

# Cancer Control

Knowledge into Action

WHO Guide for Effective Programmes



## Palliative Care



World Health  
Organization

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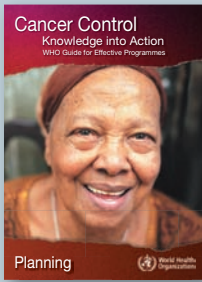
# Introduction to the Cancer Control Series

Cancer is to a large extent avoidable. Many cancers can be prevented. Others can be detected early in their development, treated and cured. Even with late stage cancer, the pain can be reduced, the progression of the cancer slowed, and patients and their families helped to cope.

Cancer is a leading cause of death globally. The World Health Organization estimates that 7.6 million people died of cancer in 2005 and 84 million people will die in the next 10 years if action is not taken. More than 70% of all cancer deaths occur in low- and middle-income countries, where resources available for prevention, diagnosis and treatment of cancer are limited or nonexistent.

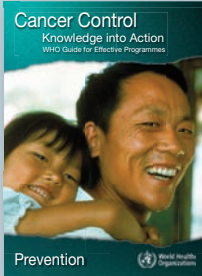
But because of the wealth of available knowledge, all countries can, at some useful level, implement the four basic components of cancer control – *prevention, early detection, diagnosis and treatment, and palliative care* – and thus avoid and cure many cancers, as well as palliating the suffering.

*Cancer control: knowledge into action, WHO guide for effective programmes* is a series of six modules that provides practical advice for programme managers and policy-makers on how to advocate, plan and implement effective cancer control programmes, particularly in low- and middle-income countries.



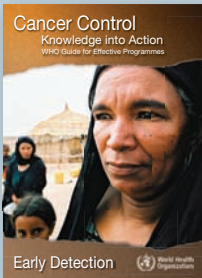
## PLANNING

A practical guide for programme managers on how to plan overall cancer control effectively, according to available resources and integrating cancer control with programmes for other chronic diseases and related problems.



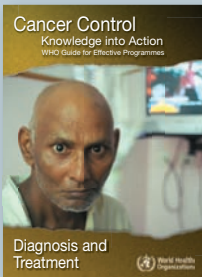
## PREVENTION

A practical guide for programme managers on how to implement effective cancer prevention by controlling major avoidable cancer risk factors.



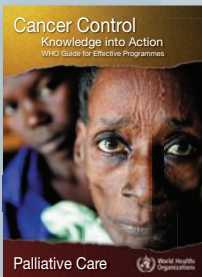
## EARLY DETECTION

A practical guide for programme managers on how to implement effective early detection of major types of cancer that are amenable to early diagnosis and screening.



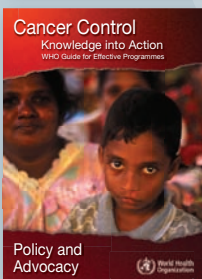
## DIAGNOSIS AND TREATMENT

A practical guide for programme managers on how to implement effective cancer diagnosis and treatment, particularly linked to early detection programmes or curable cancers.



## PALLIATIVE CARE

A practical guide for programme managers on how to implement effective palliative care for cancer, with a particular focus on community-based care.



## POLICY AND ADVOCACY

A practical guide for medium level decision-makers and programme managers on how to advocate for policy development and effective programme implementation for cancer control.

The WHO guide is a response to the World Health Assembly resolution on cancer prevention and control (WHA58.22), adopted in May 2005, which calls on Member States to intensify action against cancer by developing and reinforcing cancer control programmes. It builds on *National cancer control programmes: policies and managerial guidelines* and *Preventing chronic diseases: a vital investment*, as well as on the various WHO policies that have influenced efforts to control cancer.

Cancer control aims to reduce the incidence, morbidity and mortality of cancer and to improve the quality of life of cancer patients in a defined population, through the systematic implementation of evidence-based interventions for prevention, early detection, diagnosis, treatment and palliative care. Comprehensive cancer control addresses the whole population, while seeking to respond to the needs of the different subgroups at risk.

## COMPONENTS OF CANCER CONTROL

**Prevention** of cancer, especially when integrated with the prevention of chronic diseases and other related problems (such as reproductive health, hepatitis B immunization, HIV/AIDS, occupational and environmental health), offers the greatest public health potential and the most cost-effective long-term method of cancer control. We now have sufficient knowledge to prevent around 40% of all cancers. Most cancers are linked to tobacco use, unhealthy diet or infectious agents (see Prevention module).

**Early detection** detects (or diagnoses) the disease at an early stage, when it has a high potential for cure (e.g. cervical or breast cancer). Interventions are available which permit the early detection and effective treatment of around one third of cases (see Early Detection module).

There are two strategies for early detection:

- *early diagnosis*, often involving the patient's awareness of early signs and symptoms, leading to a consultation with a health provider – who then promptly refers the patient for confirmation of diagnosis and treatment;
- *national or regional screening* of asymptomatic and apparently healthy individuals to detect pre-cancerous lesions or an early stage of cancer, and to arrange referral for diagnosis and treatment.

**Treatment** aims to cure disease, prolong life, and improve the quality of remaining life after the diagnosis of cancer is confirmed by the appropriate available procedures. The most effective and efficient treatment is linked to early detection programmes and follows evidence-based standards of care. Patients can benefit either by cure or by prolonged life, in cases of cancers that although disseminated are highly responsive to treatment, including acute leukaemia and lymphoma. This component also addresses rehabilitation aimed at improving the quality of life of patients with impairments due to cancer (see Diagnosis and Treatment module).

**Palliative care** meets the needs of all patients requiring relief from symptoms, and the needs of patients and their families for psychosocial and supportive care. This is particularly true when patients are in advanced stages and have a very low chance of being cured, or when they are facing the terminal phase of the disease. Because of the emotional, spiritual, social and economic consequences of cancer and its management, palliative care services addressing the needs of patients and their families, from the time of diagnosis, can improve quality of life and the ability to cope effectively (see Palliative Care module).

Despite cancer being a global public health problem, many governments have not yet included cancer control in their health agendas. There are competing health problems, and interventions may be chosen in response to the demands of interest groups, rather than in response to population needs or on the basis of cost-effectiveness and affordability.

Low-income and disadvantaged groups are generally more exposed to avoidable cancer risk factors, such as environmental carcinogens, tobacco use, alcohol abuse and infectious agents. These groups have less political influence, less access to health services, and lack education that can empower them to make decisions to protect and improve their own health.

## BASIC PRINCIPLES OF CANCER CONTROL

- **Leadership** to create clarity and unity of purpose, and to encourage team building, broad participation, ownership of the process, continuous learning and mutual recognition of efforts made.
- **Involvement of stakeholders** of all related sectors, and at all levels of the decision-making process, to enable active participation and commitment of key players for the benefit of the programme.
- **Creation of partnerships** to enhance effectiveness through mutually beneficial relationships, and build upon trust and complementary capacities of partners from different disciplines and sectors.
- **Responding to the needs of people** at risk of developing cancer or already presenting with the disease, in order to meet their physical, psychosocial and spiritual needs across the full continuum of care.
- **Decision-making** based on evidence, social values and efficient and cost-effective use of resources that benefit the target population in a sustainable and equitable way.
- **Application of a systemic approach** by implementing a comprehensive programme with interrelated key components sharing the same goals and integrated with other related programmes and to the health system.
- **Seeking continuous improvement**, innovation and creativity to maximize performance and to address social and cultural diversity, as well as the needs and challenges presented by a changing environment.
- **Adoption of a stepwise approach** to planning and implementing interventions, based on local considerations and needs (see next page for WHO stepwise framework for chronic diseases prevention and control, as applied to cancer control).

# WHO stepwise framework

## 1 **PLANNING STEP 1** Where are we now?

Investigate the present state of the cancer problem, and cancer control services or programmes.

## 2 **PLANNING STEP 2** Where do we want to be?

Formulate and adopt policy. This includes defining the target population, setting goals and objectives, and deciding on priority interventions across the cancer continuum.

## 3 **PLANNING STEP 3** How do we get there?

Identify the steps needed to implement the policy.

The planning phase is followed by the policy implementation phase.

### Implementation step 1 **CORE**

Implement interventions in the policy that are feasible now, with existing resources.

### Implementation step 2 **EXPANDED**

Implement interventions in the policy that are feasible in the medium term, with a realistically projected increase in, or reallocation of, resources.

### Implementation step 3 **DESIRABLE**

Implement interventions in the policy that are beyond the reach of current resources, if and when such resources become available.

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# KEY MESSAGES

- ▣ Palliative care is an urgent humanitarian need worldwide for people with cancer and other chronic fatal diseases. Palliative care is particularly needed in places where a high proportion of patients present in advanced stages and there is little chance of cure.
- ▣ Ideally, palliative care services should be provided from the time of diagnosis of life-threatening illness, adapting to the increasing needs of cancer patients and their families as the disease progresses into the terminal phase. They should also provide support to families in their bereavement.
- ▣ Effective palliative care services are integrated into the existing health system at all levels of care, especially community and home-based care. They involve the public and the private sector and are adapted to the specific cultural, social and economic setting.
- ▣ In order to respond to the cancer priority needs in a community and make the best use of scarce resources, palliative care services should be strategically linked to cancer prevention, early detection and treatment services for both adults and children.

# *key definitions*

## **What is palliative care?**

Palliative care (WHO, 2002a) 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.

Palliative care:

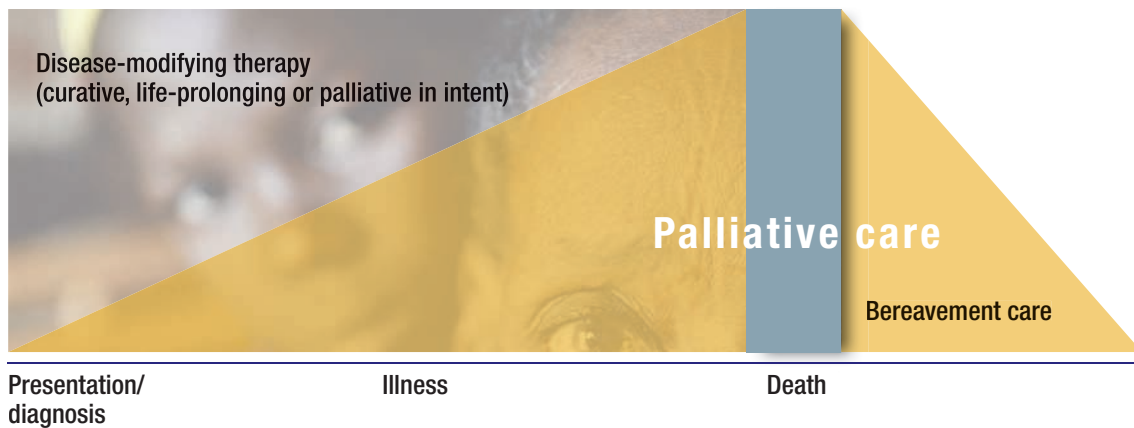
- ▣ provides relief from pain and other distressing symptoms;
- ▣ affirms life and regards dying as a normal process;
- ▣ intends neither to hasten nor to postpone death;
- ▣ integrates the psychological and spiritual aspects of patient care;
- ▣ offers a support system to help patients live as actively 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 other therapies that are intended to prolong life, such as chemotherapy or radiation therapy;
- ▣ includes the investigations needed to better understand and manage distressing clinical complications.

## Terminal cancer

Terminal cancer refers to an advanced stage when curative treatment is no longer useful, the disease is assessed to be incurable and the patient's condition is progressively deteriorating.

Figure 1 illustrates the continuum of care associated with curative and palliative care. Treatment intended to modify the disease decreases as illness progresses, while palliative care increases as the person reaches the end of life. Palliative care also provides support for the family during this entire period. After the patient dies, bereavement counselling for family and friends is important.

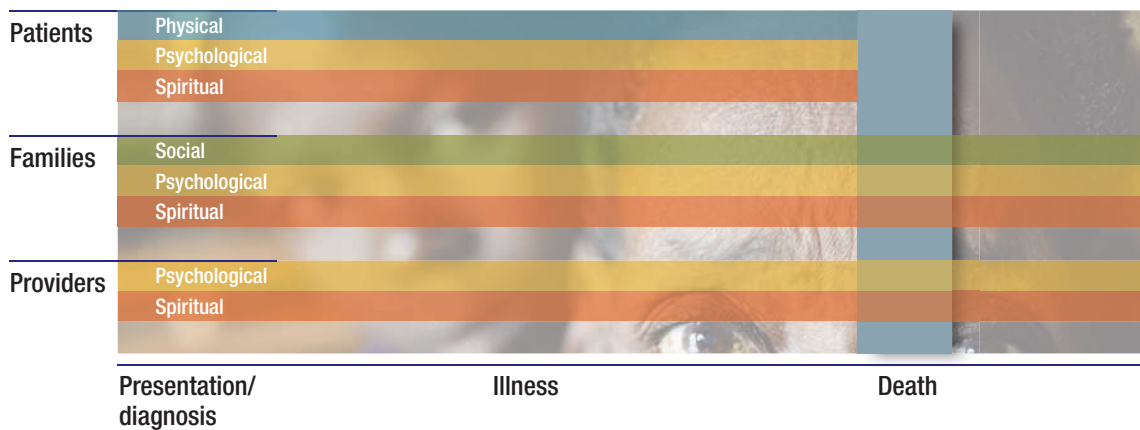
**Figure 1. Integrated model of curative and palliative care for chronic progressive illness**



Source: Adapted from American Medical Association Institute for Medical Ethics (1999). *EPEC: education for physicians on end-of-life care*. Chicago, IL, The Robert Wood Johnson Foundation.

The quality-of-life dimensions of palliative care are illustrated in Figure 2. Palliative care is concerned not only with all aspects of the patient’s needs, but also with the needs of the family and of the health-care providers.

**Figure 2. Quality-of-life dimensions of palliative care**



Source: WHO (2002a) National cancer control programme: policies and managerial guidelines, 2<sup>nd</sup> ed. Geneva, World Health Organization.

**This *Palliative* care module focuses on cancer and does not specifically address other diseases, however, it recognizes the need for developing palliative care with a public health approach that targets all age groups suffering from diseases or conditions in need of palliative care. These conditions include HIV/AIDS, congestive heart failure, cerebrovascular disease, neurodegenerative disorders, chronic respiratory diseases and diseases of older people, among others.**

# PRE-PLANNING

It is estimated that, worldwide, there are millions of cancer patients in need of palliative care. With careful planning of cancer palliative care within a comprehensive cancer control plan, a large proportion of advanced cancer patients could be relieved from their suffering and the quality of their lives could be improved significantly.

Numerous governments have already adopted national palliative care policies, including Australia, Canada, Chile, Costa Rica, Cuba, France, Ireland, Norway, Spain, Uganda, South Africa and the United Kingdom. For examples, see <http://www.who.int/cancer/modules/en/index.html>



## IS A CANCER PALLIATIVE CARE PLAN NEEDED?

Palliative care is particularly important in less developed countries where a high proportion of cancer patients are diagnosed in advanced stages when treatment is no longer effective. These patients can be relieved from suffering with relatively low-cost interventions.

A public health approach to palliative care is required in all countries in order to address the needs of all advanced cancer patients and their families, ensuring universal access to the necessary services at all levels of care within the health system.

Three measures are required as a foundation for developing palliative care with a public health approach (WHO, 1996):

- ▣ a government policy to ensure the integration of palliative care services into the structure and financing of the national health-care system;
- ▣ an educational policy to provide support for the training of health-care professionals, volunteers and the public;
- ▣ a drug policy to ensure the availability of essential drugs for the management of pain and other symptoms and psychological distress, in particular, opioid analgesics for pain relief.

All three of these measures are necessary, along with committed leadership, to achieve an effective palliative care programme.

# his story

Good palliative care has changed 50-year-old Subair's life from a daily grind of pain and penury to an active and pain-free independence.

Subair has long experience of palliative care. By 1994 he had undergone serial amputations of the limb, a full course of radiotherapy and several courses of chemotherapy, and he had started on palliative chemotherapy with Endoxan. Although from a middle-class family, the cost of treatment bankrupted Subair. He could no longer afford to support his four children and they were put into an orphanage.

Subair was having excruciating pain in the stump, and was getting little relief with non-steroidal anti-inflammatory drugs. As he says, "It was like a hot metal rod being pushed into the stump and rotated".

Searching for pain relief, Subair made the 50 km journey from his home to Calicut to a newly opened palliative care clinic. There, Subair was put on regulated oral morphine, in addition to the non-steroidal anti-inflammatory drugs. With a dose of 30 mg morphine 4-hourly he enjoyed total relief from pain.

With effective pain relief, Subair started to explore work possibilities so that he would be able to support himself financially. The palliative care unit found him a job at a coffee stall in the teaching hospital to which the unit is attached. By working hard, he managed to get his children out of the orphanage as well as to support himself. The job restored his self-esteem and had a positive effect on his quality of life.

Over the past ten years, the disease has progressed and Subair has had further surgical interventions. His dose of oral morphine has gone up to 100 mg 4-hourly. But he continues to be pain-free and active. He has been able to ensure that his children are educated and has celebrated his daughter's wedding. Subair's story is an example of what good palliative care can achieve.

Source: Information provided by Suresh Kumar, Director, Institute of Palliative Medicine, Medical College Calicut, Kerala, India.

**SUBAIR'S STORY IS AN EXAMPLE  
OF WHAT GOOD PALLIATIVE CARE  
CAN ACHIEVE.**

# PLANNING STEP 1

## *Where are we now?*

The *Planning* module offers advice on what to assess in relation to the overall cancer needs in both the general population and the groups particularly at risk. It also describes how to assess the existing cancer control plan and the services that respond to those needs. This *Palliative care* module provides more detailed guidance on how to assess palliative care needs as well as the existing palliative care plan and services.

### **ASSESS THE NUMBER OF PEOPLE IN NEED OF CANCER PALLIATIVE CARE**

Assessing cancer palliative care needs is in many ways equivalent to assessing an urgent humanitarian need to reduce unnecessary suffering of patients and their families. It is important to bear in mind that although – in the medium to long term – effective prevention, early detection and treatment will reduce palliative care needs, palliative care needs will never be eliminated, because some types of cancer will inevitably remain fatal for some patients.

If the most frequent cancer types presenting in advanced stages can be identified, then it will be possible to provide integrated palliative care services for the specialties concerned. For example, patients with Kaposi sarcoma and other cancers related to HIV/AIDS could have access to a common service for palliative care.

Table 1 provides a template for estimating the number of children and adults in need of cancer palliative care, based on the number of cancer deaths per year. It is assumed that at least 80% of terminal cancer patients will require palliative care.

**Table 1. How to estimate the number of people in need of palliative care based on the number of cancer deaths**

	Cancer deaths	Patients in need of palliative care		Caregivers per patient	Total number of people in need of palliative care
	Number	%	Number	Number	Number
	(A)	(B)	(C = A x B)	D	C x D
Adults		80			
Children		80			
Total					

To calculate the overall need for palliative care, the template in Table 1 should also include patients dying from other chronic life-threatening diseases. Estimates of palliative care needs based on deaths are low, in relative terms, as they reflect only terminal care. A more realistic assessment of the number of patients actually needing palliative care would also include those suffering from cancer or other serious illness but not dying that same year. For example, it is estimated that 50–80% of patients with HIV/AIDS would benefit from palliative care services.

A WHO palliative care project, conducted in five sub-Saharan African countries (Sepúlveda et al., 2003; WHO, 2004), made a rapid assessment of palliative care needs at the end of life based on the number of deaths from cancer and HIV/AIDS, using a method similar to that described in Table 1. The number of people needing palliative care each year was estimated to be at least 690 800 or 0.5% of the total population of these countries.



## ASSESS THE NEEDS OF PATIENTS, HEALTH-CARE PROVIDERS AND FAMILY CAREGIVERS

An overall assessment of palliative care needs should be based on information about the specific requirements of the patients concerned, as well as those of health-care providers and family caregivers. The purpose of assessing palliative care needs is to organize the services to meet those needs.

The above-mentioned WHO project (WHO, 2004) found that the greatest needs of terminally ill patients were for:

- ▣ relief from pain
- ▣ accessible and affordable drugs for symptom management
- ▣ financial support.

Family members and relatives were the main caregivers, but they generally lacked the knowledge and skills to perform their tasks adequately.

For examples of tools to assess the needs of patients and caregivers, see <http://www.who.int/cancer/modules/en/index.html>



## ASSESS THE EXISTING PALLIATIVE CARE PLAN AND ACTIVITIES

In assessing the existing palliative care plan, it is important to look at palliative care in two ways: as a key component of a comprehensive cancer control programme; and as a subsystem of a broader palliative care strategy that includes other health conditions besides cancer.

Table 2 lists what to assess in regard to the existing palliative care plan and activities for cancer. These aspects are discussed in the *Planning* module (see pages 17 and 18).

**Table 2. The palliative care plan and activities: what to assess**

Plan and activities	What to assess
<b>Palliative care plan</b>	<ul style="list-style-type: none"> <li>○ Endorsement of the plan and scope (geographical area and conditions included)</li> <li>○ Whether or not part of a comprehensive cancer control plan</li> <li>○ Timeliness (updated/outdated)</li> <li>○ Accessibility to the written plan</li> <li>○ Stakeholders' involvement in plan development</li> <li>○ Inclusion of critical sections of the plan (assessments, goals and objectives, strategies, timetable, responsible persons, resources, monitoring and evaluation)</li> <li>○ Comprehensiveness and priorities (objectives and activities related to pain relief and control of other symptoms)</li> <li>○ Integration with other related activities</li> <li>○ Utility of the plan (used to guide programme implementation)</li> </ul>
<b>Ongoing palliative care activities</b>	<ul style="list-style-type: none"> <li>○ Number and types of palliative care activities and related services offered</li> <li>○ Coverage of ongoing palliative care activities</li> <li>○ Quality of ongoing palliative care activities</li> <li>○ Evaluation of structure, outcomes, outputs and process indicators and trends</li> </ul>
<b>Resources of ongoing palliative care activities</b>	<ul style="list-style-type: none"> <li>○ Information systems (registries, surveillance of palliative care services)</li> <li>○ Protocols, guidelines, standards, manuals, educational materials, etc.</li> <li>○ Physical resources (infrastructure, technologies, list of essential drugs for palliative care)</li> <li>○ Human resources (leaders, councils, committees, health-care networks, health-care providers, partners, volunteers, traditional healers)</li> <li>○ Financial resources</li> <li>○ Regulations and legislation (insurance schemes, opioid analgesics)</li> </ul>
<b>Context of the palliative care plan and activities</b>	<ul style="list-style-type: none"> <li>○ SWOT analysis: strengths, weaknesses, opportunities and threats concerning the performance of the palliative care programme for cancer</li> </ul>

In assessing current palliative care activities, the focus should be on the gap between what is required to address the need for palliative care and what is currently available.

Ask the following questions to begin to assess existing palliative care activities:

## WHAT PALLIATIVE CARE ACTIVITIES AND OTHER RELATED SERVICES ARE BEING OFFERED?

- ▣ Are there palliative care services (medical, psychosocial and spiritual), public and private, at the different levels of care for advanced cancer patients? Are there services for end-of-life care? Are there services for bereavement care?
- ▣ Are there inpatient, outpatient or home palliative care services? How are they organized?

## HOW MANY PATIENTS ARE COVERED BY THE PALLIATIVE CARE ACTIVITIES?

- ▣ What percentage of the target population of patients is covered by the palliative care activities?
- ▣ What percentage of children?
- ▣ What percentage of adults?

## WHAT IS THE QUALITY OF THE PALLIATIVE CARE ACTIVITIES?

Quality can be assessed through the system model of inputs, process, outputs and outcomes (short-, medium- and long-term). Quality assessment can also be based on the continuous quality improvement framework, which uses a number of quality dimensions that can be explored through questions such as:

- ▣ Are all the services of the palliative care programme accessible (to ensure coverage and timeliness) to the target population?
- ▣ Are there drugs accessible for pain relief, in accordance with the WHO's ladder for cancer pain relief?
- ▣ Are there drugs accessible for the control of other symptoms?
- ▣ Are the services acceptable (ensuring providers' and patients' satisfaction) and appropriate (based on established standards) for the target groups?
- ▣ Are the competences (knowledge and skills) of the providers appropriate for the services needed?
- ▣ Is there continuity (integration, coordination and ease of navigation) in palliative care activities for cancer and other chronic fatal diseases? Is there continuity among the levels of care? Is there continuity between private and public institutions?
- ▣ Are the palliative care activities effective (do they improve quality of life)?
- ▣ Are palliative care activities efficient (do they provide the best results at the lowest cost)?

## ARE THERE REGULAR MONITORING AND EVALUATION SYSTEMS?

- ▣ Do they include evaluation of quality of life?
- ▣ What are the process and outcome indicators used?
- ▣ What are the minimum standards applied?

WHAT ARE THE EXISTING RESOURCES ASSOCIATED WITH PALLIATIVE CARE ACTIVITIES?

- ▣ Are there information systems to monitor and evaluate the palliative care services provided?
- ▣ Are there guidelines for the management of pain and other symptoms at all levels of care, including primary health-care and home-based care?
- ▣ Are there regulations on opioid analgesics favouring their appropriate medical use?
- ▣ Is there a list of essential drugs for palliative care, which includes oral morphine?
- ▣ Is there a national or regional coordinator responsible for overseeing the palliative care activities? Is there a multisectoral and multidisciplinary committee to advise on the policy and activities?
- ▣ What is the existing palliative care network? Does it include programme managers, health-care providers, community leaders and traditional healers?
- ▣ Is there a basic palliative care package for the primary health level and for home-based care programmes? How is it financed?

## SOUTH AMERICA

### Example of an evaluation of palliative care programmes using structure, process and outcome measures

#### STRUCTURE

##### Support of health authorities

Most countries in South America do not satisfy the demand for palliative care: 80% do not recognize palliative care as a discipline and it is not included in the public or private health systems. Only Chile, Costa Rica and Cuba have national programmes that provide palliative care nationwide.

##### Financing

Most health systems are under-funded, yet they pay for futile interventions but they do not pay, or they do not pay enough, for palliative care. This situation jeopardizes the sustainability of activities, which are mostly run by volunteers, with resources from charities and nongovernmental organizations, and – where possible – payments from patients.

##### Opioid availability and accessibility

There is good availability of different opioids, but poor accessibility because of their high cost, lack of training among health personnel on how to prescribe and use opioids, and restrictive regulations.

##### Teams and programmes

There is limited information on the number of teams or programmes providing palliative care services, and the type of care they deliver. The teams and programmes differ according to their development: community- or hospital-based; with one or more disciplines; with mixed or exclusive home, outpatient or inpatient care. Most services provide care for cancer patients.

##### National palliative care associations

By March 2006, Argentina, Bolivia, Brazil, Colombia, Mexico, Paraguay, Peru, Uruguay and Venezuela had national palliative care associations.

#### PROCESS

##### Education

Health professionals are increasingly interested in palliative care, and this interest is paralleled by increasing learning opportunities. However, less than 15% of those that deliver end-of-life care have received specific undergraduate education on that subject. Most have acquired knowledge and skills after graduation, through teaching programmes with differing formats.

##### Research

Resources and expertise in research are limited, so little research is carried out and it is of variable quality.

##### Care

There is limited information about how and where patients die, how many receive palliative care, and the characteristics of the caring process.

##### Coverage

The availability, accessibility and affordability of palliative care are inadequate. It is estimated that: only 5–10% of patients that need palliative care receive it; over 90% of all palliative care services are provided in large cities; and over 50% of patients cannot afford the services or the medication.

#### OUTCOME

There is no available information on how effective palliative care is or which factors determine its effectiveness.

Source: Wenk R, Bertolino M (2001). Palliative care development in South America: a focus on Argentina. *Journal of Pain and Symptom Management*, 33:645–650. Copyright Elsevier.

## UNDERSTAND THE SOCIAL CONTEXT OF THE PALLIATIVE CARE PLAN AND ACTIVITIES

The development of a palliative care plan and activities requires a thorough understanding of the context. One way to gain this understanding is by analysing the **strengths**, **weaknesses**, **opportunities** and **threats (SWOT)** associated with the existing plan and activities.

During the course of the SWOT analysis, the following questions should be answered:

- ▣ *What are the strengths and weaknesses associated with plan development and implementation?* These are factors affected by internal forces, such as political support, leadership, stakeholder involvement and resources available. For example, politicians and decision-makers often see a focus on treatment as being a more attractive approach, and neglect palliative care. They may not understand the importance of palliative care or may feel that by emphasizing palliative care they are somehow admitting defeat and giving up the struggle against disease.
- ▣ *What are the opportunities and threats associated with plan development and implementation?* These are factors affected by external forces, such as the international palliative care agenda, the political and economic situation within the country, or the existence of other pressing health priorities. For example, the fact that WHO and international partners are advocating a public health approach to palliative care represents an opportunity for influencing the development of national policies.

For details of international organizations working in palliative care, and also for further resources, see <http://www.who.int/cancer/modules/en/index.html>



## SELF-ASSESSMENT BY COUNTRIES

WHO has developed a set of tools, of different levels of complexity, for assessing population cancer needs and existing services. A description of the tools can be found in the *Planning* module.

Self-assessment tools, which can be adapted to country circumstances, are available from <http://www.who.int/cancer/modules/en/index.html>  
The WHO cancer web site also provides links to sources containing more specific tools for assessing palliative care needs.



Tools to assess opioid control policies (WHO, 2002b) are available at <http://www.who.int/cancer/modules/en/index.html>  
<http://www.painpolicy.wisc.edu/publicat>  
A tool to assess the barriers to opioid availability (Joranson, 1993) can be found at <http://www.medsch.wisc.edu/painpolicy/publicat/93jpsma.htm>



# PLANNING STEP 2

## *Where do we want to be?*

The assessment (planning step 1) identifies the gaps in services, as well as in data and knowledge, with regard to the burden of cancers in advanced stages and the palliative care services available.

The next step is to consider what *could* be done, given limited resources and capacity, in order to answer the question: *Where do we want to be?*

### DEFINE THE TARGET POPULATION FOR PALLIATIVE CARE

The selection of the target population for a palliative care plan will depend on where the greatest numbers of patients (adults and children) are concentrated; the urgent needs of those patients and of their family members and caregivers; and the resources available.

The greatest needs for palliative care are generally among cancer patients presenting with advanced stages. However, available resources may not be sufficient to target this entire group. Faced with this dilemma, many countries when starting palliative care within a comprehensive cancer control plan may decide to initially focus on terminal cancer patients and their caregivers. This group has the most pressing needs. The majority of terminal cancer patients (over 80%) suffer from severe pain and other serious symptoms that require urgent relief.

Some countries may decide to have a palliative care plan with a broader scope. The plan may include not only cancer patients but also other patients with chronic life-threatening conditions, or geriatric patients. The target population should be selected so as to include groups that constitute the most important health and social problems. For example, Spain has a national cancer control strategy that includes palliative care. Building on palliative care for cancer, Spain has recently launched a comprehensive national palliative care strategy. In sub-Saharan Africa, where over 80% of cancer patients present in late stages and there is a high prevalence of patients living with HIV/AIDS, joint AIDS and cancer palliative care initiatives have been developed.

## IDENTIFY GAPS IN PALLIATIVE CARE SERVICES

Based on the assessment, the gaps can be identified (present state versus desired state), and potential corrective interventions considered.

It is important to assess both the impact of palliative care interventions previously implemented in the target population, and the interventions that have been successfully applied elsewhere, particularly in similar socioeconomic and cultural settings.

## SET GOALS AND OBJECTIVES FOR PALLIATIVE CARE

Objectives should be set to respond to the needs of people with advanced-stage cancer, their family members and their caregivers. The objectives should be directly related to the identified gaps in services. For the palliative care plan to be effective, all process and outcome objectives need to promote the common goal of improving the quality of life of cancer patients and their families.

Table 3 provides examples of short-, medium- and long-term objectives of a palliative care plan. The objectives concern process (how resources are organized) and outcomes (impact on the people participating in the activities), and are listed according to level of resources. Core objectives can be achieved with existing resources. Expanded objectives are feasible with a realistically projected increase in, or reallocation of, resources. Desirable objectives are beyond the reach of current resources but could be achieved if resources become available.



**Table 3. Examples of short-, medium- and long-term objectives of a palliative care plan using WHO’s stepwise approach**

Component	Core	Expanded	Desirable
Overall goal	<ul style="list-style-type: none"> <li>To improve the quality of life of cancer patients and their families</li> <li>To ensure that prioritized palliative care services are provided in an integrated, equitable and sustainable way</li> </ul>		
Short-term process objectives (within 5 years)	<ul style="list-style-type: none"> <li>To ensure that standards for cancer palliative care including pain relief are progressively adopted in the target area by all levels of care</li> <li>To provide care mainly through <b>home-based</b> services</li> </ul>	<ul style="list-style-type: none"> <li>To ensure that standards for cancer palliative care including pain relief are progressively adopted nationwide by all levels of care</li> <li>To provide care mainly through <b>primary health</b> and <b>home-based</b> services</li> </ul>	<ul style="list-style-type: none"> <li>To ensure that standards for cancer palliative care including pain relief are progressively adopted nationwide by all levels of care</li> <li>To provide care through a variety of options, including home-based services</li> </ul>
Medium-term outcome objectives (5–10 years)	<ul style="list-style-type: none"> <li>To ensure that over 30% of <b>terminal cancer patients</b> in the target area get timely relief from pain and other serious physical, psychosocial and spiritual problems</li> </ul>	<ul style="list-style-type: none"> <li>To ensure that over 30% of <b>advanced cancer patients</b> nationwide get relief from pain and other physical, psychosocial and spiritual problems</li> <li>To ensure that over 30% of <b>caregivers</b> get adequate support</li> </ul>	<ul style="list-style-type: none"> <li>To ensure that over 60% of <b>advanced cancer patients</b> nationwide get relief from pain and other physical, psychosocial and spiritual problems</li> <li>To ensure that over 60% of <b>caregivers</b> get adequate support</li> </ul>
Long-term outcome objectives (10–15 years)	<ul style="list-style-type: none"> <li>To ensure that over 60% of <b>terminal cancer patients</b> in the target area get relief from pain and other physical, psychosocial and spiritual problems</li> </ul>	<ul style="list-style-type: none"> <li>To ensure that over 60% of <b>advanced cancer patients</b> nationwide get relief from pain and other physical, psychosocial and spiritual problems</li> <li>To ensure that over 60% of <b>caregivers</b> get adequate support</li> </ul>	<ul style="list-style-type: none"> <li>To ensure that over 80% of <b>advanced cancer patients</b> nationwide get relief from pain and other physical, psychosocial and spiritual problems</li> <li>To ensure that over 80% of <b>caregivers</b> get adequate support</li> </ul>

Note: The terms “core”, “expanded” and “desirable” refer to the WHO’s stepwise approach (see page vi for WHO stepwise framework for chronic diseases prevention and control, as applied to cancer control).

## ASSESS FEASIBILITY OF INTERVENTIONS

The feasibility of palliative care for a given population depends on the skills and infrastructure available, the knowledge and attitudes of the target population, and the motivation of the government and the care providers.

In order for a palliative care programme to be fully effective, it should deliver good quality services for relief of pain and other symptoms, psychosocial and spiritual support, and bereavement care, equitably and for an indefinite duration to all members of the target population in need, including patients, family members and caregivers.

Some resource-constrained countries, where a high proportion of patients present with advanced stages, have invested for decades in specialized palliative care institutions that provide excellent palliative care for only a few. In general, however, these countries have not introduced low-cost, basic services, integrated with primary health-care services and home-based care, which could be offered in a sustainable way to the majority of people presenting with advanced cancer.

A good palliative care programme encompassing interventions at all levels of care, with a particular focus on primary health-care services and home-based care, could eventually result in a reduction in hospitalization and the use of inappropriate expensive procedures.

## CONSIDER ETHICAL ISSUES

Ethical and legal issues that should be addressed in a palliative care plan and programme include the following:

- ▣ allocation of adequate human and financial resources to palliative care;
- ▣ integration of palliative care with curative care to ensure high-quality care;
- ▣ societal, individual and professional obligations and responsibilities regarding the provision of care;
- ▣ differing perceptions and attitudes in different cultural contexts concerning, for example, quality-of-life versus length-of-life goals, enduring or relieving pain, and the end of life;
- ▣ autonomy of decision-making, and valid informed consent of the patient and family;
- ▣ legal and cultural barriers to accessing palliative care, in particular opioids.

## SET PRIORITIES FOR PALLIATIVE CARE

It is essential to set priorities, because resources will never be able to meet all health needs. Careful priority-setting is particularly relevant in resource-constrained contexts in view of the importance of making the best use of very limited resources. The criteria for selecting priorities for palliative care will need to be discussed by the committee steering the overall cancer control planning process.

To set priorities among strategies for palliative care for cancer:

- ▣ First identify the patients who need palliative care and assess:
  - the burden they represent in terms of mortality and morbidity;
  - the proportion of cases in advanced stages;
  - the urgency of their needs (pain relief, control of other symptoms, social support);
  - the societal impact of the disease (for example, whether the disease affects children, underprivileged communities and caregivers).
  
- ▣ Then choose the type of palliative care strategy according to:
  - cost-effectiveness;
  - affordability;
  - sustainability;
  - political attractiveness.

For information on the cost-effectiveness of some cancer interventions, see <http://www.who.int/choice/en>



General recommendations for setting priorities (WHO, 2002a), according to the level of resources available, are summarized in Table 4.

**Table 4. Priority interventions for palliative care according to resource levels using WHO’s stepwise approach**

Core	Expanded	Desirable
<ul style="list-style-type: none"> <li>○ Provide palliative care including pain relief with emphasis on home-based care, following national minimum standards</li> <li>○ Ensure that legislative measures allow access to oral morphine and other affordable essential palliative care medicines included in the WHO Model List of Essential Medicines</li> <li>○ Develop a reference centre that can provide in-service training to community health-caregivers</li> </ul>	<ul style="list-style-type: none"> <li>○ Provide palliative care at all levels of care with emphasis on primary health-care clinics and home-based care, following national protocols</li> <li>○ Ensure availability of essential medications in both rural and urban centres</li> <li>○ Develop reference centres that can provide undergraduate and postgraduate training</li> <li>○ Develop curricula in nursing and medical schools to teach palliative care both at the undergraduate and graduate levels</li> </ul>	<ul style="list-style-type: none"> <li>○ Reinforce the network of palliative care services integrated with cancer care and other related services</li> <li>○ Provide support to national and international reference centres for palliative care</li> </ul>

Note: The terms “core”, “expanded” and “desirable” refer to the WHO’s stepwise approach (see page vi for WHO stepwise framework for chronic diseases prevention and control, as applied to cancer control).

# PLANNING STEP 3

## *How do we get there?*

What can be done with available resources? Having identified objectives for the palliative care plan, the next step is to formulate an action plan to achieve them.

A template for developing a detailed action plan is provided at <http://www.who.int/cancer/modules/en/index.html>



The process of translating a palliative care plan into action requires strong leadership and competent management. It also requires a participatory approach to identify what needs to be done in order to bridge the gaps identified in planning step 2. Actions need to be taken gradually, in a feasible and sustainable manner.

Thought should be given to the appropriate sequence of actions that will guarantee success and credibility of a palliative care programme. For example, providing palliative care for advanced cancer patients requires pain medication to be readily accessible. Pain relief can be provided by adequately trained caregivers, including family members, at home. Both non-opioid and opioid analgesics, particularly oral morphine, should be available.

## BRIDGE THE GAPS IN PALLIATIVE CARE

It is important to evaluate the actions to bridge the gaps from the perspective of those who support and will eventually implement those actions, and from the perspective of any potential opponents. Next, there is a need to identify the key person (or group) with the power to decide on the plan, and then see how that person (or group) can be activated to make the planned changes.

Table 5 provides examples of actions to bridge gaps in palliative care for cancer in a low-income country where less than 50% of the population has access to health services. The country has prioritized palliative care for terminal cancer patients, and has chosen to implement activities gradually in terms of the location of the target population (from patients identified through the formal health system to broad community outreach) and the geographical scope (from a demonstration area to other areas, and eventually to the whole country).

## RAISE THE NECESSARY RESOURCES

To make sure that the necessary human and financial resources are available to implement the strategies and actions included in the palliative care plan, the following questions will need to be answered:

- ▣ What resources are currently dedicated to palliative care? How can current resources be reallocated or shared to achieve plan outcomes?
- ▣ Besides resources currently being expended, what else is needed to achieve the objectives of the plan?
- ▣ What potential sources of funding or other resources are available to meet these needs?
- ▣ How can partners work together to raise funds from the government or private sector?

The palliative care plan should be accompanied by a resource plan that outlines existing resources, needed resources and possible strategies for acquiring the needed resources from both governmental and nongovernmental sources.

**Table 5. Examples of actions to bridge identified gaps in palliative care in a low-resource country**

Gaps, strengths and weaknesses	Level of interventions	Key actions in a selected geographical area served by the regional cancer centre	Who has the power to decide on key actions?	How could they be activated to decide?
<p><b>GAPS</b> (difference between OBSERVED and DESIRED status)</p> <p><b>OBSERVED</b> It is estimated that less than 1% of terminal cancer patients get palliative care including pain relief</p> <p><b>DESIRED</b> To provide palliative care including pain relief for at least 50% of terminal cancer patients</p> <p><b>STRENGTHS</b> The government supports a comprehensive cancer control programme</p> <p>There are two hospices, and there is a palliative care unit in the regional cancer centre</p> <p><b>WEAKNESSES</b> Only injectable morphine is available</p> <p>There are strict regulations governing opioid analgesics</p> <p>Health-care providers are in general reluctant to prescribe morphine</p>	<b>CORE</b>			
	Using available resources and reorganizing the existing services to improve palliative care	<p>Review and modify the regulations governing opioid analgesics to make them readily available</p> <p>Elaborate standards for palliative care and disseminate them to all levels of care in the public and private sectors</p> <p>Establish coordination and referral mechanisms</p> <p>Elaborate a list of essential palliative care drugs and ensure their availability in the target area</p> <p>Include palliative care packages in health insurance schemes and in home-based care programmes</p> <p>Identify the terminal cancer patients diagnosed at the different levels of care</p> <p>Estimate the demand for palliative care services</p> <p>Identify and train a network of health-care providers at the different levels of care, including community and family caregivers who need to be involved in the provision of services</p> <p>Ensure that essential drugs, including oral morphine, will be available to meet demand and that trained professionals will be allowed to prescribe these drugs</p> <p>Create a basic information system to monitor and evaluate actions at the different levels of care</p>	The local health authorities together with the leading health-care professionals of relevant sectors and organizations, supported by the national authorities	By providing relevant information on the problem and its possible solutions through personal interactions and meetings with the relevant stakeholders, including testimonies of patients and health-care providers
	<b>EXPANDED</b>			
	With some additional resources	<p>Identify partners in the community and develop joint educational strategies for reaching terminal cancer patients who do not attend the formal health-care system</p> <p>Adjust the primary health services and the specialized clinical services to meet the estimated demand</p> <p>Correct weaknesses identified through the monitoring and evaluation system</p> <p>Develop palliative care education for undergraduate and postgraduate students in medical and nursing schools</p>	<p>Local authorities from the political, health and educational sectors, supported by the national authorities</p> <p>Health-care and community leaders, traditional healers</p>	<p>By disseminating the results of the evaluation of previous (core) activities to community organizations</p> <p>By advocating in favour of reaching more people in the target age group</p>
	<b>DESIRABLE</b>			
	With more additional resources	<p>Develop educational strategies and low-cost media campaigns to reach terminal cancer patients in the wider community</p> <p>Monitor activities and evaluate results</p> <p>Start mobilizing resources to expand activities to the rest of the country using a similar stepwise approach if the evaluation in the target areas is satisfactory</p>	<p>National and local leaders in the political, health and educational sectors</p> <p>Health-care and community leaders</p> <p>Leaders of national and local associations</p>	<p>By disseminating the results of the evaluation of previous (core and expanded) activities</p> <p>By advocating to increase the coverage of palliative care for terminal cancer patients</p> <p>By advocating to expand palliative care activities to the rest of the country</p>

## ORGANIZE CANCER PALLIATIVE CARE SERVICES ACROSS ALL LEVELS OF CARE

All countries, rich or poor, that implement palliative care with a public health approach need to integrate the services at all levels of care in order to ensure accessibility to the whole target population. Comprehensive palliative care includes the following services:

- ▣ management of complications of treatment and the disease
- ▣ management of pain and other symptoms
- ▣ psychosocial care for patients and caregivers
- ▣ spiritual understanding and approaches for patients and caregivers
- ▣ care of the dying
- ▣ bereavement care.

The above services can be progressively extended across all levels of care.

### NORWAY

**Example of a rich country that has developed palliative care within a national cancer control programme, integrating palliative care services into the national health system with emphasis on a community-based approach**

Palliative care is a component of the Norwegian Cancer Control Programme. The Norwegian national cancer strategy clearly identifies palliative care for cancer as an area of work to be intensified. The main policy recommendations include the following:

- Palliative care, especially terminal care, must as far as possible be available in the patient's local community, coordinated by the general practitioner or municipal health service, and in line with agreed regional guidelines. This will require increased expertise.
- Palliative care in hospital must be integrated with the ordinary treatment services and, in principle, should be carried out in the department with the primary responsibility for treatment. Establishment of special arrangements for care is not recommended.
- Each region must establish a designated unit for cancer palliative care under the auspices of the hospital department with overall responsibility for cancer care for the whole region. This unit should serve as a knowledge base and centre of expertise for the whole region and must have the main responsibility for drawing up guidelines. The unit must be supplied with the expertise in areas that are relevant to cancer palliative care and patient support.
- The designated oncology unit in each county must serve as a source of expertise for the palliative care in the county.
- The needs of patients and their families, especially with regard to time, must be taken into account in the organization of the unit, which should not be run on the lines of an ordinary hospital department, and must be funded according to principles other than the ordinary performance-related funding.

Sources: Kaasa S, Jordhøy MS, Haugen DF (2007). Palliative care in Norway: a national public health model. *Journal of Pain and Symptom Management*, 33:599–604 and *Standard for palliative care*. Norwegian Association for Palliative Medicine, 2004 ([http://www.palliativmed.org/asset/32504/1/32504\\_1.pdf](http://www.palliativmed.org/asset/32504/1/32504_1.pdf), accessed 23 September 2007).



When organizing cancer palliative care services, it is important to keep in mind the following:

- ▣ Cancer palliative care services should respond to the needs of patients and their families, and to the objectives and priorities of the cancer palliative care plan.
- ▣ The services should be accessible to a large majority of the target population, and should be delivered in an equitable manner across all levels of care, whether services are public or private.
- ▣ It is estimated that over 80% of advanced cancer patients will benefit from relatively simple and low-cost interventions that can be integrated into primary health-care and home-care services, through a community-based approach.
- ▣ It is estimated that less than 20% of advanced cancer patients will require relatively specialized palliative care services. These specialized services can be provided by palliative care units at district hospitals or at the tertiary level.
- ▣ Inpatient and outpatient palliative care clinics at the secondary and tertiary levels serve mainly as training and referral centres for the management of complex cases and supervision of the other levels of care.
- ▣ The cancer palliative care services should be integrated with services for the prevention, early detection and treatment of cancer, as well as with other related programmes and initiatives.

## ADOPT A TEAM APPROACH

Strong leadership and overall programme management should ensure that local managers and health-care providers work in multidisciplinary teams across the health system, and coordinate closely with community leaders and organizations involved in the programme, in order to achieve a common goal. The composition of the palliative care team will vary depending on the objectives of the programme, and the health-care professionals available.

In general, palliative care requires a strong network of trained health-care practitioners, community leaders, traditional healers, and family caregivers with specific roles and functions across the different levels of care and within the community.

A WHO tool on team building, and additional resources on palliative care teams, can be found at <http://www.who.int/cancer/modules/en/index.html>



## UNDERSTAND THE ROLE OF HEALTH-CARE PROVIDERS

Health-care providers involved in palliative care may include physicians, nurses, social workers, psychologists, spiritual counsellors, volunteers, pharmacists and traditional healers. Each can play a useful role.

### PHYSICIANS

Physicians play a crucial role in interdisciplinary palliative care. They must be competent in general medicine, competent in control of pain and other symptoms, and must also be familiar with the principles of management of the patient's disease. Physicians working in palliative care may be responsible for assessment, supervision and management of many of the difficult treatment dilemmas. They may also be responsible for leading the interdisciplinary teams. They clearly play an important educational role as they discuss medical management decisions, and should regard research, and the critical application of research findings, as an integral part of their work.

In countries where there are as few as one physician to 50 000 people, it is unrealistic to have this scarce resource devoted totally to palliative care. By incorporating palliative care into the services provided by all doctors dealing with cancer patients (gynaecologists, surgeons, radiotherapists, paediatricians etc.), as well as including it in the undergraduate curriculum, wider, but less expert coverage can be obtained.

### NURSES

The nurse is the team member who will typically have the greatest contact with the patient. This prolonged contact gives the nurse a unique opportunity to know the patient and the caregivers, to assess in depth what is happening and what is of importance to the patient, and to assist the patient to cope with the effects of advancing disease. The nurse's expertise in providing physical and emotional care to the patient, symptom management, patient and family education, and in organizing the patient's environment to minimize loss of control, is critical to palliative care. Nurses are able to work closely with patients and families to make appropriate referrals to other disciplines and health-care services. In some settings, where the number of doctors is small, nurses may lead the multidisciplinary team and be responsible for the provision of all aspects of palliative care. In such settings, nurses need specialist training that is appropriate to the cultural and economic circumstances in which they work. Nurses in many settings play a role in providing public and volunteer education about palliative care.

## SOCIAL WORKERS AND PSYCHOLOGISTS

The role of the social worker or psychologist is to help the family and patient deal with the personal and social problems of illness and disability, as well as to provide support during the progression of the disease and the bereavement process if the patient is at the end of life. The social worker's assessment helps define the patient's and family's needs from a psychosocial perspective, and helps anticipate problems within the family that may result from dysfunction and financial difficulties, particularly as the family begin planning for the future. Social work and psychology are both instrumental services. They may offer such interventions as referral to needed community services, emotional support (including individual counselling of patients and family members) and bereavement counselling.

## SPIRITUAL COUNSELLORS

The spiritual counsellor should be a skilled and non-judgemental listener, able to handle questions related to the meaning of life. Such questions invariably arise for patients and their families. The role of the spiritual counsellor is often one of listening, to facilitate recollection of the past and growing readiness for what lies ahead. The spiritual counsellor also often serves as a confidant and source of support for those with a religious tradition, organizing religious rituals and sacraments that are meaningful to them. Spiritual counsellors need to be trained in end-of-life care.

## VOLUNTEERS

The role of the volunteer within the palliative care team will vary according to the setting. In some low- or middle-resource settings, volunteers may provide most of the care for the patients. Volunteers are included in hospice and palliative care teams with the aim of assisting health-care professionals to provide the optimal quality of life for patients and families. Volunteers come from all sectors of the community, and often provide a link between health-care institutions and patients. Incorporating volunteers in a palliative care team brings in a dimension of community support and community expertise. With the appropriate training and support, volunteers can provide direct service to patients and families, help with administrative tasks, or even work as counsellors. They can also take on several other roles, such as raising awareness, providing health education, generating funds, helping with rehabilitation, or even delivering some types of medical care.

## PHARMACISTS

Drug therapies are a major component of symptom management in palliative care, so the pharmacist plays an important role. The pharmacist ensures that patients and families have access to the essential drugs for palliative care. The pharmacist's expertise is also needed to support the health-care team by providing information on drug doses, drug interactions, appropriate formulations, routes of administration, and alternative approaches.

Morphine and other suitable medicines are necessary for palliative care. In many low- and middle-income countries, access to medicines is limited not only by the general lack of pharmacists to dispense medications, but also by the relatively high cost of medicines which makes them unaffordable for many cancer patients. For these reasons, pharmacists, even those with fairly basic skills and limited training are vital to palliative care service delivery. They can constitute analgesic medicines from the starting materials, like morphine powder, which is very cheap. Furthermore they can play a role in the management of an adequate distribution system for home care patients.

## TRADITIONAL HEALERS

The role of traditional medicine and traditional healers is well recognized. Worldwide, about two thirds of cancer patients resort to some form of complementary or alternative therapy (Ott, 2002). In most settings, traditional healers do not usually become members of the palliative care teams. Nevertheless, there should be scope for an open discourse between health-care providers and traditional healers with a view to coordinate their efforts to address the needs of patients and their families, in a sensitive and respectful way, taking into account the diverse cultures of communities and individuals.

## CREATE PALLIATIVE CARE TEAMS

Figure 3 illustrates the distribution of professionals and community caregivers in palliative care teams at the different levels of care in a low- or middle-income country. This model assumes that the following conditions apply:

- ▣ At *tertiary level*, all physicians and nurses dealing with cancer patients will get basic training in managing pain and other symptoms, and in providing psychosocial support. In complex cases, they will refer patients to a specialized team composed of a physician specialized in palliative care, a nurse, a part-time social worker (or psychologist) and a pharmacist. This team will also act as a national reference and training group.
- ▣ At *secondary level*, all physicians and nurses dealing with cancer patients will get basic training in managing pain and other symptoms, and in providing psychosocial support. In complex cases, they will refer patients to a specialized team composed of a physician and/or nurse specialized in palliative care, a part-time social worker and a pharmacist. This team will also act as a district reference and training group.
- ▣ At *primary level*, all nurses dealing with cancer patients will get basic training in managing pain and other symptoms, and in providing psychosocial support. In complex cases, they will refer patients to a specialized team at the secondary or tertiary level. The specialist nurses in the primary-level teams will be trained to train and supervise community leaders, family caregivers and traditional healers.

**Figure 3. Network of palliative care teams across the levels of health-care**



Across the levels of care, services can be provided through inpatient care, outpatient care and home-based care.

## INPATIENT CARE

In low-income countries, where a stand-alone unit for inpatients would be relatively cost-intensive, a specialized palliative care team is an effective way of providing palliative care services to inpatients in a variety of health-care settings. A specialized team may be more sustainable than a free-standing unit.

A palliative care team is typically composed of a physician trained in palliative medicine, at least one clinical nurse and a part-time social worker, all supported by adequate administrative staff. Such a team has no dedicated beds of its own but advises on every aspect of palliative care. This approach makes it possible to provide palliative care consultations to a large number of patients, in a hospital or nursing home. It is an ideal way of providing specialist care while at the same time training the large numbers of physicians and nurses with whom the team interacts.

## OUTPATIENT CARE

In some developing countries, the day-care unit or outpatient unit performs the important role of offering low-cost care to people who are not too sick to attend. It also offers an opportunity to review a patient's need for periodic procedures (such as draining pleural effusions or ascites), and to train the patient's family in how to provide care. Often, day-care services may focus on providing respite for relatives by ensuring that patients get medications and food, and have their physical, psychological and spiritual needs met.

## HOME-BASED CARE

In high-income countries, home-based care services are usually more resource-intensive than in low- and middle-income countries. They often operate from a specialist palliative care unit or hospice, and sometimes provide round-the-clock coverage.

In low- and middle-income countries, where patients usually prefer to die at home, home-based care is generally more acceptable and affordable than hospital care. For example, with the support of local nongovernmental organizations, the Ministry of Health of Uganda has included pain relief and palliative care in a home-care package, based on a needs assessment of patients and their caregivers. Services include essential drugs for the relief of pain and other symptoms, as well as the provision of food for the patient, and support for the patient's family (Logie and Harding, 2005).

A variety of models of home-based palliative care are currently being implemented in low-resource countries. A popular approach in low-resource settings, where the number of people needing care is high and the number of nurses and doctors available to provide that care is low, is to provide care through community caregivers or volunteers who are supervised by a nurse trained in palliative care. The Neighbourhood Network in Palliative Care in Kerala, India, and the Hospice and Palliative Care Association of South Africa, for example, have developed community-based, home-based care along these lines.

Ideally, any model of home care will have strong links to an inpatient facility for patients requiring more intensive palliative care for symptom control or for terminal care.

Examples of models for organizing palliative care services can be found at <http://www.who.int/cancer/modules/en/index.html>



## EDUCATE CAREGIVERS

In order for a palliative care programme to be successful, education and training in palliative care need to be tailored to meet the objectives and priorities identified in the plan. An effective education programme will ensure that appropriately trained programme managers and health-care practitioners exist across all levels of care. Because the complexity, scope and coverage of care differ at different levels of services, health-care providers working at different levels need different types of training.

For example, if the palliative care plan calls for home-based care services in a target area, the educational efforts should concentrate on raising awareness in the target community, and training health-care workers, community leaders and family caregivers in basic home-based care. The health-care workers at the community level should be trained and supervised by professionals from the district level.

For a palliative care programme to be effective, education needs to be synchronized with the introduction of the new services, which will include making oral morphine and other essential medications available. Health workers trained in palliative care often get discouraged because they lack the necessary resources to carry out their work. A viable option is to organize in-service training in the target area for the palliative care teams, with the support of the local authorities. With this type of training, health-care providers remain connected to their working environment and contribute to organizing and implementing the needed palliative care services as the team jointly progresses in its learning activities.

When initiating a palliative care programme in a low- or middle-income country, education and training should be provided for all health workers in the target area. The following steps will ensure that priority services for the majority of patients are in place in a relatively short time:

- ▣ First, provide basic training (20–40 hours) for the health-care providers working at the primary and community levels.
- ▣ Second, provide intermediate-level training (60–80 hours) for the physicians and nurses working at the secondary and tertiary levels, who are dealing with cancer patients.
- ▣ Third, provide proficiency (specialized) training (3–6 months) to the specialized teams or palliative care units at the secondary and tertiary levels.
- ▣ Finally, provide undergraduate training in medical and nursing schools.

Palliative care services require skills in the following areas:

- ▣ communication
- ▣ decision-making
- ▣ management of complications of treatment and the disease
- ▣ management of pain and symptoms
- ▣ psychosocial care for the patient and family
- ▣ spiritual understanding and approaches
- ▣ care of the dying
- ▣ bereavement care.

For each of these sets of skills, innumerable educational modules have been developed for the wide range of health-care professionals who are involved in palliative care. For example, such educational materials exist for community health-care workers and volunteers, and for nurses, physicians, medical students, pharmacists, health managers and policy-makers.

Links to e-learning courses and publications on palliative care education for health professionals and caregivers can be found at

<http://www.who.int/cancer/modules/en/index.html>



Palliative care training materials developed by WHO (Integrated Management of Adolescent and Adult Illness and Integrated Management of Childhood Illness) are available to download from

<http://www.who.int/hiv/capacity/modules/en/index.html>



## EDUCATE FAMILY AND VOLUNTEER CAREGIVERS

The empowerment of family members and volunteers to be effective palliative caregivers may be the most realistic approach for meaningful coverage, especially in rural areas. Family members and volunteers can also sensitize relevant local and national governmental organizations to the need for palliative care. In order to provide appropriate home care, the training of families and volunteers needs to focus on personal care, personal services, social companionship, and applied medical care.

## INDIA

### Example of a nongovernmental initiative to train volunteers in community-based palliative care

The Neighbourhood Network in Palliative Care (NNPC) in Kerala, India, is a successful programme that involves volunteers at various levels. Under the programme, people who can spare at least 2 hours per week to care for the sick in their area are enrolled in structured training (16 hours of interactive theory plus 4 days of clinical practice under supervision, with an evaluation at the end). On successful completion of this “entry point” training, the volunteers are encouraged to form themselves into groups of 10–15 people per community. Each group then works to identify the problems of the chronically ill in their area and to organize appropriate interventions. These NNPC groups are supported by trained doctors and nurses. The NNPC groups work closely with existing palliative care facilities in their area or, if necessary, create such facilities themselves. Volunteers from these groups make regular home visits to follow up the patients seen by the palliative care team. Volunteers also identify patients in need of care, and address a variety of non-medical concerns, including financial problems, organizing programmes to create awareness in the community and raising funds for palliative care activities.

Source: Kumar S (2007) Kerala, India: a regional community-based palliative care model. *Journal of Pain and Symptom Management*, 33:623–627.



## ARGENTINA

### Example of a nongovernmental initiative to deliver home-based palliative care

Since 1985, LALCEC San Nicolas – the Palliative Care Programme of the Medical Federation of Buenos Aires (FEMEBA) Foundation – has been delivering palliative care in San Nicolas, Argentina, with a team of two anaesthesiologists, one psychologist, one social worker and five to seven trained volunteers. All the team members work on a voluntary basis. Most of the patients are from low-income groups, and care is free; medications and administrative expenses are funded by charities. The volunteers, under the supervision of the team physicians, assess patients at home and collect data on the evolution of treatment. They also educate the family about analgesic use and treatment issues. Treatments are delivered according to WHO guidelines. Patients are provided with opioid analgesics for oral use, prepared by the team or at a public pharmacy (6 mg/ml morphine or 10 mg/ml methadone in aqueous solution).

Sources: Wenk R et al. (1991). Argentina's WHO Cancer Pain Relief Program: a patient care model. *Journal of Pain and Symptom Management*, 6:40–43. Additional information provided by Roberto Wenk, Medical Federation of Buenos Aires Foundation, Argentina.

## EDUCATE PATIENTS

Patients have a right to know what choices they have at the end of life, and to know how to demand better management of pain and control of other symptoms. They need to be aware that they do not have to suffer, and that appropriate treatment of pain and other physical and emotional symptoms can dramatically improve their quality of life. Patients and families need to know what services can allow patients to be cared for at home instead of in hospital, enabling them to make choices about quality of life and, when dying, place of death.

## EDUCATE THE GENERAL PUBLIC AND POLICY-MAKERS

In order to increase the likelihood of reaching people who need palliative care with the required services, it is important for the general public to understand what palliative care is, who should be referred for services, what those services are, and how patients and families may benefit from palliative care programmes. The general public can play a role in palliative care, for example, by volunteering to help teams of health professionals. Before volunteering, however, people need to know how they can help.

It is particularly important for policy-makers to understand that palliative care is part of the continuum of care of cancer and other diseases, that it can be integrated into the existing health-care system at a relatively low cost, and that it requires opioids to be available across all levels of care.

The media need to be involved in disseminating reliable information of educational value, while avoiding sensationalism. This can be achieved by putting journalists in touch with patients with advanced illness who wish to talk about the importance of pain relief to their quality of life. Safeguards should be put in place to ensure that the media respects the dignity and rights of patients and their families. The media should also be informed of the needs of patients and their families for support and care.

## ENSURE THE AVAILABILITY OF ESSENTIAL DRUGS FOR THE MANAGEMENT OF PAIN AND OTHER SYMPTOMS

A national palliative care plan must include policy measures to provide the wide range of drugs required to manage the common symptoms of cancer, including pain, nausea, vomiting, delirium, agitation, insomnia, fatigue, depression and anxiety. These drugs should be included in an essential medicines list to ensure that decisions regarding resources are based on the medical needs of the majority of the population.

The preparation of an essential drugs list and a palliative care protocol should be done by a multidisciplinary team. These documents should be mandatory, and should apply nationally to the selection of palliative care medicines in all private and public institutions. WHO provides a model list of essential medicines (WHO, 2007), including palliative care drugs, as a guide for countries to develop their own essential drugs list. Also, the International Association for Hospice and Palliative Care has recently published a list of 34 drugs that experts consider essential for palliative care.

For the International Association for Hospice and Palliative Care list of essential drugs, see

<http://www.hospicecare.com/resources/emedicine.htm>



Various governments have adopted palliative care drug lists. National drug policies should also address the handling of medications. Guidelines produced by the Ministry of Health of Uganda provide an example that can be used as a model (Ministry of Health of Uganda, 2001).

Fear of the misuse of opioids sometimes obstructs the medical use of these drugs. Law-makers and even health professionals are often insensitive to this problem.

The medical need for opioid analgesics is clear, and guidance is available to help governments develop a national policy for palliative care drugs, specifically opioids (WHO, 1996; WHO, 2002b).

## UGANDA, INDIA, ROMANIA

### Examples of improvement of opioid availability

#### UGANDA

Uganda is the first African country to prioritize palliative care in its National Health Plan (2001–2005). It has made oral morphine freely available to those districts that have specialist palliative care nurses or clinical officers, and has promoted morphine use down to the village level. Because doctors are scarce in rural areas, Uganda has passed laws that allow nurses to prescribe morphine. There are no limits to the number of days or doses which doctors or trained nurses and clinical officers can prescribe within the hospice setting, although the doses available are weak. Doses of 5 mg/ml are available to community nurses outside the hospice setting. The programme is in its early stages but it is a working model of morphine access achieved through policy, legislative and clinical efforts.

Source: Jagwe JGM (2002). The introduction of palliative care in Uganda. *Journal of Palliative Medicine*, 5:160–163.

#### INDIA

Pain relief and the availability of morphine were designated priorities in the National Cancer Control Programme in India in 1992. The Ministry of Health convened national workshops to ascertain why morphine use was not being implemented. The assessment of opioid availability revealed that stringent state laws and the multiplicity of licences were significant barriers. Gradually, the situation has changed. By 2002, a total of 7 out of 28 states or territories had adopted a model rule to make morphine available for palliative care.

This rule has, however, been implemented successfully only in Kerala. In Kerala, the state government simplified the licensing process and stipulated that for morphine to be available from a health centre there must be at least one physician at the health centre with at least one month of practical experience in palliative care. As well, the national drugs controller exempted palliative care programmes from needing a drug licence, thereby eliminating the need for a pharmacist. Kerala established an integrated palliative care network consisting of about 50 small programmes, thus creating a system to facilitate the distribution of morphine for palliative care.

Sources: Joranson DE, Rajagopal MR, Gilson AM (2002). Improving access to opioid analgesics for palliative care in India. *Journal of Pain and Symptom Management*, 24:152–159 and Rajagopal MR, Venkateswaran C (2003). Palliative care in India: successes and limitations. *Journal of Pain and Palliative Care Pharmacotherapy*, 17:121–128.

#### ROMANIA

The reform of drug control policy for palliative care in Romania reflects a government-sponsored effort to undertake a fundamental, guideline-based, comprehensive assessment of drug control policy, with the aim of addressing regulatory barriers and improving access to opioids for pain relief and palliative care. The ultimate goal of the Romanian Ministry of Health Commission in revising the national opioid control policy was to improve patient access to opioids for pain relief. The Romanian process serves as a positive example of how outdated and restrictive national anti-narcotic laws can be reformed into legislation that embodies the principle of balance: retaining essential control over the security and distribution of controlled substances, while allowing physicians to practise modern medicine and provide palliative care for their patients.

Source: Mosoiu D et al. (2006). Reforming drug control policy for palliative care in Romania. *Lancet*, 367:2110–2117.

## DEVELOP PALLIATIVE CARE STANDARDS

Palliative care standards should be developed with the wide participation of stakeholders, to ensure that palliative care services meet minimum service requirements. Their aim is to improve the care provided to all patients with life-threatening illnesses, including vulnerable patients such as children and people with low incomes.

Standards should be based on current evidence of palliative care practice. They should set out core functions that are optimal, achievable and measurable. The implementation of standards should be monitored regularly.

Standards should be developed for palliative care because they:

- ▣ provide a common understanding of the work to be done and indicate a level of quality for service provision;
- ▣ help to ensure that the quality of service being provided is maintained as operational coverage is extended;
- ▣ help the process of continuous improvement of service quality by determining those areas of service provision where problems that require remedial attention exist;
- ▣ serve to inform patients and their families of what quality of care they can expect and should demand as service users;
- ▣ enable staff to know what they are expected to provide;
- ▣ serve as a resource for palliative care training.

Examples of standards of palliative care in various countries are available at <http://www.hospicecare.com/standards/>



## EVALUATE AND MONITOR THE PALLIATIVE CARE PLAN AND ACTIVITIES

Both the development and the implementation of a palliative care plan need to be monitored and evaluated periodically in order to ensure that the objectives of the plan are achieved. Evaluation requires careful design and planning. This should start early in the process of programming the implementation of activities. A basic information system needs to be put in place early on so that the necessary data for monitoring and evaluation are collected on a regular basis.

The performance of palliative care activities can be evaluated using the quality improvement framework described above (see page 12). Guidance is available on monitoring and evaluating cancer control programmes, including palliative care, using the quality improvement and the system model frameworks (WHO, 2002a).

No matter which framework is used, the evaluation plan needs to define clearly:

- ▣ who will evaluate the implementation of palliative care activities;
- ▣ what will be evaluated;
- ▣ what will be the core indicators (measures) and their respective standards (values set by stakeholders);
- ▣ how will the evaluation be designed and carried out to ensure credibility;
- ▣ how will the results of the evaluation be used to improve the performance of palliative care activities.

Table 6 gives examples of structure, process and outcome indicators, and related standards, for use in evaluating palliative care activities.

**Table 6. Examples of structure, process and outcome indicators, and their associated standards, for use in evaluating the fully established activities of a cancer palliative care programme**

Core indicators	Standards
<b>STRUCTURE</b>	
<ul style="list-style-type: none"> <li>○ Policies and regulations include palliative care as a key component of national cancer control</li> </ul>	Official documents, laws, regulations, guidelines and manuals published, updated and available
<ul style="list-style-type: none"> <li>○ Funding and service delivery models established to support the provision of cancer palliative care in all settings where patients receive care</li> </ul>	
<ul style="list-style-type: none"> <li>○ Opioid prescribing laws and regulations for pain relief</li> </ul>	
<ul style="list-style-type: none"> <li>○ List of essential medications for palliative care</li> </ul>	
<ul style="list-style-type: none"> <li>○ Network of health-caregivers across the different levels of care</li> </ul>	Accreditation of palliative care services delivery at all levels of care
<ul style="list-style-type: none"> <li>○ Network of community leaders and caregivers trained and motivated to provide good quality palliative care services, including home-based care</li> </ul>	Accreditation of community based-care initiatives
<ul style="list-style-type: none"> <li>○ Communities that own and support palliative care services</li> </ul>	Mapping of communities
<ul style="list-style-type: none"> <li>○ Educational courses that provide:                             <ul style="list-style-type: none"> <li>- core knowledge and skills to practising health-care professionals across all levels of care</li> <li>- expert knowledge and skills to a few selected health-care professionals to lead palliative care services at the secondary and tertiary levels</li> <li>- undergraduate palliative care education for health-care professionals (physicians, nurses, pharmacists, social workers)</li> </ul> </li> </ul>	Undergraduate and postgraduate courses available, including in-service training for health-caregivers across all levels of care
<b>PROCESS</b>	
<ul style="list-style-type: none"> <li>○ Number of advanced cancer patients receiving palliative care according to established standards</li> </ul>	
<ul style="list-style-type: none"> <li>○ Number and type of trained health-care professionals at the different levels of care qualified to provide palliative care according to established standards</li> </ul>	
<ul style="list-style-type: none"> <li>○ Proportion of advanced cancer patients who get early palliative care according to established standards</li> </ul>	>80%
<ul style="list-style-type: none"> <li>○ Proportion of advanced cancer patients who get palliative care according to established standards</li> </ul>	>80%
<ul style="list-style-type: none"> <li>○ Proportion of advanced cancer patients receiving home-based care provided by trained caregivers</li> </ul>	>80%
<ul style="list-style-type: none"> <li>○ Proportion of advanced cancer patients receiving home-based care who need to be referred for specialized palliative care services at the secondary and tertiary levels</li> </ul>	<20%
<ul style="list-style-type: none"> <li>○ Proportion of family caregivers who get psychosocial support through the course of the disease, and through bereavement care, according to established standards</li> </ul>	>80%
<b>OUTCOME</b>	
<ul style="list-style-type: none"> <li>○ Proportion of advanced cancer patients who get timely relief from pain and other physical, psychosocial and spiritual problems</li> </ul>	>80%
<ul style="list-style-type: none"> <li>○ Proportion of caregivers of advanced cancer patients who get timely relief from psychosocial and spiritual problems</li> </ul>	>80%

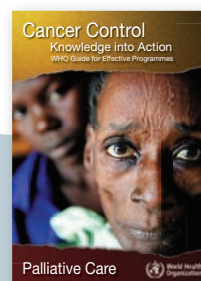
# CONCLUSION

Palliative care is a key component of an overall cancer control plan and programme. It responds to the needs of advanced cancer patients and their families. Palliative care services should be linked to cancer prevention, early detection and treatment strategies in order to respond to all the cancer priority needs in a community and make the best use of scarce resources.

A cancer palliative care programme should also be part of a broader palliative care strategy that addresses all patients with chronic life-threatening conditions.

Evidence-based standards of palliative care services, focusing on improving clinical and organizational knowledge and practice are needed in all settings. Simple and low-cost public health models of palliative care can be implemented to reach the majority of the target population, particularly in low-resource settings, where the majority of cases are diagnosed in late stages. These models consider the integration of palliative care services in the existing health system at all levels of care, but with special emphasis on community- and home-based care. They involve the public and the private sector, and are adapted to the specific cultural, social and economic settings.

**This module on palliative care is intended to evolve in response to national needs and experience. WHO welcomes input from countries wishing to share their successes in palliative care. WHO also welcomes requests from countries for information relevant to their specific needs. Evidence on the barriers to cancer palliative care in country contexts – and the lessons learned in overcoming them – would be especially welcome (contact at <http://www.who.int/cancer>).**



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The World Health Organization estimates that 7.6 million people died of cancer in 2005 and 84 million people will die in the next 10 years if action is not taken.

More than 70% of all cancer deaths occur in low and middle income countries, where resources available for prevention, diagnosis and treatment of cancer are limited or nonexistent.

Yet cancer is to a large extent avoidable. Over 40% of all cancers can be prevented. Some of the most common cancers are curable if detected early and treated. Even with late cancer, the suffering of patients can be relieved with good palliative care.

***Cancer control: knowledge into action: WHO guide for effective programmes*** is a series of six modules offering guidance on all important aspects of effective cancer control planning and implementation.

Worldwide, millions of cancer patients could be relieved from pain and unnecessary suffering if they had timely access to good palliative care.

This module explains how to develop an effective palliative care programme within the context of a national cancer control programme. It is based on the *Planning* module, which provides a comprehensive understanding of the overall cancer control planning process.

Although this *Palliative care* module focuses on cancer and does not specifically address other diseases, it recognizes the need for developing palliative care with a public health approach that targets all age groups suffering from diseases or conditions in need of palliative care. These conditions include HIV/AIDS, congestive heart failure, cerebrovascular disease, neurodegenerative disorders, chronic respiratory diseases and diseases of older people, among others.

The principles guiding the development of palliative care within a cancer control programme are very similar to those needed in providing palliative care for people with other chronic diseases.

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