have its own budget and result-accountable director with clearly defined responsibilities.
- Medical responsibility shall lie with the attending physician.
- The palliative care unit should have sufficient nursing coverage, preferably one nurse per patient at daytime. Small units may find it practical to have partly shared staff with another ward/unit during evenings, nights, and parts of the weekends.
- The centre shall have formalized cooperation with the pain management clinic and the department of oncology.
- The palliative care centre and the pain clinic should be colocated.
- The centre shall have organized cooperation with its regional palliative care centre and with palliative care units in nursing homes in its catchment area.
- The centre should have organizational responsibility for the network of resource nurses in its catchment region (see p. 34).
- Staff should have individualized plans for professional development and education. Continuing education must be adapted and prioritized. Staff shall be offered guidance and supervision.
- Time and personnel shall be allocated to research and development.

Patient responsibility

1. Ambulant function: The palliative care team will have a consultative function (advice and guidance) for the responsible hospital physician or the primary care physician and the remaining treatment team inside and outside the hospital. The team may take over treatment responsibility for shorter periods such as at the start of specialized treatment.
2. Palliative care unit: The attending physician and additional staff are responsible for the patients admitted to the palliative care unit.
3. On-call services: On-call service and possible shared call must be clearly defined with explicit assignment of responsibility, for example, shared call with the department/section that the palliative care centre is organized under.
4. Follow-up after discharge: At the time of discharge from the palliative care unit, all relevant parties shall be informed and responsibility assigned according to the individual plan. Location for the next admission should be agreed upon at this time. If the term "open admission" is used, this must be clearly defined.

Personnel

With the exception of office staff, personnel should have clinical experience in palliative care.

Physicians

- The number of physicians on staff depends on the patient load. There should be at least one consultant with specialist qualifications in a relevant clinical specialty. The consultant should have level C expertise in palliative medicine (pp. 38-40) and the ability and willingness to cooperate with other specialties and professions. The physician's primary workload should be within the area of palliative care.
- Additional specialists should be permanently engaged as (part-time) staff or consultants. In addition to an oncologist and an anaesthesiologist, an internist, surgeon, psychiatrist, and/or general practitioner are relevant. In order to create a professional working environment, it is important that several physicians are employed at the centre.
- Fellow doctor (in rotation).

Nurses

Ambulant function

- at least one full time nursing position in the ambulant team. The nurse should have experience in palliative care and appropriate specialized training.

Palliative care unit

- The palliative care unit should have a reinforced experienced nursing staff with relevant specialized training (see p. 40).

Office staff

- Sufficient for clinical service functions, research, and development

Other professional groups

- physiotherapist
- chaplain
- social worker

These three professionals should always be linked to the palliative care centre. In addition, larger centres should also have a dietician, occupational therapist, and psychologist/ psychiatrist (see above).

Facilities and Equipment

- Quiet, private rooms
- Facilities for families, including the possibility for overnight stay
- Family meeting rooms
- Personnel meeting rooms, on-call room, and sufficient office space

DAY CARE

Definition

Outpatient palliative care provided as day care (more than 5-hour duration).
Day care can be given in the outpatient clinic at the palliative care centre, in the palliative care unit, or on a separate day care ward.

Tasks

Day care is appropriate for palliative care patients with moderate treatment and care needs, and minimal nursing needs. Experience shows that day care is effective to

alleviate patients' symptoms and allow for careful follow-up in order to sustain quality of life. In addition, patients are able to function for longer periods outside the institution. A minimum number of patients is needed to warrant opening a separate day care service (ward).

Clinical Services

Day care shall be a medical service and include physician and nursing services and access to all members of the palliative care team.

- Assessment, evaluation, and efforts in relation to
  - physical
  - psychological
  - social
  - spiritual/existential

  symptoms and problems
- Assessment and provision of relevant oncological treatment, possibly through further referral
- Unhindered access to laboratory and radiology services
- Systematic support for families
- Systematic grief therapy and bereavement care.

In addition, day care can include services of a more socio-medical nature to improve coping and overall quality of life.

Organization

Day care is provided at the palliative care centre. If day care is given on a separate day care ward, this shall be a part of the palliative care centre. Refer to the section describing the regional palliative care centre (p. 23) and the hospital-based palliative care centre (p. 25) for further information regarding organization.

Personnel

The day care ward shall have its own nurses, or caregivers may rotate between the palliative care unit and the day care ward. The positions for other professionals in the palliative care team must be adequate to cover the number of patients receiving day care.

Facilities and Equipment

The day care ward shall include

- a doctor's office
- sufficient examination/treatment rooms for consultations with other members of the multidisciplinary team
- meeting rooms
- relaxation room
- kitchen and dining/living room
- activities room (optional)

If day care is provided in the outpatient clinic or the palliative care unit, these should be equipped accordingly.

Palliative Care Unit at Nursing Home, Infirmary, or Rural Medical Centre

Definition

A unit within the nursing home allocated to care of the palliative care patient and his/her family. The unit shall admit patients in need of palliative care beyond what regular nursing home wards can offer.
This definition is also applicable to palliative care units at infirmaries and rural medical centres.

Tasks

- Short-term stay for adjustment of symptom management.
- Short-term stay for respite care, when this cannot be given in a regular nursing home ward.
- Short- or long-term stay with competent medical treatment, nursing and care until death.

Patients may be admitted from home or hospital.

Palliative care units in nursing homes will vary with regard to size, staff, clinical services, and patient complexity, from "1&1/2 line services" (with hospital cooperation) to designated palliative care beds in smaller municipalities. This means that the medical services will vary and that the level of advanced treatment will reflect medical and nursing expertise.

Clinical Services

- Assessment, evaluation, and efforts in relation to
  - physical
  - psychological
  - social
  - spiritual/existential

  symptoms and problems
- Procedures for pain and symptom management such as
  - subcutaneous and intravenous infusion of medications
  - subcutaneous and intravenous administration of fluids
  - blood transfusion
- Qualified nursing of cancer patients
- Physiotherapy
- Laboratory services
- Protocols for referral to palliative treatments (e.g., radiation treatment)
- Systematic support for families
- Systematic grief therapy and bereavement care

Organization

- The nursing home is integrated in the municipal health care plan, and the unit is organized as part of the nursing home.

- The palliative care unit may be organized as a separate unit, or as part of another department/ward in the nursing home; however, in this instance it should remain physically distinguishable.
- Admissions are determined at the municipal admissions meeting in cooperation with the physician and home care nurses. Patients can be referred directly from the hospital-based palliative care centre if a previous agreement to this end is reached.
- The unit shall have its own care staff and shall be well staffed with nurses. Care staff should exceed that which is required by regular nursing home wards. The unit should strive to have one nurse per two patients at daytime. Small units may find it practical to have or partly have shared staff with another ward/unit during evenings, nights, and parts of the weekends.
- The unit shall have more extensive physician coverage than is required on regular nursing home wards. The unit physician shall engage in 2-3 hours' service per patient per week. It is preferable that the physician be available by telephone during the working hours when not present in the unit. In the case of a planned absence, an alternate physician shall be engaged who shall be informed about the patients.
- As-needed medication, advance prescriptions, and information supplied to colleagues should minimize reliance on the on-call service physician who has no or limited information about the patients.
- The unit shall cooperate with the primary care physicians and municipal home care nurses.
- The unit shall cooperate with the hospital-based palliative care centre in the administrative region. Arrangements should be made for coordinated multidisciplinary updates, observations, and meetings.
- The regional palliative care centre should have regularly scheduled audits.
- A nurse from the unit should be a member of the network of resource nurses in the region (see p. 34).
- Continuing education and training should be adapted and prioritized. Staff should be offered guidance and supervision.

Personnel

Physician

- A permanent on-site physician must be assigned to the unit. The physician should be a specialist in general practice (or other relevant clinical specialty) and shall have expertise in palliative medicine corresponding to level B (see p. 38; level C is recommended for larger units). The physician should have the ability and willingness to cooperate with other specialties and professions.
- A physician from the hospital-based palliative care centre (palliative care team) in the administrative region shall have a consultative function to the unit.

Nurses

- Preferably nurses with relevant specialty training (see p. 40)

Assistant nurses

- Assistant nurses can also be employed in the unit.

Other professionals, in part-time positions or as consultants

- physiotherapist
- chaplain
- social worker

Facilities and Equipment

- Private rooms with bathroom, technical nursing facilities such as lift and beds with optimal positioning capability
- Facilities for families with possibility for overnight stay
- Meeting room
- On-call room and doctor's office
- Living room and kitchen facilities preferable

Palliative Care in Nursing Homes without a Designated Palliative Care Unit

Tasks

Provide effective symptom management and competent terminal care to all patients in the nursing home.

Clinical Services

- All nursing homes shall be able to provide basic palliative care (see pp. 12-15)
- All nursing homes should develop quality assurance measures for pain and symptom management and for terminal care

Organization and Personnel

- At least one nurse from the nursing home should be included in the network of resource nurses in the administrative region (p. 34).
- The nursing home physician should hold level B expertise in palliative medicine.
- Physician services should be organized so that use of public on-call physicians is kept to a minimum.

Facilities and Equipment

- Private rooms for terminal care
- Facilities for families
- Meeting room

Home Care

Definition

The palliative care that the patient and family require when the patient spends all or most of the end stage of life in the home.

Tasks

- To arrange for patient and family, the necessary physician, nursing, and care services at any given time.

- To coordinate services around the patient.

Clinical Services

Basic palliative care shall be practised (see pp. 12-15). The service shall include:

- home care nursing
- assistance obtaining the necessary aids and equipment
- follow-up and essential home visits from the primary care physician
- assessment, evaluation, and efforts from other professionals in the community as needed (e.g., chaplain, physiotherapist, social worker)
- essential cooperation with specialist services, including palliative care team
- referral to, and cooperation with, nursing home or palliative care unit in nursing home, as needed

Organization

- Responsibility for home care will primarily lie with the municipal home care nursing services and with the patient's primary care physician. Some locations have unique solutions, for example, Fransiscushjelpen in Oslo, which is an ambulant service with 24-hour availability.
- Home care nurses and the primary care physician shall cooperate with the hospital-based palliative care team when necessary to give effective treatment and care. The palliative care team will primarily serve a consultative function.
- At least one nurse in each community/district should participate in the network of resource nurses in the administrative health care region (see p. 34). If an oncology nurse specialist is employed in the home care service, it is appropriate for this nurse to serve that function. The resource nurse shall assist the remaining staff in home care nursing with advice and guidance, and may also be involved in the hands-on nursing as is necessary. The resource nurse is the contact person for the hospital-based palliative care centre in the administrative health care region.
- Patients who need complex services have the right to a coordinator from the primary care services, as stated in the individual plan. This function should normally fall on the resource nurse or another nurse from the municipal home care nursing service.
- Home care must be organized such that the patient and family have 24-hour access to qualified help. This means:
    a. 24-hour home care nursing service must be available. Mobile phone number for home care nursing shall always be available to patient and family (see p. 14).
    b. The coordinator shall ensure that there are planned visits in the home according to patient needs.
    c. The primary care physician should conduct home visits as agreed with patient/family and the home care nursing staff. A routine for physician services outside office hours must be developed.
    d. In the case of planned absence, the primary care physician must arrange an alternate physician and provide information regarding patient/family and any possible problems that may arise.
    e. The primary care physician has coordinating responsibility for the medical treatment of the patient. In special cases the hospital-based palliative care team can assume responsibility for treatment (see pp. 18-19 and 27).

Personnel

- Physician: the patient's primary care physician
- Nurses: sufficient nursing staff from the home care nursing service. All municipal home care services should have an oncology nurse specialist on staff.
- Assistant nurses can also work with palliative care patients in home care.
- Other professionals (e.g., physiotherapist, chaplain, social worker) should be brought in as needed.

Competence Network of Resource Nurses

Definition

A network of nurses with defined responsibility and purpose within palliative care in the administrative health care region.

- There should be a resource nurse in each community/district, in each nursing home, and at each hospital department (or ward) that treats cancer patients.
- The network is essential in order to maintain continuity of care to cancer patients and to disseminate knowledge and expertise regarding palliative care in the entire health care region.
- The network model is consistent with the suggestions of NOU 1999:2: "At least one nurse and one physician in the municipal primary care services shall have expertise in palliative care and assist other personnel in the services".

Tasks

The network has the following functions:

1. Clinical services in the workplace
   The resource nurse has special responsibility for:
   - organization of nursing and care services for cancer patients in need of palliative care in their department/district (refer to Basic palliative care, pp. 12-15).
   - advice and guidance for colleagues (need not be the nurse in charge of the patient).

   It is appropriate that the resource nurse:
   - together with the department head, is responsible for efficient systems and routines for follow-up and nursing of palliative care patients, including terminal care.
   - has an overview of the palliative care patients in his/her department/district.
   - is informed and consulted about these patients.
   - often serves the role of coordinator for individual plans.
   - is the contact person for the palliative care centre.

   The resource nurse in the hospital can function as a link between his/her department and the primary care services (often referred to as the contact nurse).
2. Cooperation – system work:
   - The network shall develop and implement routines for cooperation and collaboration in the area, for example, routines for admission and discharge from hospital, checklists, and guidelines for "open admission".
3. Strengthening competence
   - The resource nurses shall be offered appropriate training when they are designated for this function.

- They shall also receive systematic continuing education, training, and follow-up.
- The resource nurse has responsibility to disseminate his/her skills and knowledge in the workplace, including information regarding common and cooperative routines.

Organization

- The palliative care centre is responsible for the competence network of resource nurses within its administrative health care region.
- A "leadership group" with leaders from hospital departments and municipal primary care services should be set up. The resource nurses should be represented in the leadership group.
- It may be appropriate to cooperate with other institutions and organizations, such as colleges of nursing or the Norwegian Cancer Society, regarding operation of the network.
- The network should meet at least once every 6 months, focusing on cooperation and improving expertise.
- The employer must accommodate the resource nurse's need to participate in network meetings and other relevant courses/conferences.
- The employer must accommodate the daily work of the resource nurse such that he/she is able to perform this function.
- The resource nurse should be given the opportunity to observe at the palliative care centre, oncology outpatient clinic, or department of oncology, preferably through a structured observation program.
- The resource nurse should be offered guidance and supervision.

Personnel

- If an oncology nurse specialist is employed in the home care service, it is appropriate for this nurse to serve as resource nurse. All municipal home care services should have an oncology nurse specialist on staff.
- Multidisciplinary postgraduate education in palliative care is also an appropriate background.
- Where there are no nurses with appropriate training, the resource nurse position must be given to nurses who take a special interest in cancer patients, work with this patient group, and are personally well-suited for the role.

Volunteers

Definition

A corps of volunteers can be built up within palliative care services. The role of the volunteer is independent of profession and largely unrelated to age. Volunteer assistance is intended to supplement that of professional staff. Volunteers shall not participate in the provision of medical treatment, nursing and care. Volunteers shall take an oath of patient confidentiality in the same manner as medical staff, but are not bound by the Health care Professional Law. Details with respect to confidentiality must therefore be clearly defined.

Tasks

1. Adapt the environment (e.g., in the palliative care unit in nursing home or on day care ward) for the patient and family so that they feel supported through holistic care.
2. Give practical assistance such as:
   - completing practical tasks in the home
   - transport/accompany in travel
   - being present with the patient when family members must be away
   - watching over the patient
3. Help medical staff with tasks that are not treatment or nursing tasks but are being carried out by them, like
   - preparation and serving of food
   - measures to improve welfare
   - secretarial work

Volunteers can be useful in home care, nursing homes, and hospitals.

Organization

1. The institution or municipality itself has formal responsibility for its volunteers.
2. Designated employees, primarily a nurse, must administer and take responsibility for the daily function of the group. In the communities, the public volunteer centres usually serve this function.
3. All volunteers shall have preparatory teaching and training. They shall have regular follow-up, guidance, and supervision during their service.

Cooperative Partners

THE NORWEGIAN CANCER SOCIETY

The Norwegian Cancer Society is a national non-profit organization that supplements public health care. One of the goals of the Cancer Society is to assure the best possible quality of life for cancer patients and their families. The Cancer Society has 19 centres of excellence for cancer care throughout the country (2004).

In the area of palliative care, the Cancer Society is an important advocate and partner in the following areas:

- Help and support for cancer patients and their families
- Information and teaching to patients, family members, health care workers, and school and kindergarten personnel.
- Creating a network of health care workers in cancer care. In many locations, the Cancer Society is a natural cooperative partner for palliative care centres in establishing a network of resource nurses.
- Financial support for research
- Providing information to the public

THE NORWEGIAN ASSOCIATION FOR PALLIATIVE CARE

The Norwegian Association for Palliative Care is a multidisciplinary, national umbrella organization for all professionals working in or taking an interest in palliative care. The association arranges national conferences, regional courses in palliative care, and similar projects. Information on the Norwegian Association for Palliative Care can be found on their internet website.

Expertise

A fundamental prerequisite for optimal palliative care is that all health care providers have the necessary professional expertise. The term "professional expertise" refers to knowledge, skills, and attitudes.

PHYSICIANS

Levels of Expertise

In Great Britain, palliative medicine has been recognized as a medical specialty since 1987. The British curriculum for palliative medicine has also been the basis for EAPC's recommendations and the Swedish training plan in palliative medicine (see references p. 45). Since palliative care is carried out at all levels of the health care system, these documents distinguish between three different levels of expertise within palliative medicine. The workgroup has adopted this model.

Level A	Basic expertise. This is required of all physicians, and must be acquired in medical school.
Level B	Necessary expertise for physicians who have palliative care as a part of their clinical practice. This includes, but is not limited to, primary care physicians, surgeons, gynaecologists, and pulmonologists who treat palliative care patients as a part of their work.
Level C	Necessary expertise for physicians who lead or work in a palliative care team or unit. This level is consistent with specialist level.

The curriculum includes the following topics:

- Physical aspects: the natural history of disease, pain and symptom control, pharmacology, comorbidity
- The imminently dying
- Psychosocial aspects: care of the family, communication, psychological reactions, grief and bereavement
- Religious and cultural aspects
- Ethical aspects
- Multidisciplinary teamwork. Approach to the palliative patient and decision-making
- Organizational aspects
- Research and development. Audit, quality improvement, and research methods in populations with advanced disease.

Several of these topics are not included in any specialist training program in Norway today.

All physicians who treat cancer patients shall

- be familiar with different types of pain and the effect of different palliative treatment methods
- be able to assess, investigate, diagnose, and evaluate pain and other symptoms
- be familiar with and able to use common symptom assessment tools (ESAS, pain chart, MMSE)

- understand the significance of adequate diagnostics in order to clarify the cause of pain and other symptoms, and be able to carry out, or refer for, such diagnostic procedures
- be able to prevent and treat pain, nausea, constipation, and other distressing symptoms in cancer
- have insight into urgent/emergent conditions in cancer patients, especially spinal cord compression, superior vena cava obstruction, and hypercalcemia, and their treatment
- ensure that patients are adequately evaluated and referred for tumor-specific treatment
- be familiar with the WHO analgesic ladder
- be able to set up a syringe driver for subcutaneous infusion of analgesics or other drugs such as antiemetics
- be familiar with treatment complications and side-effects and their management.
- have protocols for referral to appropriate palliative treatment for patients with incurable cancer
- engage in multiprofessional cooperation with other specialties and professions and be able to develop a care plan where physical, psychological, social, and spiritual/ existential aspects are taken into consideration
- be able to make ethical decisions together with the patient, family, and other health care professionals

Expertise at level C shall equip the physician for full-time work as consultant in specialist palliative care (palliative care team / palliative care unit) with responsibility for a significant number of patients with advanced, life-threatening disease and complex problems. This responsibility includes:

- understanding the pathology and natural history of the disease, including basic understanding of the pathophysiological processes
- diagnosis, prevention, and treatment of pain and other distressing symptoms in patients with advanced, life-threatening disease, using a holistic approach that takes into consideration physical, psychological, social, and spiritual/existential aspects
- daily assessment and evaluation of the degree to which pain and symptom control is achieved
- summoning physicians from other specialties when necessary for diagnostics or treatment
- active contribution to team-building and cooperation between the professionals in the multidisciplinary palliative care team
- teaching and information about palliative care to colleagues, other health care workers, and the public
- coordination of services together with the patient's primary care physician such that the patient and family experience a continuous chain of treatment services
- cooperation with other professional groups to prevent pathological grief in family members
- providing advice and guidance concerning clinical problems to colleagues within and outside the hospital
- participation in research and development within the field of palliative medicine

Education

Level A: All faculties of medicine shall give their students a basic education in palliative care. The students should be examined in the field at least once in the course of their study.

Level B: All relevant specialties such as oncology, surgery, gynaecology, internal medicine, and general practice should be encouraged to consider introducing mandatory courses in palliative care in their specialty training. The Norwegian Association for Palliative Medicine runs courses in palliative medicine corresponding to level B, including a course especially designed for the general practice specialty. In specialty training for oncology, training programs at all institutions should include a mandatory minimum 3-6 month rotation at a palliative care unit.

Level C: The associations for palliative medicine in the Nordic countries have together developed a two-year course program which gives specialists in relevant clinical fields expertise in palliative medicine level C. In addition to this theoretical education, candidates must have relevant clinical training. It is a goal that all consultants at palliative care centres have this formal education and the necessary clinical practice.

OTHER PROFESSIONALS

The Nordic Cancer Union will complete a multidisciplinary curriculum in 2004. This curriculum will also specify levels of expertise for other professional groups in the palliative care team. As for now, no specific requirements for formal expertise have been developed. There is also no formalized postgraduate education in palliative care for other professionals.

Generally, it is important that all professional groups represented in the palliative care team sharpen the expertise within their own fields in order to be able to contribute in an optimal way to the multidisciplinary services provided to patients and their families. It is also important that all professions concerned partake in research and development.

The network of resource nurses in palliative care is described on page 34. Similar regional networks should be established within other professional groups. There are interest groups within oncology and palliative care in several of the national professional organizations.

Nurses

The following continuing education programs are appropriate for nurses who shall work in palliative care centres:

- oncology nursing
- intensive care nursing
- geriatrics nursing, especially with emphasis on palliative care
- psychiatric nursing
- anaesthesia nursing

Multidisciplinary postgraduate education in palliative care is relevant for both nurses and other professional groups. Deacon education may be useful. At several universities and

colleges there are other part-time studies and postgraduate education programs that may be relevant, for example, pain management, guidance/advising, and family therapy.

Palliative care puts great demands on medical knowledge and clinical nursing skills. At the palliative care centre, a certain portion of the nursing staff must be oncology nurse specialists or have other relevant postgraduate training. Palliative care units in nursing homes, infirmaries, and rural medical centres should also preferably have nurses with relevant specialty training.
There is a great need for further development of expertise in palliative care, which should be directed toward the establishment of a specialist training program in palliative nursing. A program for a master degree in palliative care should also be developed.

All municipalities/districts should have position(s) for oncology nurse specialist(s).

Chaplains

Chaplains working in palliative care centres should have pastoral-clinical training.

Physiotherapists

Physiotherapists at palliative care centres should have courses in oncological physiotherapy provided by the Norwegian Physiotherapy Association. Expertise in lymphoedema treatment is also desired. Multidisciplinary postgraduate education in palliative care is also relevant for physiotherapists, as are other courses and continuing education programs, such as in neurology, geriatrics, pulmonary medicine, and rehabilitation.

Social workers

The social worker in the palliative care team should have a special interest in this patient group and in multidisciplinary team work. Multidisciplinary postgraduate education in palliative care is also relevant for social workers. Education in family therapy and welfare may also be relevant.

Dieticians

The Association of Clinical Dieticians should take part in the development of a continuing education program in palliative care for this group. Multidisciplinary postgraduate education in palliative care is relevant.

Occupational therapists

Multidisciplinary postgraduate education in palliative care is also relevant for occupational therapists.

Psychologists

The Norwegian Association of Psychologists should contribute with the necessary continuing and postgraduate education. Internationally, a specific field within psycho-oncology has developed. The Norwegian Association of Psychologists is discussing a specialization within health psychology.

Research and Development

The universities have the main responsibility for research in Norway. Within the field of medicine this responsibility lies with the medical faculties, and research and development are important functions of the university hospitals (regional hospitals). According to the Specialist Health Care Law (Law 1999-07-02, no. 61), not only university hospitals, but all public hospitals in Norway are required to participate in research. It is customary that all institutions and services with a structured palliative care service partake in research projects.

Research within palliative care shall be founded on the same quality principles as other medical research. Research in palliative care should primarily focus on evaluating treatment methods. This requires a computer-based registry, which should follow national standards.

The regional centres of excellence for palliative care at the university hospitals should have responsibility for the research efforts in the region, as well as for maintaining national and international research cooperation. The centre of excellence at the regional palliative care centre should have:

- formal ties to the university's faculty of medicine in the form of an academic section with at least one chair in palliative medicine. The structure will depend on the local organizational model.
- one or more ongoing, relevant research projects at any given time.
- at least one PhD student in palliative medicine at any given time.
- responsibility for ensuring that research is performed at the palliative care centres in hospitals within the region.
- responsibility for offering instruction pertaining to research within palliative care.

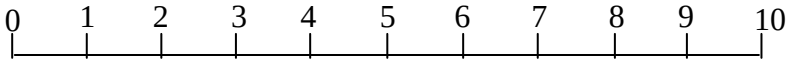
Appendix: ESAS tool and Symptom assessment graph

How are you today? **Name:_____ DOB:_____**

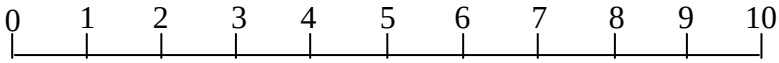
Date of Completion: _____ Time: _____



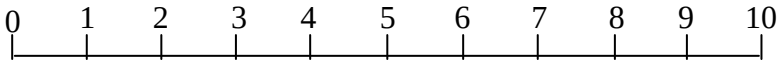
No pain at rest — Worst possible pain at rest



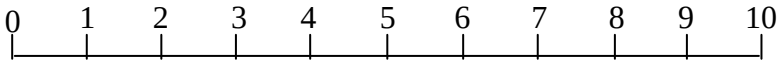
No pain on movement — Worst possible pain on movement



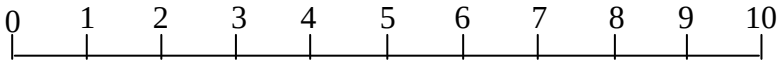
Not tired — Worst possible tiredness



Not nauseated — Worst possible nausea



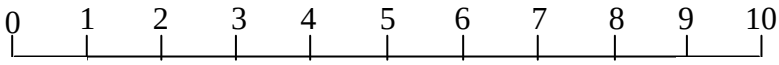
No shortness of breath — Worst possible shortness of breath



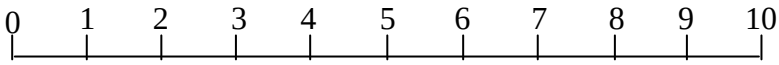
No dryness of mouth — Worst possible dryness of mouth



Best appetite — Worst possible appetite



Not anxious — Worst possible anxiety



Not depressed — Worst possible depression



Best feeling of well-being — Worst possible feeling of well-being

Completed by: _____

ESAS, Edmonton Symptom Assessment System, modified at the Palliative Medicine Unit, St. Olav's Hospital, Trondheim, Norway (TPAT)

ESAS Symptom assessment graph

DOB……..
Name……..

Date																	
Hospital day Hour		09	18	09	18	09	18	09	18	09	18	09	18	09	18	09	18
Pain at rest	10																
Pain on movement	10																
Tiredness	10																
Nausea	10																
Shortness of breath	10																
Dryness of mouth	10																
Appetite	10																
Anxiety	10																
Depression	10																
Well-being	10																
ECOG																	
Assessed by																	
Sign.:																	

PW = Patient, written PI = Patient, interview

ECOG/WHO scale:

0 = Normal activity. No restrictions.

1 = Restricted but ambulatory; able to carry out light work.

2 = Ambulatory and self-caring but unable to carry out light work; up more than 50% of waking hours.

3 = Limited self-care; symptomatic, confined to bed or chair more than 50% of waking hours.

4 = Completely disabled; totally confined to bed; may need hospitalization.

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