



HANDBOOK *of* PALLIATIVE CARE

FOURTH EDITION

EDITED BY

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WILEY Blackwell

Handbook of Palliative Care

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Fourth edition

WILEY Blackwell

This edition first published 2024
© 2024 John Wiley & Sons Ltd

Edition History

John Wiley & Sons, Inc (3e, 2012)

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John Wiley & Sons, Inc., 111 River Street, Hoboken, NJ 07030, USA

John Wiley & Sons Ltd, The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK

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A catalogue record for this book is available from the Library of Congress

Paperback ISBN: 9781119784364; ePub ISBN: 9781119784388; ePDF ISBN: 9781119784371; eBook ISBN: 9781119784395

Cover Image: A water-colour titled *Between Night and Day* (1995) © Michele Angelo Petrone, for more about the artist, see onca.org.uk/about-us/michele-angelo-petrone/

Cover Design: Wiley

Set in 9/11.5pt Minion Pro by Integra Software Services Pvt. Ltd, Pondicherry, India

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Foreword

'I think that light and shadow have exactly the same duality that exists between life and death'. (Manuel Alvarez Bravo)

Few things in life are as certain as that we are all going to die. This means we should all have a vested interest in developing, testing and implementing services and training staff, in order to be able to deliver high quality palliative and end-of-life care for all. We now live in an ageing society where the benefits of living longer may be outweighed by the burden of multiple comorbidities. We are seeing many more patients living with dementia, which rises year on year as the possibility of developing it approximately doubles every five years after the age of sixty five. Frailty is now recognised as a condition and brings its own challenges for health and social care workers, who endeavour to promote and encourage independence, alongside living as well as possible for as long as possible. We need to truly understand dementia and older frail persons' palliative needs in order to be able to deliver the best and most appropriate care to them. We must also remember, and cast an eye over, the informal carers of these patients who must be supported and valued to ensure they have the resilience to continue in their unpaid and extremely important and necessary roles.

The conundrum of choice for patients who have life limiting conditions has boundaries which clinicians need to be mindful of, particularly prior to embarking on advance care planning conversations. We strive for seamless and coordinated care for our patients in the right place at the right time by the right people but resourcing this can be expensive and challenging and often not seen as a priority for commissioning. We cannot guarantee timely and suitable care and/or interventions out of hours, which then falls to urgent care providers who are frequently not prepared or equipped to deliver it. Ambulance services are

increasingly filling gaps in community care provision and, as generalist clinicians whose focus of training is to provide life-saving and emergency interventions, recognising dying as opposed to a condition that is potentially reversible, and considering a palliative and end-of-life care approach, requires a massive paradigm shift. More emphasis is now rightly being placed on furnishing generalists with palliative and end-of-life care skills. This will go some way to improve their knowledge and confidence in this important area of care.

Alongside this is our ageing workforce. We need to refocus and reframe our attitudes to training our clinicians of the future. Work is progressing in developing competencies and a framework for nursing, and medical schools are building on their palliative care specialist training, but we need to accolade the significance of this area of care and pay attention to safeguarding our recruitment and retention strategies. A key area of that is providing education and training to hone a workforce fit for purpose and one that is able to safely care for this patient population.

As a society we welcome a public health approach to death and dying. There is a desire to move away from the medical model and work more collaboratively with communities to improve the experience of death, dying and bereavement. Working with, and sharing an understanding of people's different faiths, cultures, ethnicity and sexual orientations, will positively influence the way we care by demonstrating skill, empathy, compassion and sensitivity to their specific needs.

This book, now in its 4th edition, and edited by Professor Christina Faull, Dr Rich Kitchen, Dr Sarah Russell and Dr Jo Wilson offers contemporary information and reference material for the generalist palliative care provider, in primary and secondary care. In addition to the key chapters,

there are sections related to frailty, mental health and learning disability. These new chapters indicate and highlight the novel challenges we are encountering in health care and they are warmly welcomed to help with symptom control and decision making.

It is refreshing and pleasing to see a chapter on wellbeing – both for health care professionals and the patients and carers. It is vital we pay due attention to the welfare of ourselves and colleagues. We cannot be expected to care for others if we do not care for ourselves. Sourcing appropriate avenues of support, both professionally and personally, is recognised as being of paramount importance. In addition, the patient and carers need to maintain and preserve their strength in order to receive and manage the care required and develop a robust infrastructure of support.

The book provides a pragmatic approach to care by generalists and, most importantly, in any care setting. It is practical and informative with helpful detail of what and how to do things safely and with assurance that the

clinician is providing evidence based care. The variety of topics addressed aims to serve to equip the reader with sufficient knowledge and confidence in managing this cohort of patients and their carers, and enable them to die well in their place of choice.

Dying well should not necessarily be dependent on a specialist palliative care team. Many patients can be safely, effectively and compassionately cared for by the multi-disciplinary team which will include the General Practitioner/doctor, nursing/community team, social care, allied health professionals and the ambulance and urgent care providers. I believe this book will provide a necessary and valuable source of information, guidance, signposting and support for generalists delivering palliative and end-of-life care and I therefore recommend its place on your bookshelf.

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Preface

We four have practiced in palliative and end-of-life care as nurses and doctors for over a 100 years between us in hospital, hospice, care home and community settings. We have a passion for education to improve palliative and end-of-life care and Faull and Kitchen have previously led e-ELCA, the UK national end-of-life care e-learning programme from e-Learning for Healthcare. We want professionals to have ready access to up-to-date and current thinking and hope that this 4th edition of the *Handbook of Palliative Care* provides that in an accessible and engaging way. The COVID-19 pandemic has shone a spotlight on the importance of compassionate palliative and end-of-life care, skilled discussions about preferences, weighing of the burdens and benefits of treatments and the vital integration of families and loved ones into care. It has also revealed the impact caring for dying patients can have on the staff, especially if circumstances mean that care is not able to be provided in the ideal of 'a good death' with human comfort, minimised distress, and with the family present.

As before, the aim of this handbook is to provide a practical and pragmatic approach to supporting patients and those around them. The book does include a good amount of detail, and could also be used as a source of reference. The text is particularly targeted towards those supporting patients with palliative care needs, in the community (General Practitioners, district nurses and others) and in the hospital (a number of members of the multi-disciplinary team). The book is also likely to be useful for those learning their trade as specialists in palliative and end-of-life care.

This 4th edition focuses on holistic care and therapeutic interventions, including several new chapters building on

previous editions with content significantly updated to reflect new evidence and practice.

A new chapter 16 'Palliative and end-of-life care: Frailty, dementia and multi-morbidity' looks at these increasingly important areas of practice. As global populations age, it is imperative that staff can effectively and compassionately support people with these conditions. The chapter utilises current evidence to highlight principles of optimal palliative care in these groups.

Talking to patients and those around them about their preferences for the future is an important aspect of supporting patients with palliative care needs. The chapter 9 'Recognising deterioration, preparing, and planning for dying' discusses offering and supporting discussions in a timely fashion, allowing patients to receive care that is consistent with their values, goals and preferences.

There is increased recognition of the importance of supporting professionals caring for those with palliative care needs. The chapter 23 'Creating space, clarity, and containment in order to sustain staff: managing the emotional impact of palliative care work' highlights the emotional challenges that staff face, and outlines strategies and interventions that can protect staff.

The *Handbook of Palliative Care* has previously covered 'Palliative Care in the Community', and the chapter in this edition looks at important contemporary publications such as the Daffodil Standards for GPs, reviewing how these can be used to deliver best care. The book also now contains a new complementary chapter 5 'Hospital palliative care', which focusses on how teams can effectively work together in a hospital setting to best support patients.

We hope you enjoy reading each of the chapters as much as we have.

Acknowledgements

This 4th edition has only been made possible through the great endeavour of the many chapter authors, who have contributed much of their own time towards this book. Their time was during the COVID-19 pandemic, with all its consequent increased commitments, so we are particularly appreciative. We are also grateful for the authors' commitment to building the palliative care knowledge of readers and trying to ensure that high-quality palliative care is available to all who need it.

Cover Illustration

About the cover art: This is a water-colour titled "Between Night and Day" (1995) by artist Michele Angelo Petrone,

who sadly died in 2007. It is reproduced with kind permission of ONCA, an arts and environment charity which has been looking after Michele Angelo's work since 2017, when it was entrusted with the assets of the MAP Foundation. MAP was an arts in health organisation founded by Michele Angelo to promote expression, communication, and understanding for people affected by life-threatening illness.

1

The Context and Principles of Palliative Care

Christina Faull

Introduction

In my 30 years as a specialist in adult palliative care I consider myself immensely privileged to have worked with patients and their families and learnt so very much from them. As I write this chapter I find myself recalling many of them;

- the man I looked after in my first weeks as a doctor, who had taken an overdose because of his lung cancer;
- the couple with a clear advance directive of “no-intervention” for whom, in the end, it was the right thing to be admitted to intensive care;
- the man who despite multiple pathological fractures needed to travel for a trial chemotherapy as “giving-up” was beyond his ability to cope with;
- the silent lady I couldn’t reach;
- the English man with Native American spiritual beliefs who was terrified of being buried alive.

Dying happens to us all and although there is some uniformity in the physical experience of this, all of us live this last part of our life and die in our own, unique way. I am profoundly humbled by the psychological, spiritual, and socio-cultural diversity of approaches that people have expressed in their living and their dying. I also recognise the challenge that this poses for health and care staff in providing effective, personalised care at the end-of-life.

Every man must do two things alone; he must do his own believing and his own dying. Martin Luther King

Dying is a wild night and a new road. Emily Dickinson

Indeed, Allah [alone] has knowledge of the Hour and sends down the rain and knows what is in the wombs. And

no soul perceives what it will earn tomorrow, and no soul perceives in what land it will die. Indeed, Allah is Knowing and Acquainted. (Quran, 31:34)

Irrespective of your particular specialty or place of work, most health and care professionals will encounter people with advanced illness, and caring for people in the last months, weeks, and days of life is an important and valued part of their work [1, 2]. It is estimated that 40 million people worldwide require palliative care of whom 69% are adults over sixty years of age and 6% are children [3]. Caring for someone who is nearing the end of their life can be an extremely rewarding area of practice, and this satisfaction is enhanced by confidence in core interpersonal skills and through a basic knowledge of physical and non-physical symptom management [4, 5].

In the developed world at least, most people die from conditions that have been diagnosed for some time and they have multiple contacts with healthcare professionals, offering numerous opportunities for discussions about deterioration, dying and the “trade-offs” or personal priority setting so eloquently argued by Atul Gawande in his book *Being Mortal* [6]. However, we know that these conversations are challenging and there is an ambivalence on the part of professionals to initiate such discussions for a number of well-intended reasons. The COVID-19 pandemic exposed healthcare professionals in a new way to the needs of patients and families for open and honest conversations about prognosis and individual requirements and preferences [7]. This Handbook aims to build your confidence and diminish your ambivalence in having such discussions with people in the last stage of their lives. It will

aim to equip you with knowledge and skills in assessment of the patient’s needs and context, in physical symptom management and in communication, enabling your practice in empathetic, personalised, holistic care.

Palliative care offers much to patients with advanced illness and to their families. For some patients this is the main approach in their care. For many patients it can improve the quality of their life when used as shown in Figure 1 not as an alternative to other care (brink-of-death care) but as a complementary and vital part of their management, integrated alongside appropriate care to reverse illness or prolong life [8]. The challenges of the parallel approaches of trying to improve physical well-being and prolong life while also addressing the realistic probability of deterioration and death are significant, especially in those illnesses characterised by episodes of acute deterioration. Perhaps one of the biggest challenges we face in medicine and indeed in society is balancing the clinical and ethical “pros and cons” (weighing the burdens, benefits, and risks) of investigation and intervention in those with advanced illness and in the frail elderly. In the United Kingdom, the General Medical Council (GMC) has recommended that end-of-life should be an explicit discussion point when patients are considered likely to die within 12 months [9, 10]. Box 1 identifies the mandated expectations in this guidance [10].

The majority of care received by patients during the last year of their life is in their home or, for many elderly people, in their care home. The fact that their illness is progressing and their functional status deteriorating often means however, that many patients will spend significant time in hospitals during their last year of life. It has been

Box 1: Mandated expectations of the GMC guidance – Treatment and care towards the end-of-life: good practice in decision making [9, 10]

- Identification of patients approaching the end-of-life.
- Provision of information on this matter.
- Determination of preferences regarding life-sustaining treatment including cardiopulmonary resuscitation (CPR).
- Documentation of the above in an unambiguous and accessible format.
- Communication of decisions within relevant healthcare teams.

estimated that 20% of hospital beds are occupied by patients near the end-of-life many of whom do not need, or want, to be there [11] and despite the majority wishing to die at home, almost 50% of patients still die in a hospital in the United Kingdom [12]. The lack of recognition of the fact that patients are nearing the ends of their lives and open discussion of this with the patients and their families is considered a major barrier in achieving better outcomes including enabling people to die with comfort and dignity, to be cared for where they would most want to [11, 13, 14] and fulfilling the many other “wishes” that are important to them.

Palliative care is more than just end-of-life or “brink-of-death” care. Some of the newest challenges are in providing effective support for those living with cancer, or other advanced illness, for long periods of time who are suffering from a complex mix of effects of the illness itself,

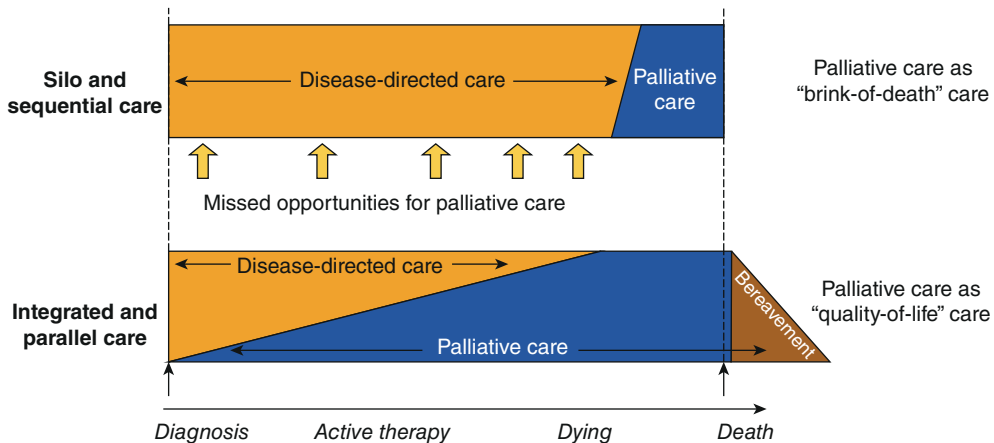


Figure 1 Integrating palliative care alongside disease directed care to achieve quality of life. Amended from [8].

the effects of the treatments for the disease and the psychosocial and psychospiritual impacts of facing not only the fear of recurrence, flare-ups, deterioration and death but also the ongoing symptoms such as fatigue, disability, and the change of role and social and family dynamics [15–17].

There are a broad range of challenges in delivering high-quality palliative, end-of-life, and terminal care including professional competence and confidence, teamwork, and organisational factors, and access to resources. Patients with advanced disease can present some of the most challenging ethical, physical, psychological, and social issues, and it is vital to have a grasp of the communication skills required to explore these issues effectively. It is also important to be able to identify when referrals to specialists and other services are needed.

This chapter outlines the principles that underpin effective care for people with advanced disease, provides some definitions and contexts and presents an overview of the attainment and assessment of quality in palliative care. It focusses mostly on the needs and care of adults although most of the principles are transferable to the care of children. The palliative care of children and young people has some very specific requirements and services and these are discussed in Chapter 15 (Palliative care for infants, children and young people).

Definitions and Explanations

Box 2: Etymology

The word “hospice” originates from the Latin *hospes* meaning host; *hospitalis*, a further derivative, means friendly, a welcome to the stranger. The word *hospitium* perhaps begins to convey the vital philosophy of the hospice movement: it means the warm feeling between host and guest. Hence, a hospice denotes a place where this feeling is experienced, a place of welcome and care for those in need. The word “palliative” derives from the Latin *pallium*, a cloak. Palliation means cloaking over, not addressing the underlying cause but ameliorating the effects.

Hospice and Palliative Care

Much of our understanding and knowledge of the philosophy, science, and art of palliative care has developed and grown through the work of the hospice movement. Dame

Cicely Saunders worked with patients suffering from advanced cancer and undertook systematic narrative research to understand what patients were experiencing and needed. The bedrock of the hospice philosophy is that of patient-centred holistic care focusing on quality of life and extending support to significant family members:

What links the many professionals and volunteers who work in hospice or palliative care is an awareness of the many needs of a person and his/her family and carers as they grapple with all the demands and challenges introduced by the inexorable progress of a disease that has outstripped the possibilities of cure [18].

Saunders opened the first Hospice in London in 1967 and since then services supporting people with terminal illness have spread across the world with more than 16,000 hospices or palliative care units. Although “hospice” has perhaps become thought of as a location of care, a place, it is much more than this and in essence is synonymous with palliative care. Both have a philosophy of care not dependent on a place or a building but on attitude, expertise, and understanding.

The term “palliative care” was coined by Canadian urological cancer surgeon, Balfour Mount, as a term to apply hospice principles more broadly including within the hospital and home settings. More recently, the term *specialist palliative care* has been used to represent those professionals and services that concentrate on this area of health care as their main role and expertise, recognising that almost all healthcare professionals provide elements of palliative care for patients as part of their practice.

Palliative care has been defined by the World Health Organisation 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” [19 p. 84].

Palliative care [19]:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor 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; and
- 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.

To this end palliative care is a partnership between the patient, their family carers, and a wide range of professionals. It integrates the psychological, physical, social, cultural, and spiritual aspects of a patient's care, acknowledging and respecting the uniqueness of each individual:

You matter because you are you, and you matter until the last moment of your life. We will do all that we can to help you not only to die peacefully, but to live until you die [20].

End-of-life Care

End-of-life care can be a confusing term since it may be interpreted by patients, families and professionals as meaning someone is dying very soon, within days (see last days of life below). However, in health and care policy and practice standards such as for instance those of the UK National Institute for Health and Care Excellence (NICE) and the General Medical Council, end-of-life care is usually regarded as a focus on the last 6-12 months of life and refers to the care needed by everyone as they approach the end part of their lives [9, 21]. It is of course difficult to define the last 12 months of life prospectively and much thought has been given to how indicators may help identify people. Figure 2 shows an example developed in Scotland of how such indicators can be incorporated into guidance to help professionals and services identify people who are at risk of deteriorating and dying.

The End-of-Life Care strategy (EoLCS) in England and Wales defined a pathway to optimise the quality of care in the last months of life (Figure 3) [12]. Many other countries have had similar initiatives.

To ensure that "I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)." the UK

National Palliative and End-of-Life Care Partnership has introduced six ambitions with six underpinning foundations (Figure 4) [22].

Last Days of Life and Terminal Care

When a patient becomes so unwell that they will die soon, that they are actively dying, this may be called terminal care or care in the last days of life. In some countries this is referred to as "brink-of-death" care. The standards of care needed at this time has been a focus of considerable attention and resulted in defining the priorities of care for the dying person in England (Figure 5) [23].

Care after Death and Bereavement Care

After a patient has died there is still much that needs attention. The persons' body will need care and preparation that is personalised to their religious, cultural, and pre-morbid instructions. The family and religious practitioners may wish to be involved in this to say good-byes or in performing cleansing and dressing for burial or cremation.

Bereavement and grief are universal experiences but can have diverse impacts on individuals. The impact of the loss of a loved-one is life-long. It may cause immediate critical issues such as the care of a child and the grief may be problematic for some causing significant changes in wellbeing, mental health, and social and financial functioning. More information on this is available in Chapter 8 (Integrating new perspectives: Working with loss and grief in palliative care).

Specialist Palliative Care

Specialist palliative care came into focus with the founding of St Christopher's Hospice by Saunders. It was here that an approach was developed that formed the basis for the role of specialist services which include hospices, hospice at home, and hospital and community palliative care teams. These services provide:

- High-quality care for patients and their relatives, especially those with complex needs.
- A range of services to help provide optimum care: whether the patient was at home, in hospital, or required specialist in-patient care.
- Education, advice, and support to other professionals.
- Evidence-based practice.
- Research and evaluation.

The subsequent, mostly unplanned, often charitably funded, growth of specialist palliative care services has led



Supportive and Palliative Care Indicators Tool (SPICT™)



The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility (eg. The person stays in bed or in a chair for more than half the day).
- Depends on others for care due to increasing physical and/or mental health problems. The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

<p>Cancer</p> <p>Functional ability deteriorating due to progressive cancer</p> <p>Too frail for cancer treatment or treatment is for symptom control.</p>	<p>Heart/ vascular disease</p> <p>Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.</p> <p>Severe, inoperable peripheral vascular disease.</p>	<p>Kidney disease</p> <p>Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.</p> <p>Kidney failure complicating other life limiting conditions or treatments.</p> <p>Stopping or not starting dialysis.</p>
<p>Dementia/ frailty</p> <p>Unable to dress, walk or eat without help.</p> <p>Eating and drinking less; difficulty with swallowing.</p> <p>Urinary and faecal incontinence.</p> <p>Not able to communicate by speaking; little social interaction.</p> <p>Frequent falls; fractured femur.</p> <p>Recurrent febrile episodes or infections; aspiration pneumonia.</p>	<p>Respiratory disease</p> <p>Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.</p> <p>Persistent hypoxia needing long term oxygen therapy.</p> <p>Has needed ventilation for respiratory failure or ventilation is contraindicated.</p>	<p>Liver disease</p> <p>Cirrhosis with one or more complications in the past year:</p> <ul style="list-style-type: none"> • diuretic resistant ascites • hepatic encephalopathy • hepatorenal syndrome • bacterial peritonitis • recurrent variceal bleeds <p>Liver transplant is not possible.</p>
<p>Neurological disease</p> <p>Progressive deterioration in physical and/or cognitive function despite optimal therapy.</p> <p>Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.</p> <p>Recurrent aspiration pneumonia; breathless or respiratory failure.</p> <p>Persistent paralysis after stroke with significant loss of function and ongoing disability.</p>	<p>Other conditions</p> <p>Deteriorating with other conditions, multiple conditions and/or complications that are not reversible; best available treatment has a poor outcome.</p>	

Review current care and care planning.

- Review current treatment and medication to make sure the person receives optimal care; minimise polypharmacy
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family/people close to them. Support carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, share, and review care plans.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™ 2022

Figure 2 The supportive and palliative care indicators guidance (2019) used in Lothian National Health Service (NHS), Scotland. (Reproduced with permission from NHS, available at www.palliativecareguidelines.scot.nhs.uk).

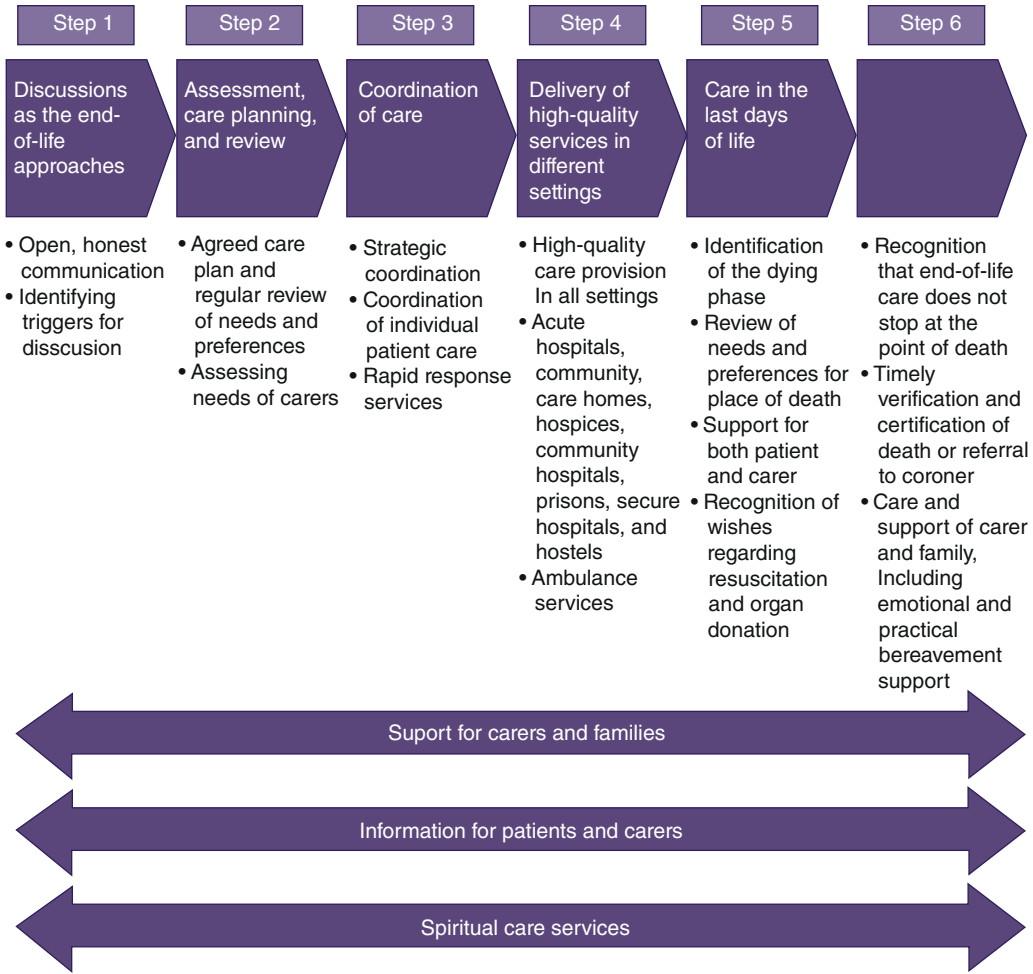


Figure 3 The end-of-life care pathway. (Reproduced from [12]).

Six ambitions to bring that vision about

- 01 Each person is seen as an individual
- 02 Each person gets fair access to care
- 03 Maximising comfort and wellbeing
- 04 Care is coordinated
- 05 All staff are prepared to care
- 06 Each community is prepared to help

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."



Figure 4 The ambitions of the National Palliative and End-of-Life Care Partnership in England [22].

Priorities for Care of the Dying Person



Figure 5 The five priorities of care for the dying person [23].

to a wide variety of models of service provision, distribution, and funding, with some areas, and therefore patients, being better served than others.

Not everyone that dies will have such complex needs that they require direct contact with specialist palliative care services. In integrated services that provide high quality care for people at the end of their lives those that provide the direct contact are advised, supported, and trained by this small group of specialists.

Issues for Palliative Care Worldwide

Fifty-nine million people die across the world each year, 80% of deaths occurring in developing countries. The world population is estimated to increase by 50% in the next 50 years and almost all of this increase in population will be in the developing world. In addition, there will be a huge shift in age of the population with a two- to threefold

increase in population aged over 60 years in both the developed and the developing world.

The 2018 the *Lancet* Commission on Palliative Care and Pain Relief stated that no other important health intervention is as lacking or inequitably distributed as pain relief, the pillar of palliative care [24]. It estimated that 45% of all deaths in 2015 (25 million people) experienced serious suffering, 80% of whom were in low income countries. Despite the 2014 World Health Assembly resolution calling for all member states to develop, strengthen, and implement palliative care services as part of universal health coverage [25], such services remain underdeveloped or non-existent in many parts of the world, 45% of countries having no access to palliative care [26]. The global burden of serious health-related suffering is projected to double by 2060 [27].

Although not enshrined in the Human Rights Act, most would agree that every individual has the right to pain relief and the International Association for the Study of Pain constructed a declaration to this effect in 2010. Inexpensive, effective methods exist to relieve pain and other symptoms but tens of millions of people die each year in unrelieved suffering. The *Lancet* Commission recommended that morphine be made available alongside an essential package

of other low cost drugs, medical equipment and human resources (Box 3). They call for all countries to ensure universal access to this Essential Package by 2030.

Under the international treaty, *Single Convention on Narcotic Drugs* [28], governments are responsible for ensuring that opioids are available for pain management. The 2021 report from the International Narcotics Control Board, marking sixty years of the treaty, showed that opioids are still not widely available for medical needs [29]. More than 90% of the global morphine is used in industrialised countries where 17% of the world's population live. Over 75% of the world population will have insufficient analgesia, or no analgesia at all if they suffer from pain.

The main impediments to opioid availability are government concern about addiction; insufficient training of healthcare professionals; and restrictive laws over the manufacture, distribution, prescription, and dispensing of opioids. There is also considerable prescribing reluctance on the part of the healthcare profession, due in part to concerns about legal sanctions. This is made worse by the burden of regulatory requirements, the often insufficient import or manufacture of opioids, and the fear of the potential for diversion of opioids for non-legitimate use.

Box 3: The Essential Package of medications that need to be universally available [24]

Amitriptyline
Bisacodyl (Senna)
Dexamethasone
Diazepam
Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate)
Fluconazole
Fluoxetine or other selective serotonin-reuptake inhibitors (sertraline and citalopram)
Furosemide
Hyoscine butylbromide
Haloperidol
Ibuprofen (naproxen, diclofenac, or meloxicam)
Lactulose (sorbitol or polyethylene glycol)
Loperamide
Metoclopramide
Metronidazole
Morphine (oral immediate-release and injectable)
Naloxone parenteral
Omeprazole
Ondansetron
Paracetamol
Petroleum jelly

Unmet Need and Continued Suffering in the Developed World

The major challenge for those who seek to improve the care for patients with advanced disease is to ensure that all healthcare professionals consider palliative care an important part of the care of their patients, is a responsibility in their own role and that they have adequate skills, knowledge, and specialist support to undertake it effectively. This is of crucial importance in the 70% of the week that occurs “out-of-hours” when patients are especially vulnerable to the deficits in healthcare systems.

There are defined groups of patients who have poor outcomes, who underutilise specialist palliative care services, who have insufficient access to services and for whom service models need to develop to meet their needs in an appropriate way. Patients with illnesses other than cancer and those who are old and frail are considerably disadvantaged compared to those with cancer, and chapters later in this book discuss these issues in some depth and provide information on how to tackle them.

Health professionals over the world recognise the fundamental human right to die with dignity. However, the notion of what constitutes a “good death” may vary considerably between and within cultures. Additionally, while it has been shown that there are greater similarities than

differences between cultures when living and dealing with illness such as cancer we know that it is more difficult for people from ethnically minoritised communities to access or obtain information, support, and services that will meet their needs. Issues of communication, applicability of information, organisational and staff attitudes, and discrimination are contributing factors across the spectrum of health and illness contexts, and having cancer is no exception to this experience [30, 31, 32]. Compounding this disadvantage and poor quality of life is that people from diverse ethnic communities are more likely to be poor and have financial and housing difficulties. Professionals need to tailor their care for patients with greater understanding of socio-cultural and spiritual contexts as well as to individual variations in concepts of disclosure and open discussion of deterioration and dying, patient autonomy and collective decision making, and preferences and wishes that constitute a good death.

Gatrad and colleagues [33] suggest that realising high-quality palliative care for all will need fundamental changes on at least three fronts:

1. Tackling institutional discrimination in the provision of palliative care.
2. Progress in incorporating transcultural medicine into medical and nursing curriculums.
3. A greater willingness on the part of health-care providers to embrace complexity.

Cicely Saunders developed the model of holistic care termed “Total Pain” which is explored further in Chapter 10 (Pain and its management). Using this model can help us see how marginalised groups of people may suffer more “social pain” than others. For example Gunaratunum has done much to help us understand more about migrant communities and the suffering that may be unfathomable to health professionals unless we open our minds to understand their life journey [34, 35].

Enabling People to Be at Home

The majority of people wish, ideally to die at home with the family around them. However, some people don’t want this. For some leaving this memory or bad spirit for the family may be something they don’t want. For others they only want to be at home if their symptoms are well managed and for many the prime consideration is whether their family can cope.

Death in the patient’s preferred place of care can sometimes be used as a measure of quality of care and is quite a reductionist construct given that for many people the “choice” is so dependent on a number of variables

(symptoms, family, money, services, and support) and how they play out. However, wherever the patient wants to be at the end they will spend a lot of time at home in the last months of their illness.

The key things that need to be in place to achieve the best possible care for people in the last months of life include:

- identifying people that are approaching the end-of-life (around 1% of GP list), maybe using the Supportive and Palliative Care indicators (SPICT) tool (Figure 2) and for the patient who has become very unwell, the “uncertain recovery” model such as AMBER Care can help integrate a palliative care approach [36].
- Information sharing, discussions and care planning for deterioration (steps 1-2 of the pathway in Figure 3);
- coordination of care, availability of medication and equipment, and rapid access to help and expertise (Ambitions statement 4, Figure 4);
- delivery of high-quality care by trained and competent practitioners in all service sectors. (Ambitions statement 5, Figure 4)

These facets of care are discussed in depth in other chapters of this book, and Chapter 20 (Care in the last days of life and after death) focusses specifically on enabling people to die in the place of their choice.

Thomas [37, 38] developed seven standards (Box 4) to help primary care providers and teams improve their

Box 4: The seven “Cs”: gold standards for palliative care in primary care

Communication: Practice register; regular team meetings for information sharing, planning, and reflection/audit; patient information; patient-held records.

Coordination: Nominated coordinator maintains register, organises meetings, audit, education symptom sheets, and other resources.

Control of symptoms: Holistic, patient centred assessment and management.

Continuity out-of-hours: Effective transfer of information to and from out-of-hours services. Access to drugs and equipment.

Continued learning: Audit/reflection/critical incident analysis. Use of continuing professional development time.

Carer support: Practical, financial, emotional, and bereavement support.

Care in the dying phase: Protocol-driven care addressing physical, emotional, and spiritual needs. Care needs around and after death acted upon.

delivery of palliative care. In partnership with Marie Curie these have been used to develop the “Daffodil” quality standards of the UK Royal College of GPs to help optimise the care of patients in their homes [39]. This is explored further in Chapter 4 (Palliative care in the community).

Communication with, and the quality of, out-of-hours primary care services is of critical importance in achieving the goals of care [40, 41]. In more closed health systems such as the hospice programme in the United States, achievement of care and death at home is almost a prerequisite criterion of entry to the programme and therefore self-fulfilling; however, 80% of deaths in America are in hospital and only 7% die at home under hospice care.

The Principles of Palliative Care

Knowing how to approach patients with advanced illness is the first step in achieving effective care. Six key principles underpin effective, holistic care:

1. Consider the patient and their family/carers as the unit of care while respecting patient autonomy and confidentiality and acknowledge and encourage their participation.
2. Perform a systematic assessment of physical, psychological, information, social, financial, cultural and spiritual needs.
3. Communicate findings to the patient, providing information and support at all stages.
4. Relieve the patient’s symptoms promptly: *There is only today.*
5. Plan proactively and thoroughly for potential/anticipated future problems.
6. Use a team approach listening to suggestions and views and involving resources for extra support at an early stage.

What Do Patients and Their Carers Need?

The uniqueness of each individual’s situation must be acknowledged and the manner of care adapted accordingly. The essence of what patients and their carers may need is outlined in Box 5.

It should be clear from this that communication skills (see Chapter 7: Conversations and communication) play a fundamental role in achieving good palliative care and quality of life for the patient:

Almost invariably, the act of communication is an important part of the therapy; occasionally it is the only constituent. It usually requires greater thought and planning than a drug prescription, and unfortunately it is commonly administered in subtherapeutic doses [42].

Box 5: The rights and needs of patients and their carers

Patients have a right to confidentiality, pain control, and other symptom management and, wherever possible, to choose the setting of death and the degree of family and professional involvement. They also have a right to deny the illness.

Information

The patient has a need to be offered sensitive, clear explanations of:

- the diagnosis and its implications;
- the likely effects of treatments on activities of daily living and well-being;
- the type and extent of support that may be required and how it may be addressed; and
- expected symptoms and what may be done about them.

Quality of life

The patient has a need for life that is as normal, congenial, independent, and as dignified as possible.

An individual’s quality of life will depend on minimising the gap between their expectations and aspirations and their actual experiences. This may be achieved by:

- respect, as a person as well as a patient, from properly trained staff who see themselves as partners in living;
- effective relief from pain and other distressing symptoms;
- an appropriate and satisfying diet;
- comfort and consolation, especially from those who share the patient’s values and beliefs and/or belong to the same cultural community;
- companionship from family and friends and from members of the care team;
- continuity of care from both the primary care team and other services;
- consistent and effective response to changes in physical and psychosocial discomfort; and
- information about support and self-help and other groups and services.

Support for carers

The patient’s family or other carers have a need for support at times of crises in the illness and in their bereavement. These needs include:

- practical support with financial, legal, housing, or welfare problems;
- information about the illness (with the patient’s consent) and the available support;
- respite from the stress of caring;
- involvement of carers in the moment of death and in other aspects of care;
- bereavement support; and
- special support where the patient’s death may directly affect young children or where the patient is a child or adolescent.

Achieving Good Symptom Management

The management of any problem should be approached as follows:

- Anticipation
- Evaluation and assessment
- Explanation and information
- Individualised, personalised treatment
- Re-evaluation and supervision
- Attention to detail
- Continuity of care.

Anticipation

Many physical and nonphysical problems can often be anticipated and in some instances prevented. Failure to anticipate problems and to set up appropriate management strategies (e.g., who should they call?) is a common source of dissatisfaction for patients. Understanding the natural history of the disease with specific reference to an individual patient, awareness of the patient's psychosocial circumstances and identification of risk factors allows planning of care by the team. For an example of applying this in practice, see Box 6.

Evaluation and Assessment

An understanding of the pathophysiology and likely cause(s) of any particular problem is vital in selecting and directing appropriate investigations and treatment. Deciding what treatment to use is based on consideration of the evidence of the mechanism of the symptom and of the treatment's

efficacy, safety, and appropriateness in the situation. This is illustrated by the following specific examples:

- Sedation for an agitated patient with urinary retention is not as helpful as catheterisation.
- Antiemetics for the nausea of hypercalcaemia are important but so too is lowering the serum calcium (if appropriate).
- A patient who is fearful of dying may be helped more by discussing and addressing specific fears rather than taking benzodiazepines.
- Pain in a vertebral metastasis may be helped by analgesics, radiotherapy, orthopaedic surgery, transcutaneous electrical nerve stimulation, and acupuncture. A decision as to which to prescribe is made only by careful assessment.

Comorbidity is common and should always be considered. For example, it is easy (and unfortunately common) to assume that the pain in a patient with cancer is caused by the cancer. In one series almost a quarter of pains in patients with cancer were unrelated to the cancer or the cancer treatment [43].

The multidimensional nature of symptoms, such as pain, means that the use of drugs may be only one part of treatment. A holistic assessment is vital in enabling the most effective management plan. This includes eliciting the patient's concerns and focusing on their feelings.

Explanation and Information

Management of a problem should always begin with explanation of the findings and diagnostic conclusions. This usually reduces the patient's anxieties, even if it confirms their worst suspicions – a monster in the light is usually better faced than a monster unseen in the shadows. Further information may be useful to some patients. A clear explanation of the suggested treatments and follow up plan is important for the patient to gain a sense of control and security. Allow plenty of space for questions and check that what you meant to convey has been understood. Some real examples:

- Mr H, with advanced liver disease, was very anxious in the outpatient department. He told me he had developed a tender lump on his chest. On examination this turned out to be gynaecomastia, most probably, I thought, due to the spironolactone. With this explanation, and the relief of his anxiety, he chose to continue the drug rather than have recurrence of his ascites.
- Mrs S looked worried and was angry. We discussed the scan results she had had six months earlier, before her chemotherapy and surgery. "So what does that mean?" she asked. "I'm afraid that means the cancer cannot be cured,"

Box 6: Applying an understanding of the natural history of a disease and psychosocial awareness to care planning

A 45-year-old woman has recently been found to have spinal metastases from her breast cancer. Potential issues that could be anticipated are:

- Pain – due to the bony origin; this may need non-steroidal anti-inflammatory drug (NSAID), opioids, and radiotherapy.
- Constipation – start laxatives when opioid is prescribed.
- Spinal cord compression – examine neurology if unsteady or complains of numbness.
- If she has young children – may need help, practically and in telling the children.
- Work – may she need financial and benefit advice?
- Hypercalcaemia – check blood if nauseated or confused.
- Psychospiritual – how is she coping with the impact?

I said. She dissolved in tears and said “Thank you doctor. I have been thinking this, but no one would tell me.”

Individualised Treatment

The individual physical, social, and psychological circumstances of the patient and their views and wishes should be considered in planning care. For example, lymphoedema compression bandages may be unused unless there is someone available to help the patient to fit them daily.

Treatment options need to be shared with the patient and their perspective on choices be explored. For example:

- Mr K developed arterial occlusion in his leg. Because of his other symptoms, he was thought to have recurrent bladder cancer, but this was not confirmed by scans. He needed to consider whether to have an amputation. It appeared most likely that he would die from his cancer within the next weeks to months. He decided that he would only have the amputation if he had six months or more to live and he declined the operation.

Re-evaluation and Supervision: Be Proactive

The symptoms of frail patients with advanced disease can change frequently. New problems can occur and established ones worsen. Interventions may be complex (many patients take more than 20 pills a day), and close supervision is vital to ensure optimum efficacy and tailoring to the patient. Family carers may take on a lot of new tasks including managing medicines and using equipment. Educating and empowering family carers to feel safe, listened to, and supported is vital for the patient's care but also the family carer wellbeing and bereavement. One key action is to make sure that family carers know how to safely dispose of medicines when they are no longer needed (take them to the pharmacy).

Attention to Detail

The quality of palliative care is in the detail of care. For example, it is vital to ensure that the patient not only has a prescription for the correct drug but also can obtain it from the pharmacy, have adequate supplies to cover a (long) weekend, and understand how to adjust it if the problem worsens.

Continuity of Care

No professional can be available for 24 hours, and 7 days a week, but patients may need support at all hours of the day. Transfer of information within teams and to those that may be called upon to provide care (e.g., out-of-hours

services) is one way of ensuring continuity of care. Patient-held records, clear plans in nursing care records at the patient's house, team handover/message books, and formalised information for out-of-hours services [44] are all ways to achieve this.

Limits of Symptom Control

There is always something more that can be done to help a patient, but it is not always possible to completely relieve symptoms. Specialist advice should usually have been sought for help in the management of intractable symptoms. This extra support is in itself an important way of helping the patient.

In such situations an acceptable solution must be found to provide adequate relief of distress for the patient. For the management of a physical symptom and sometimes of psychological distress, this may be a compromise between the presence of the symptom and sedation from medications. It is hard for a team to accept suboptimal relief of symptoms, and discussions with the patient and the family may be very difficult. It is important for the team to remember the great value of their continuing involvement to the patients and their carers, to acknowledge how difficult the situation is, and not to abandon the patient because it is painful and distressing for the professionals:

Slowly, I learn about the importance of powerlessness.
I experience it in my own life and I live with it in my work.
The secret is not to be afraid of it—not to run away.
The dying know we are not God.
All they ask is that we do not desert them [45].

Attaining Quality in Palliative Care

The quality of palliative and end-of-life care is an area of increasing focus. Discussion of treatment benefits and burdens and of end-of-life choices is an important feature of quality in advanced disease.

The National Institute for Health and Clinical Excellence (NICE) in the United Kingdom has developed Quality Standards for end-of-life care for adults [46] and for the care of adults in the last days of life [47]. The four statements of quality for priority areas for improvement in care in the last days of life are shown in Box 7. The NICE quality standards for end-of-life care for infants, children and young people are shown in Box 8 [48].

Box 7: Quality standards for Care of adults in the last days of life [47]

Statement 1 Adults who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising, or recovering.

Statement 2 Adults in the last days of life, and the people important to them, are given opportunities to discuss, develop, and review an individualised care plan.

Statement 3 Adults in the last days of life who are likely to need symptom control are prescribed anticipatory medicines with individualised indications for use, dosage, and route of administration.

Statement 4 Adults in the last days of life have their hydration status assessed daily, and have a discussion about the risks and benefits of hydration options.

Box 8: Quality standards for end-of-life care for infants, children, and young people [48]

Statement 1 Infants, children, and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Statement 2 Infants, children, and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.

Statement 3 Infants, children, and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.

Statement 4 Infants, children, and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.

Statement 5 Parents or carers of infants, children, and young people approaching the end-of-life are offered support for grief and loss when their child is nearing the end of their life and after their death.

Statement 6 Infants, children, and young people approaching the end-of-life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

The End-of-life care strategy in England and Wales has defined an array of quality outcomes markers [49]. Similar initiatives are in place in many countries across the world [50-53].

Audit of Quality

Various measures of outcomes in palliative care have been developed [54] and the Australian palliative care sector is world leading in using routine clinical assessment information for measurement and benchmarking of outcomes of specialist care [55]. The National Audit of Care at the End-of-Life (NACEL) examines and benchmarks care in community and acute hospitals in England and Wales through retrospective patient case note reviews, organisation self-assessment questionnaires and survey of experience of bereaved family. In 2019–2020 audit 6823 casenotes were reviewed in 239 hospitals. This indicated, for example, that 74% of families felt the quality of care provided to the patients was good, excellent or outstanding [56].

The experiences of patients is often gathered by proxy, through seeking the feedback of bereaved relatives such as in the national survey of bereaved people (VOICES) survey [57]. Recently, the “Care of the Dying Evaluation” has been tested across a number of countries to develop a common, core international questionnaire (i-CODE) and in time data set [58].

Conclusion

The majority of people die with a progressive illness and most will benefit from integrating palliative care alongside other care and treatments. As illness progresses the need for symptom management and the balancing of the burdens and benefits of treatments increases. Sharing information with patients and their families about their illness is pivotal to enabling them to make decisions and accessing care and support that is right for them. There are huge deficits worldwide in providing adequate pain relief and inequities within countries of access to services and in achieving the best outcomes for patients and the families.

This Handbook will help you know more about what to do to care for your patients and aims to improve outcomes and reduce the inequities for our patients who are diverse in their social-cultural and medical contexts but all of whom need holistic, personalised, compassionate, and competent care.

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