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Enhanced Palliative Care

A Handbook for Paramedics,
Nurses and Doctors

Edited by
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Disclaimer

Please note that any prescribing information in this program will be compliant with the Scottish Palliative Care Guidelines. These are regularly reviewed and the online guidelines updated when required. The details and dosages in this book are presented for information purposes only and any guidance, although accurate at the time of publication, may be subject to change. For the purpose of the case studies in the manual, or where symptom control is specifically related to, please check the current advice at: <https://www.palliativecareguidelines.scot.nhs.uk/>.

Practitioners should always work to local protocols, and within their own level of governance and experience.

Acknowledgement

The idea for an *Enhanced Palliative Care* educational programme grew from many years learning and teaching on several different courses based on the well-established model of a pragmatic and evidenced manual, underpinning a short interactive course. This was catalysed following feedback on the Scottish Palliative Care Guidelines highlighting that many colleagues would appreciate broader and more detailed teaching. A proposal was taken to Macmillan Cancer Support to fund the development of a practical course for paramedics, nurses and doctors to enhance their knowledge and skills in palliative care. They generously agreed to this. I would like to thank all the Macmillan team, and specifically Jean Sargeant who has been a stalwart from the start.

The programme adheres to the principals of the NHS Education for Scotland (NES) framework for Palliative and End of Life Care, and follows the general structure and the drug regimens of the Healthcare Improvement Scotland (HIS) Scottish Palliative Care Guidelines. I am grateful for the support given by HIS, NES, the Scottish Partnership for Palliative Care and the College of Paramedics.

Almost 100 colleagues, from across the professions, gave freely of their time in writing the manual and preparing the course. This was made more demanding due to the pressures on time and resources caused by the COVID-19 pandemic. I owe an enormous debt of gratitude to everyone who is named in the list of contributors. I would like to especially thank the lead chapter authors, and the members of the steering group.

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Foreword

It is well known that the field of modern palliative care developed from modest beginnings, was led by a small band of enthusiasts, and often operated outside or on the margins of the mainstream health and social care system. But as hospice founder Cicely Saunders famously said, ‘we moved outside the NHS in order to let new ideas and practices come back in.’

This training manual is an eloquent testimony to the success of that ideal.

In the last half century, huge strides have been made to bring about the recognition of palliative care as a specialist activity. We have seen the growth of clinical centres of excellence, accredited training programmes, academic research groups and professional societies that support the local, national and international development of palliative care.

There is much to celebrate.

Yet at the same time, evidence of the growing need for palliative care continues to mount. It is estimated that the current number of 56 million deaths worldwide each year will rise to 92 million by 2050 (Clark et al., 2017). One recent calculation from a Lancet Commission suggests that every year 50 million people could benefit from palliative care (Knaul et al., 2018). At the same time, we know from global mapping studies that just 30 countries, accounting for only 15% of the global population, have access to the highest levels of palliative care provision (Clark et al., 2019). Even within those jurisdictions, we recognise there remains a significant problem of access to the care which is required.

A major and badly needed shift in orientation is therefore under way.

Specialist palliative care, research, education and clinical services will continue to have an important role. But increasingly we must look to raise overall standards of palliative care competence and confidence across the entire care system. This means palliative care enhancement in the practice of people working in many areas and specialisms, new collaborations with other fields, and the strengthening of palliative care in community and primary care settings.

Here in Scotland, we are fortunate to have a group of people who are massively committed to these ideals of ‘generalist’ palliative care. This manual is packed full of evidence-based wisdom and insight that will prove invaluable to so many people wishing to improve their palliative care practice. The optional accompanying one day course adds further depth and detail. Put together by contributors with high hopes and feet firmly on the ground, the *Enhanced Palliative Care* programme will be an invaluable resource to many and a direct benefit to many, many more who will receive care that has been influenced and improved by it.

David Clark Professor Emeritus

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Chapter 1

Principles of Palliative and End-of-Life Care

Paul Baughan, Sandra Campbell and Neil Pryde

Learning Objectives

At the completion of this chapter, you will:

- Be able to describe the philosophy that underpins the principles of palliative and end-of-life care
- Be able to define what is meant by 'palliative care' and 'end-of-life care'
- Be able to describe why early identification of those who may benefit from a palliative approach to care is important, and the tools that can support this
- Understand the importance of anticipatory care planning and the various tools which support this.

The Origins of Palliative Care

The transformation of end-of-life care in the modern era began in 1967, thanks to Dame Cicely Saunders, founder of St Christopher's Hospice in London. Since then, the hospice movement has grown, and the field of generalist and specialist palliative care has evolved. Today there are still variations in how those who require palliative and end-of-life care receive it, with inequity of service provision evident across settings. One of the key aims of this book and the associated course is to reduce these inequalities.

Dame Cicely Saunders trained as a nurse in the 1940s. During her time as a registered nurse at St Luke's Hospital in London she learned a great deal about pain control via the administration of morphine on a four-hourly basis (Doyle, 2002). This would eventually become the foundation model for the treatment of chronic and terminal pain. She then studied to become a doctor, qualifying in 1957, and later became the first modern physician dedicated to palliative and end-of-life care (Stevens et al., 2009).

At her memorial service in 2006, Robert Twycross quoted her philosophy as:
(St Christopher's Hospice, 2021)

'You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.'

Definitions of Palliative Care

The term 'palliative care' can mean different things to different people. It is important for health and care professionals to have a firm understanding of what palliative care is and what it is not.

The World Health Organization (WHO) definition of palliative care

The World Health Organization (WHO) defines palliative care as:

'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 or 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, and includes those investigations needed to better understand and manage distressing clinical complications.'*

(NICE, 2021)

The Scottish Government definitions of palliative care

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Non-specialist palliative care and support is provided by professionals across health and social care in a variety of different settings. This care may be delivered alongside active treatment, where this is appropriate. Such care can be delivered with varying degrees of specialist palliative support throughout the health and social care system.

Specialist palliative care can help people with more complex palliative care needs. It is provided by specially trained multi-professional palliative care teams, who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital. Specialist palliative care has a particular role in providing support, advice and education to the rest of the health and care system.

End-of-life care is care of the person living through the dying phase of life. This phase could vary between weeks, days or hours, the exact timing often being unpredictable. Changes and deterioration may occur suddenly and unexpectedly. It is helpful to explore and address individuals' needs concerning end-of-life care, and not assume it is covered within the remit of palliative care. End-of-life care should be seen as everyone's responsibility.

Bereavement is understood as 'the experience of losing someone important to us. It is characterised by grief, which is the process and the range of emotions we go through as we gradually adjust to the loss' (Mind, 2019). Bereavement care may be defined as any care provided formally or informally, through statutory or voluntary services or by members of the community to those affected. The need for support will apply to those affected by both expected and unexpected loss and death.

(Scottish Government, 2018)

The Four Dimensions of Palliative Care

In assessing needs, and planning how the full breadth of those needs will best be met sustainably, the following four dimensions of palliative care should always be considered (Figure 1.1). Attending to spiritual, social and psychological and emotional, in addition to physical ones, is not an optional extra, and doing so may impact positively on the physical supports a person needs. Palliative care involves all of these dimensions.



Figure 1.1 The four dimensions of palliative care.

Source: Image by Hazel White, Open Change.

Realistic medicine

From these definitions it is clear that effective palliative care should be available to anyone with an incurable, life-threatening disease. Their need should be identified at the appropriate time, with care and support provided to the patient and their 'family'. This practical and holistic approach sits well with the concept of 'Realistic Medicine', as outlined by Dr Catherine Calderwood in her 2017 report, 'Realising Realistic Medicine'. In the report, Calderwood surmises that:

'Realistic Medicine puts the person receiving care at the centre of decision making and creates a supported, personalised approach. It aims to reduce harm, waste and unwarranted variation, whilst acknowledging and managing the inherent risks associated with all healthcare, and championing innovation and improvement. These concepts are essential to a well-functioning and sustainable NHS for the future.'

Realistic Medicine is about supporting people using healthcare services, and their families, to feel empowered to discuss their treatment. It is not about failing to offer treatments that are likely to have benefit. That's why changing our style to sharing decisions with our patients is one of our priorities. A move away from the 'Doctor knows best' approach to shared decision making between the professional and patient will require more meaningful discussions about the treatment options available as well as their risks and benefits.'

The Importance of Dignity

It is helpful to approach palliative care issues in a way that has a dignity conserving approach. The following ABCD approach is a useful tool to adopt.

Attitudes
Behaviours
Compassionate **D**ialogue

In situations of distress, or in shared decision making, it is important to ensure **Attitudes** held and expressed are empathetic, demonstrate a sense of calm, and communicate the aim to work together positively to improve the situation. The **Behaviours** exhibited by the health professional, in word and deed, should evidence this attitude and intent. This foundation should set the right tone to enter into purposeful **Compassionate Dialogue**, and will underpin the gaining of therapeutic benefit from interventions. Dialogue allows for symptom experience to be described, heard, understood, acknowledged and managed.

Dr Harvey Max Chochinov, Director of the Manitoba Palliative Care Research Unit, CancerCare Manitoba in Winnipeg, and his team developed a dignity-conserving model of care as a succinct way of thinking about, and addressing, the issue of dignity. As part of this they use the following question to help them provide care: 'What do I need to know about you as a person to give you the best care possible?' (Chochinov et al., 2005).