

Foreword

This handbook was initially created at the request of physicians, nurses, social workers and other health professionals who collaborate with the International Network for Cancer Treatment and Research (INCTR). More recently, we have revised this user-friendly guide, based on feedback and new evidence.

We hope that handbook will continue to help in the management of common palliative care problems. It is, therefore, primarily aimed at those who have completed some basic training in palliative care but are not necessarily specialists in the field.

The handbook focuses on the needs of children and adults with serious health-related suffering, those living with life-threatening and life-limiting illnesses, including cancer, but also other serious illnesses including severe respiratory, cardiovascular, renal, and neurological conditions, as well as dementia, and HIV/AIDS.

Although we have aimed at brevity there are four topics that we thought deserved special mention in this foreword. These are the philosophy of palliative care, the need for good assessment, the importance of palliative care for children and "balanced care".

The Philosophy of Palliative Care

This has been defined by the World Health Organization and other healthcare organizations in a variety of ways. In essence, it should be viewed as a holistic and interdisciplinary approach that aims to improve the quality of life of people of all ages – and their caregivers – who live with life-limiting health conditions.

In general terms, palliative care:

- Is both a philosophy and a clinical approach to care
- Responds to physical, psychosocial, and spiritual dimensions of suffering – both of the patients and of their caregivers
- Responds to people's beliefs and practices as well as their social and cultural values
- Is applicable throughout the illness continuum, including bereavement
- Can be applied in combination with other therapies or may be the sole focus of care
- Responds to the unique needs of children and their families

Assessment

Assessment is the process of gathering information to help guide patient care. Thoughtful and thorough assessments are the foundation of

good palliative care, requiring the practitioner to listen well, ask relevant questions, and understand physical evaluation. However, the physical, emotional, and spiritual dimensions of an illness that affect quality of life can also be further evaluated using appropriate tools. The patient is at the centre of this process, but it should also include the family and other caregivers.

An on-going cycle of assessment and reassessment is vital in the management of palliative care patients who often have rapidly changing symptoms from multiple causes. Investigations, particularly those which carry a physical or psychological burden, require a balanced consideration of the patient's prognosis, his or her wishes, and any likely benefit.

Palliative Care for Children and Young People

Caring for seriously ill children requires particular attention, and sensitivity to the developmental stage and cognitive abilities of the child. It is extremely important to recognize the profound distress parents and siblings may experience when a child is ill, and to provide additional family support. Children often understand more about their illness than we realize or acknowledge, and it is best to



answer their questions as honestly as possible. Children may also use art, drawings, or play to express what they are feeling inside, and this can be a helpful way to explore a child's fears, worries, and hopes. The management of physical symptoms in paediatric palliative care has much in common with that of adults. However, there are some differences both in medication choice and dosage. We should ensure that children with life threatening and serious illness remain foremost in our minds and are not abandoned when cure is no longer possible. They and their parents need to be supported with compassion and understanding combined with expert symptom assessment and management.

Balanced Care

Within the context of patient's wishes and prognosis it is important to balance the benefits of investigation and treatment against the burdens and possible harm. Perhaps more than any other area of medicine a balanced approach is needed in palliative care to achieve the best quality of life for our patients. Trying to decide whether or not to carry out any particular intervention (such as an investigation or a treatment) often creates a complex clinical dilemma – and sometimes an ethical one. It may be helpful to reflect on the following questions:



Is there a reasonable chance of benefit to the patient?

Is the intervention likely to improve symptoms for the patient and enhance quality of life? Is the improvement likely to be maintained? For instance, a transfusion of blood may help a feeling of fatigue or breathlessness in a patient with anemia who has months of life ahead but for a patient close to death it is much less likely to make a positive contribution.

Will the intervention likely cause harm to the patient?

Most interventions will have drawbacks either in terms of physical suffering, wasting of valuable time, or sometimes in raising "false hope" with either the patient or the family.

For instance, carrying out a CT scan when the result will not change the treatment but may exacerbate pain as well as creates a possible expectation for disease modifying treatment (when none is planned) should be avoided.

Is the intervention a proper use of available resources (justice)?

In most situations medical resources are limited and have to be used in a fair manner. For instance, in a situation where there is a shortage of platelets for transfusion these may have to be

reserved for patients who are having curative treatment rather than those with terminal illness.

Having tried to find a balance between these elements one should ask: What are the patient's wishes?

When appropriate, the patient should be informed of the possible benefits and drawbacks of the intervention and his or her wishes identified. Their beliefs, developmental stage, cognitive abilities and life experiences (especially that of their illness) will influence their decision making and should be taken into consideration. The family or other caregivers are often a part of this process.

Caring for children creates an added complexity. Sometimes children's wishes may differ from their adult caregivers. Special effort should be made to try and understand the needs and wishes of all concerned.