The subject of death in late modern culture has become a rich field of theoretical, clinical and policy interest. Widely regarded as a taboo until recent times, death now engages a growing interest among social scientists, practitioners and those responsible for the organization and delivery of human services. Indeed, how we die has become a powerful commentary on how we live and the specialized care of dying people holds an important place within modern health and social care.

This series captures such developments in a collection of volumes which has much to say about death, dying, end-of-life care and bereavement in contemporary society. Among the contributors are leading experts in death studies, from sociology, anthropology, social psychology, ethics, nursing, medicine and pastoral care. A particular feature of the series is its attention to the developing field of palliative care, viewed from the perspectives of practitioners, planners and policy analysts; here several authors adopt a multi-disciplinary approach, drawing on recent research, policy and organizational commentary, and reviews of evidence-based practice. Written in a clear, accessible style, the entire series will be essential reading for students of death, dying and bereavement and for anyone with an involvement in palliative care research, service delivery or policy making.

Current and forthcoming titles:

David Clark, Jo Hockley, Sam Ahmedzai (eds): New Themes in Palliative Care
David Clark and Jane Seymour: Reflections on Palliative Care
Mark Cobb: The Dying Soul: Spiritual Care at the End of Life
Kirsten Costain Schou and Jenny Hewison: Experiencing Cancer: Quality of Life in Treatment
Catherine Exley: Living with Cancer, Living with Dying
David Field, David Clark, Jessica Corner and Carol Davis (eds): Researching Palliative Care
Jenny Hockey, Jeanne Katz and Neil Small (eds): Grief, Mourning and Death Ritual
David Kissane and Sidney Bloch: Family Grief Therapy
Gordon Riches and Pam Dawson: An Intimate Loneliness: Supporting Bereaved Parents and Siblings
Jane Seymour: Critical Moments: Death and Dying in Intensive Care
Tony Walter: On Bereavement: The Culture of Grief
THE DYING SOUL
Spiritual care at the end of life

MARK COBB
Open University Press
Celtic Court
22 Ballmoor
Buckingham
MK18 1XW

email: enquiries@openup.co.uk
world wide web: www.openup.co.uk

and
325 Chestnut Street
Philadelphia, PA 19106, USA

First Published 2001

Copyright © Mark Cobb, 2001

All rights reserved. Except for the quotation of short passages for the purpose of criticism and review, no part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without the prior written permission of the publisher or a licence from the Copyright Licensing Agency Limited. Details of such licences (for reprographic reproduction) may be obtained from the Copyright Licensing Agency Ltd of 90 Tottenham Court Road, London, W1P 0LP.

A catalogue record of this book is available from the British Library

ISBN 0 335 20053 2 (pb) 0 335 20054 0 (hb)

Library of Congress Cataloging-in-Publication Data available

Typeset by Graphicraft Limited, Hong Kong
Printed in Great Britain by Biddles Limited, Guildford and Kings Lynn
## Contents

*Series editor’s preface*  
*Acknowledgements*  

**Introduction**  
1 *The palliative care quadrilateral*  
4 *Spiritual care, pastoral care and Christianity*  
7 *The book in outline*  

1 **Understanding spirituality**  
13 *Being specific*  
19 *Science, medicine and spirituality*  
22 *Transcendence and the nature of spirituality*  
25 *Soul*  
29 *The challenge of spirituality*  

2 **Expressions of the spiritual**  
32 *Religion*  
41 *Sacred and secular*  
44 *Spirituality of a new age*  

3 **Dying and death: a spiritual place?**  
50 *Death is nothing*  
53 *Facing death*  
56 *The rituals of death*  
60 *After death*
As the Facing Death series becomes well established, the scope of its interests is widening and deepening. We began with early volumes focused on the development of palliative care in Europe and around the world. These were concerned with matters of policy, with the recognition and need for palliative care service provision, as well as with some of the complexities of service delivery, audit and evaluation. A recent volume has been entirely devoted to the issue of research in palliative care. Another early focus has been on the personal and cultural experience of life threatening illness and of bereavement in which the authors have drawn on sociological and psychological perspectives to locate these issues within wider theoretical debates relating to the body, identity, gender and culture.

In the present volume Mark Cobb turns our attention to the question of spiritual care at the end of life. He is extremely well qualified for the task. Mark Cobb is an Anglican chaplain with several years’ experience of working in hospitals and hospices. During this time he has developed a particular interest in palliative care and made important contributions to service developments, to teaching and to research in this field. He is widely known for his involvement in a series of conferences on the theme Body and Soul, which have explored the relationships between spirituality, religion and the delivery of health care. He is educated in the natural sciences and also in ethics, disciplines which enable him to bring a steady and analytic eye to his subject matter. At the same time his writing displays a warmth, a humanity and a compassion which is born of wide reading and generous reflection upon the nature of spiritual issues in the late modern context.

Why is this such an important book?
There are several answers to the question. The Dying Soul is a beautifully written, multi-faceted book which explores its subject matter from many
perspectives. Running throughout is a willingness to tackle the vexed issue of what we mean by ‘spirituality’. Here Mark Cobb is refreshingly prepared to forge a distinction between those aspects of human experience which constitute the *spiritual* and those which are better designated *existential*. In this he differs from some of his colleagues who prefer a less clear cut elision between the two and who thereby can run the risk of playing fast and loose with traditions within theology and philosophy that are quite distinct. In turn this raises the stakes on how ‘the spiritual’ can be cared for, particularly within the context of palliative care. For, as Mark Cobb demonstrates, spiritual care forms (at least rhetorically) part of a palliative care ‘quadrilateral’, the other components of which relate to the physical, the social and the psychological. So in opening up a space for the analysis of spirituality in this setting, he also makes us consider what we understand by the wider enterprise of palliative care, not least as it moves on from its roots in the hospice movement and the terminal stages of illness. Always he is eager to bring us back to social context, something which can get lost in the more inward and narrowly focused debates emerge in this evolving specialty. He is particularly strong in reminding us about death as an aspect of modern culture, the need to see palliative care as a force both responding to and also shaping that culture, and above all the permeability of those aspects of human experience which biomedicine prefers to separate into hermetically sealed zones. And all this in a wider context of discussion about the alleged ‘secularization’ of society and indeed of hospice and palliative care itself.

Many readers are now following the Facing Death series with enthusiasm and commitment. It is becoming an essential source for clinicians, social scientists, service planners and policy makers who appreciate that the care of those with life threatening illness and the understanding of human mortality are enterprises which are fundamentally intertwined. In doing this we are trying to move understanding beyond that which compartmentalizes these issues into matters of ‘epidemiology’, ‘clinical care’, ‘policy’ or ‘theory’. It is an exciting and intellectually challenging approach. Mark Cobb’s contribution here, in line with others in the series, is of vital importance in moving forward our understanding.

*David Clark*
The palliative care quadrilateral

The spiritual domain is routinely asserted as an integral part of palliative care alongside the physical, psychological and social aspects. This quadrilateral provides four views of an holistic philosophy of care and represents four interrelated ways of approaching the relief of suffering and the promotion of human well-being. This plausible convention is not without difficulties, particularly when we pay attention to the spiritual domain. To begin with, the term 'spiritual' is notoriously vague and obscure, yet widely used. It seems to provide a way of addressing something fundamental about humanity but remains abstract. In the past this openness was given a framework and orientation through Christianity. Today there is an insistent separation of the two. When we consider the practical matter of how the spiritual can be cared for, there is a range of responses that involve, to a lesser or greater extent, religion, psychology and aesthetic sensibility. Spirituality dissociated from a unitary belief system relies upon an eclectic mixture of ideas and philosophies. Further difficulty is added when questions of training, expertise and authority are raised: who should be providing spiritual care and what does this entail?

Where there is sorrow there is holy ground. Some day people will realize what that means. They will know nothing of life till they do.

(Wilde 1986: 143)

Spiritual care is written into the constitution of hospice and palliative care services and yet it remains the least explored and understood aspect. One reason for this is that when people contemplate the end of life they often find themselves having to look beyond the facts. The meaning and value of
death transcend empirical reality and we can find in death a glimpse of the sacred which is both awesome and fascinating. If we find something of the sacred in death, then in approaching death through suffering and sorrow we may find ourselves having to walk on holy ground. Perhaps we do not or cannot take this step or we find the meaning of death sublime but inexpressible; either way there is an inevitable silence whenever we approach the sacred. However, this does not prevent us from exploring this domain and considering the very real questions of what all this means for the practical tasks of palliative care.

This, then, is the project of this book: to explore the familiarly unknown fourth side of the palliative care quadrilateral which is a way both of understanding and of responding to the spiritual dimension of being human. I have written out of my experiences as a hospice and hospital chaplain alongside an academic study of the subject. I therefore consider both theory and practice set within the wider contexts of health care and society. What will become quickly evident to the reader is that this is a field which readily spills out onto so many other fields. The reader will therefore find references well beyond the obvious subject matter and I readily draw upon a wide range of sources from the humanities and science. This book is written, therefore, to engage with readers in a number of different ways about the spiritual aspects of living, dying and death. Crudely, I take two approaches. Firstly, I write from the position of someone who takes the spiritual dimension of life, both embodied and intangible, as part of reality, and that ‘[a]lthough we seem to have an innate tendency to experience the natural in terms of the supra-natural, we are nevertheless under no compulsion to do so’ (Hick 1999: 37). In doing so I take account of this aspect of human life at face value. Secondly, I write from the more distant perspective of the explanations and descriptions of spirituality proposed by various academic disciplines. The naturalistic theories provide empirical discourses and accounts of the spiritual phenomena in terms of human constructs, both individual and societal. Other perspectives study what is before them, tracing the surfaces and shapes of spirituality in order to provide clear descriptions. This analytical approach seeks to advance a better grasp of its subject without necessarily venturing to uncover hidden meanings or disprove the claims of a spiritual dimension. It will be evident that I work with both these approaches and take questions from one to the other in what I hope is a useful and creative attempt to bridge what is often considered something of a divide.

Questions of spirituality inevitably return us to questions about the nature and meaning of life. These are questions that are at the very heart of our existence and it is no surprise to find scientists alongside philosophers involved in attempting to explain such mysteries. In particular, the questions relating to consciousness, self and other mind/body problems (Damasio 1999) cause us to consider a fundamental question as to whether reality
can be entirely accounted for by materialism. If it can be, then we may logically conclude that:

the notion of an immaterial entity, of something thus outside of this domain, of something not directly observable, is viewed as a kind of intellectual violation and as a holdover from a less sophisticated era of human understanding.

(Nicholson 1997: 31)

If, however, we consider reality to be broader and richer than this view allows then the material account is limited and we must search for other ways of making sense of and finding meaning in life. The spiritual dimension is what I generally take to refer to those aspects of the transcendent nature of reality which are part of human experience and which point beyond the material world. It is when we contemplate the end of life and face death that many people are aware of this dimension. This is because questions of our existence relate so closely to what we understand by death. The world faiths offer widely accepted perspectives on these universal questions, and Christianity in particular has been central to western thought on these matters. Yet we must also acknowledge approaches to these questions which do not rely upon an appeal to the transcendent or to theology but are broadly based in what can be considered the humanist philosophy of existentialism:

We are all men hanging on the thread of a few rapidly vanishing years over the bottomless pit of death, destruction, and nothingness. Those objective facts are starkly real. Let us not try to disguise them. Yet I find it marvellously interesting that man’s consciousness, his reason and his passion, can elevate these routine, objective, external events, in a moment of lucidity and feeling, to the status of a personally appropriated ideal – an ideal which does not annul those objective facts, but which reinterprets them and clothes them with the apparel of man’s subjectivity.

(Klemke 2000: 197)

The spiritual perspective, I contend, is distinct from the existential perspective in that although the latter allows for subjective transcendence it does not look beyond the ‘universe of human subjectivity’ (Sartre [1946] 1997: 55). This differentiation is readily overlooked in palliative care when the two perspectives are collapsed into a generic category that is a coverall for anything other than the physical, psychological or social. Another area of confusion and contention can be found in the use of the emotive phrase ‘the sanctity of life’ which is employed with reference to euthanasia and which resonates with a notion of the spiritual. The conviction that life is valuable and that it should not end prematurely seems to be a generally held view.
But the intrinsic value of human life can be understood in different ways, for example by appealing to the wonder of creation in either the evolutionary or the theological sense. It is wrong to assume that ‘the sanctity of life’ always refers to a religious doctrine and it cannot be presumed that it necessarily implies a spiritual perspective.

It will now be apparent that in approaching a book about spiritual care there is much weight that has to be borne repeatedly by a single word. Language enables us to communicate information and meaning. Sometimes the words we use are inadequate for what we try to convey, sometimes they are inaccurate and misinform, and sometimes we use words which no longer mean what they originally meant and there is uncertainty. Language is highly fluid, but it is also a vast repository of history: it is the place not only for creativity and novelty but also for convention and tradition. When we talk of the ‘spiritual’ we allude to a profusion of meanings, references and ideas. It is most obviously the currency of many religions. The humanities readily use the term and it has become a description of life’s less tangible aspects. The spiritual is therefore a term from which can be inferred a vast range of meaning, some of which I allude to in this book and some of which the reader will bring to the text.

**Spiritual care, pastoral care and Christianity**

What I think is upon us with the advent of the modern hospice is a counter-revolutionary movement – albeit modest – that nevertheless takes its stand against a secularized, impersonal, utilitarian and increasingly hostile world. What makes hospice philosophy or practice problematic for some is that many within hospice or the caring professions profess humanistic rather than traditional religious beliefs and in this post-Samaritan world find it difficult to acknowledge the fount of spiritual insight that guides and informs our actions. Many of us are thus conflicted and find it difficult to articulate a totally satisfactory philosophy for either our work or our lives.

(Fulton 1986: 155)

The image of the hospice movement united in militant stance against the mundane forces of a secular world lends itself to apocryphal accounts of the hospice history. Fulton’s use of ‘Samaritan’ is a direct reference to the eponymous biblical story which he takes as a classic example and inspiration for the hospice movement. However, what is apparent from the proceedings of the Yale colloquium of 1986 at which Fulton was speaking is that there was considerable dissension about the place of Christianity in the care of the terminally ill and whether there can be derived from it a universal notion of the spiritual (Wald 1986). Strong disagreement also emerged in a
British working party set up to examine the impact of hospice experience on the Church’s ministry of healing (Working Party on the Impact of Hospice Experience on the Church’s Ministry of Healing 1991). Differences in theology and practice surfaced as this interdisciplinary and interdenomi-
national group met to consider the nature of hospice, healing and care. The issue of a universal or an exclusive spirituality appeared to be a par-
ticularly contentious matter and reflects a long-standing debate about what 
are the boundaries of the Church as a community. This difficulty is to some 
extent averted if, as the working party decided, the now familiar distinction 
is made:

‘Spiritual’ is often confused with ‘religious’. Religious, however, means 
pertaining to a religion, i.e. a framework of theistic beliefs and rituals 
which give expression to spiritual concerns. While everyone has a spir-
itual dimension, in Britain today only a minority practise a formal 
religion. Hence, although people commonly say, ‘I am not religious’, 
they do not say ‘I am not spiritual’.

(Working Party on the Impact of Hospice 
Experience 1991: 151–2)

The problem of religion in palliative care is symptomatic of wider cultural 
issues. Religion is not abandoned, it is gradually relocated, and in its 
absence we are left with a spirituality not orientated towards God or the 
institution of the Church, but towards humanity and the organization of 
care. This can be traced from the social context in which hospice and 
palliative care has developed as well as from changes taking place within 
Christianity. In particular it is important that we recognize that spiritual 
care did not spontaneously materialize as the solution to a sudden problem 
but emerged to some extent from the direction followed by pastoral care 
(Wright 1996).

In the postwar period leading up to the opening of St Christopher’s 
Hospice in London, the insights of psychotherapy and counselling were 
increasingly influential upon Christian theology and ministry. In the USA, 
the clinical pastoral education movement, founded by Anton Boisen, came 
to be a ‘dominating force in pastoral care education within and outside the 
thelogical schools’ (Gerkin 1997: 65) some of which crossed the Atlantic. 
In Britain similar developments were taking place, most notably in the 
establishment of the Westminster Pastoral Foundation and the Clinical 
Theology Association. Inevitably this was also a period in which pastoral 
care moved towards being more professionally organized and recognized as 
a specialist or ‘expert’ form of ministry: something evident in the institutional 
role of the chaplain. The scene was gradually set in the following decades 
for pastoral care to become transposed from a faith community to a health-
care organization where humanistic elements could be readily appropriated
as relevant to all people. The spiritual could thus exist without an explicit theology: a contrast that is illustrated in the following definitions.

pastoral care . . . [is] the healing, sustaining, guiding, personal/societal formation and reconciling of persons and their relationships to family and community by representative Christian persons (ordained or lay), and by their faith communities, who ground their care in the theological perspective of the faith tradition and who personally remain faithful to that faith through spiritual authenticity.

(Goodliff 1998: 10)

spiritual care . . . [is] responding to the uniqueness of the individual: accepting their range of doubts, beliefs and values just as they are. It means responding to the spoken or unspoken statements from the very core of that person as valid expressions of where they are and who they are. It is to be a facilitator in their search for identity on the journey of life and in the particular situation in which they find themselves. It is to respond without being prescriptive, judgmental or dogmatic and without preconditions, acknowledging that each will be at a different stage on that personal spiritual journey.

(Stoter 1995: 8)

If we can trace a line between these two modes of care it will be when the individual and the Christian community enter into dialogue, seeking connections between their stories and finding ways of interpreting each other’s position. Because Christianity remains embedded in the cultural background of society and provides people some orientation for their beliefs, then this dialogical relationship may exist to varying degrees. For the person without such an orientation, pastoral care as defined above is rightly to be considered an imposition unless invited. Spiritual care overcomes this difficulty, despite its close relationship to pastoral care, because it faces away from a faith tradition towards the individual and does not seek to return. Therefore the individual’s awareness and experience become normative within a permeable frame of reference constructed to some extent on-site.

Spiritual care is now a well established concept in palliative care, however ambiguous, where it clearly fits within the notions of individualized and holistic care. Spiritual care also provides a credible face to a society in which many faith traditions are represented and where many people are increasingly unfamiliar with any belief system. What is perhaps less certain are the ways in which spiritual care is actually implemented. There is currently a paucity of published descriptive research or accounts of practice, and so a normative approach cannot be presumed. I have therefore chosen to set much of my enquiry into the practice of spiritual care within an ethical framework which I take as applicable across all modes of care. This
will allow us to consider particular claims of practice as well as the more fundamental issue of the place of spirituality in palliative care.

**The book in outline**

This book can be considered as falling into three sections. The first three chapters consider the concepts and theories that relate to spiritual care and the following three are concerned with matters of practice. The final chapter provides a summary of all the major themes dealt with in the book and draws from them directions for the development of spiritual care. What will become evident is that in looking at spiritual care we find ourselves having to attend to the overlapping frameworks of other discourses and the wider social context in which palliative care is embedded.

Chapter 1 is intended to provide an introduction to the vast subject of spirituality as it is understood and conceptualized from a variety of perspectives. I address specifically the nature of palliative care spirituality and suggest that there is a confusion between the generic use of the term and the heterogeneous nature of the spiritual. It may be considered that the spiritual dimension readily conforms to an holistic philosophy of care and yet it seems inconsistent with the approach of clinical science. I therefore consider the claims of medicine as they challenge spirituality and the meaning of dying and death. I suggest that a dissatisfaction with materialism and the widely reported experience of people support the notion of transcendence as a significant key to the nature of spirituality. This leads us into the contentious idea of the human soul which expresses for some the idea that we may transcend even death. Finally I set out the challenge which spirituality places before palliative care, both in the way it has become neglected and negated as well as in the way it is understood as part of well-being and suffering, life and death.

The spiritual is experienced and expressed in many ways, and I consider some of these in Chapter 2. Religious traditions of spirituality persist in an age where many do not actively participate in faith communities. I therefore explore the phenomenon of religion in contemporary society and its influence upon the way we face illness, suffering and death. To do this I take a multidimensional view and consider some of the major theories advanced to explain religion. I then sketch the religiously diverse terrain of Britain and the issues this raises for palliative care services. The secular argument is one that sees religion as outmoded and redundant, but there is sufficient evidence that religion is responsive to culture and therefore more prevalent and dynamic than predicted. This is no more apparent than in New Age religions which I consider as a paradigm of detraditionalized religion. However, the social and cultural transitions which have reshaped religion have also influenced how we care for the terminally ill. I end this
The dying soul

chapter by drawing some analogies between palliative care and New Age religion, noting that contemporary expressions of the spiritual permeate palliative care both in terms of philosophy of care and in practice.

Dying has traditionally been viewed as a spiritual activity as much as a physical event. The modern hospice movement has attempted to reaffirm this aspect in the face of the grim postwar experiences of many in a predominantly curative healthcare system. In Chapter 3 I consider the spiritual significance of death and explore some of the major ways in which philosophy has tried to explain the nature of death. Death is symbolic of a range of meanings, some of which represent a complete ending and some of which point towards an ultimate destiny. I suggest that people's attitudes and approaches to death depend in part upon their beliefs, which include for many a spiritual dimension. Beliefs help to structure our worldview and can enable us to make sense of loss and find meaning in it. Yet few palliative care professionals consider these matter in their training or practice. One area that cannot be avoided is the rituals of death which are ubiquitous in health care. Rituals enact meaning, which around death can transform the cessation of life into a sacred event. They also point many people beyond death, and I consider some of the explorations that have been advocated of what happens after death. Finally I assert that the spiritual dimension of death is significant to bereavement and should not be disregarded by palliative care services in the support they offer.

In Chapter 4 I consider the contentious subject of who cares for the spirit. If palliative care claims to offer holistic care and to recognize the spiritual dimension then it is not unreasonable to expect that a service is capable in some way of responding to spiritual need. I therefore explore the notion of need in terms of spiritual care, particularly in terms of promoting the patient's good. In response to need, most palliative care services count a chaplain as part of their multidisciplinary team. I examine the role of the chaplain in providing spiritual care to patients and the wider roles that involve those people significant to patients, the staff and the service as a whole.

Spiritual care is also considered an aspect of the nurse's role, and I examine the claims and evidence for this both conceptually and in practice. I advocate that spiritual care is not a general obligation in a team and requires that responsibilities are specifically identified to avoid ambiguities and confusion. I also challenge the assumption that spiritual care happens inevitably in palliative care despite apparent uncertainty within some professions as to what this means. In conclusion I consider an interdisciplinary approach that provides an example of developing enhanced and integrated spiritual care.

Spiritual care is a defining and distinctive aspect of palliative care which, in Chapter 5, I consider from the organizational perspective. To begin with I examine the moral case that spiritual care should be intrinsic to palliative care in promoting the whole of the patient's good. If it is intrinsic then it
must be practised with due regard to an ethical patient/carer relationship, but it also becomes an aspect of a managed organized service. The idealism of the vision in palliative care, the focus on performance and the measurement of outcomes are all considered. This leads me to suggest that a process of assimilation has taken place in palliative care that has had an impact upon the spiritual such that it may be reduced to a function of utility. Finally, I recognize that palliative care has become an increasingly mobile philosophy which is influencing practice in diverse settings and is itself being influenced by new demands. I therefore discuss some of the challenges that arise when spiritual care is considered in the contexts of acute hospitals and community care as well as with people of different faiths and people with non-cancer diagnoses.

Spiritual care cannot lie outside of the moral compass of health care and I therefore consider the issues of training, competence and accountability in Chapter 6. I begin by exploring whether or not spiritual care warrants professional practice and consider the claims of what it means to be professional. I suggest that if spiritual care is to contribute to more than a general sense of well-being then it should be established upon a professional ethic. This provides the grounds for practice which benefits patients and therefore fosters trust.

Inevitably, in exploring the issues of professional practice in spiritual care wider debates in health care are disclosed concerning the nature of orthodox practice, the grounds for therapeutic interventions and the moral nature of care. I argue that if spiritual care is an important aspect of palliative care then it should be done well and there should be some definition of what this means. A standard of spiritual care is provided as an example of promoting good practice. Despite a number of important caveats, I suggest that standards may help spiritual care to become more consistent, purposeful and integrated. Finally in this chapter I consider the inadequacy of training in spiritual care and propose that a range of knowledge and skills is necessary to respond to levels of competence appropriate to need. In addition to rigorous education I advocate that the provision of good spiritual care also requires adequate professional formation and the discipline of reflective practice.

Chapter 7 summarizes and reviews what I understand to be some of the key themes discussed in this book which affect the development of spiritual care. In each section I critically examine arguments and focus the challenges that they present. In the concluding section I note that spiritual care is replete with assumptions but short on creative dialogue and critique. Consequently I suggest three areas that need addressing in order to provide some direction to spiritual care. First, there is the neglected area of rigorous research which is crucial in developing some form of an evidence base. Spiritual care has been subject to very little study to ascertain either the nature of practice or the perspective and experience of patients. Second,
there is the need to expand the knowledge base of the spiritual aspect of palliative care. This is not a unitary field of study but covers a range of academic disciplines. However, extant sources of knowledge and the knowledge of palliative care experience may provide a rich interdisciplinary source for critical enquiry given effective opportunities and support. Third, there is the need to develop the practice of spiritual care. Training health professionals is a key issue and I suggest that cognitive and behavioural modes of learning are complemented with experiential learning that draws upon an expanding research and knowledge base.
Spirituality represents something of a conundrum. It is a term both ancient and modern, an anachronism and a contemporary issue. It occupies an increasingly popular space in western culture and yet is shrouded in mystery and ambiguity. Spirituality is to be found at the very foundation of the modern hospice movement, and it receives copious mention in palliative care, but it has no standard definition, practice or policy. There is a paucity of research about spirituality and few claim any expertise. And yet a concern for spirituality is one of the distinguishing features of palliative care, which prides itself in its holistic philosophy. Spirituality is apparently self-evident, but inscrutable, an unavoidable factor in dealing with suffering, dying and death but one which is elusive. It even has an inalienable place in the vocabulary of palliative care but is often referred to as a ‘private’ matter and therefore out of bounds for personal discussion.

There are a number of explanations that could be offered for this conundrum. A significant argument which we shall meet elsewhere in this book is that spirituality overlaps too much with religion, and religion is something that many people have become disaffected with. However, most people have not given up on their religious beliefs altogether; the problem then becomes one of how to find ways of describing and validating those beliefs outside of religious frames. Another well rehearsed explanation overlapping the first concerns the compelling claims of science. With a systematic world-view based on matters of fact, anything as undetermined as spirituality is easy to discount. Therefore, because palliative care trades to an increasing extent in the credibility of empirical science, spirituality must remain tacitly behind the scenes of this paradigm.

A further explanation hinges upon the relationship we have with death and with the question of how should we die.
The dying soul

We live in a world that panics at this question and turns away. Other civilizations before ours looked squarely at death. They mapped the passage for both the community and the individual. They infused the fulfillment of destiny with a richness of meaning. Never perhaps have our relationships with death been as barren as they are in this modern spiritual desert, in which our rush to a mere existence carries us past all sense of mystery.

(Mitterrand 1997: vii)

Death frightens, fascinates, humbles and remains an outstanding enigma. How can we articulate the spiritual character of dying and death when the brutal facts of mortality cause such pain and anguish? How can we admit to the place of death in life when death contradicts so much of life and the expectations of death-defying health care.

Spirituality is an awkward subject to discuss, perhaps because we are all too close to it. The word can mean literally that which is of the essence of life, the animating breath, a vital and sustaining element of life. Talking personally about spirituality therefore requires people to become acquainted with and to lay bare their intimate thoughts and feelings. Spirituality consequently lends itself to metaphor, analogy, symbolism and art. It may be equally well described by saying what it is not. There are similarities here between spirituality and health. Health is hard to objectify, describe and measure; its absence less so, and it is readily concealed until disturbed. Spirituality, like health, is enigmatic and its familiar presence seldom registered until it is challenged or dislocated.

Despite its apparent abstruse and obscure character, spirituality as a term is frequently present in discussions about well-being, dying and death. In this sense, spirituality is closely linked to considerations of personhood. It is also applied to experiences of an esoteric or mystical nature, adding a significance of meaning and value. The playwright David Hare captures something of this in his play Skylight. Tom’s wife has died from cancer, and in the following extract Tom expresses his grievance at his wife’s spiritual feelings:

She got hold of this bloody word ‘spiritual’. It’s one of those words I’ve never quite understood. I mean, I’ve always hated the way people use it. They use it to try and bump themselves up. ‘Oh I’ve had a spiritual experience’, they say . . . As if that’s the end of the argument. Spiritual meaning: ‘it’s mine and shove off.’ People use it to prove they’re sensitive. They want it to dignify quite ordinary things. Religion. Now, that is something different. I like religion. Because religion has rules. It’s based on something which actually occurred. There are things to believe in. And what’s more, what makes it worth following – not that I do, mind you – there’s some expectation of how you’re meant to behave. But ‘spiritual’ . . . well, it’s all wishy-washy. It means
‘well for me, for me this is terribly important, but I’m fucked if I can really say why . . .’

(Hare 1995: 44–45)

‘Spiritual’ for some is therefore a vacuous word because it is so bland or unfathomable, made more elusive by being considered sacrosanct. It may also suffer from being used in such a generic form that it has become too malleable and therefore lost its distinguishing features. This points to a further aspect of the conundrum: the ambiguity of spirituality and the elusiveness of clarification. Spirituality therefore becomes a self-fulfilling prophesy, respectfully ring-fenced and considered out of bounds to examination, research and exposition.

But is spirituality too fragile to withstand closer inspection or is it so self-evident that it is innately understood? There are parallels here with another popular palliative care notion, that of the ‘good death’. This commanded similar reverence and unquestioned assent as it achieved popularity in the early history of the modern hospice movement. But through engaging with it there has been a beneficial revision and development of what a ‘good death’ means, and as a result palliative care has articulated more clearly not only its aims but also its presumptions, values and ideals.

**Being specific**

It is evident that the term ‘spiritual’ requires some specification and the benefit of points of reference. A simple map (Figure 1.1) of the conceptual landscape that spirituality covers indicates something of the taxonomy and lexicon which are circumscribed. These areas sometimes interrelate, overlap and flow into one another. They can also be sharply divided and contested. In palliative care the spiritual domain acquires a vague homogeneity simply because it concerns dying and death. The domain finds coherence therefore around the motifs of human finitude, hope, suffering, wholeness and destiny.

If, like David Hare’s character Tom, the use of the word ‘spiritual’ incites in you exasperation, attempts at definition, although not abundant, are available. Many are found outside of palliative care in other contexts. One such example comes from the American academic Nelson. In his study of male sexuality and masculine spirituality he offers a broad account of spirituality which finds echoes in many others:

It is simply our basic life orientations and the patterned ways in which we express them. It is the patterning of our thinking, feeling, experiencing, and nurturing of whatever we take to be fundamentally important.

(Nelson 1992: 24)
This definition captures some of the key ‘components’ of spirituality as it is commonly portrayed: spirituality is basic to being human and therefore something common to humanity; it gives shape and direction to life relative to essential principles, and is formative of, and in turn manifested in, being human. The qualification that it is what is held to be of fundamental importance is the critical determinant of spirituality. Nelson explains this to mean what is of ultimate reality and worth for a person; others use the phrase ‘ultimate values’. However, whatever form these may take, content and their authorship are of equal significance. These may be developed or discovered, and range from an existential imperative of making meaning out of life to the ‘reading’ of universal values out of texts, traditions, the ‘natural’ order and supernatural revelations. And because these values are taken as fundamentally important they frame the ‘world’ which a person inhabits and are embodied by that individual in the way the person relates to life. In palliative care, spirituality acquires further definition by focusing upon the terminal orientation of life:

The realisation that life is likely to end soon may well stimulate a desire to put first things first and to reach out to what is seen as true and valuable – and to give rise to feelings of being unable or unworthy to do so. There may be bitter anger at the unfairness of what is happening,
and at much of what has gone before, and above all a desolate feeling of meaninglessness.

(Saunders 1988: 1–2)

The unfinished business of the dying is a common idea which many views of spirituality complement (Dudley et al. 1995). At the hour of death, so convention has it, it is to be expected that people will want to have their lives in order, all outstanding matters resolved and their destiny clear. For patients who do not hold consoling beliefs about death, what faces them may be considered 'the obscene mystery, the ultimate affront' (Sontag 1991: 56) which is the cause of anguish, anxiety and emptiness. The spiritual task in palliative care is often portrayed, therefore, as that of finding meaning in death through which dying can be translated into the fulfilment of living, thus inspiring hope, wholeness and asserting the self in the midst of disintegration.

If death represents anomie and alienation of the individual, an authentic spirituality represents a means of personal growth and reintegration, in other words an aspect of psychological development (Bragan 1996). Psychology therefore offers a further detail to the complex spiritual map in recognizing the significance of belief (a sense of meaning) and faith (the capacity to believe) in the way that people face illness, dying and death (Jacobs 1998). Beliefs are ways of making sense of experience and exist on many levels and in many forms. Jacobs reminds us that ‘Letting go at death is often just as much a psychological act as it is a physical one’ (1993: 172), and that it is our beliefs which govern the way we understand and relate to death. This can have both negative or diminishing qualities, such as a crisis of faith, anxiety and doubt, as well as positive or enriching qualities, such as ‘the courage to be’ (Tillich 1952), trust and a sense of well-being.

A psychology of belief suggests that there is therapeutic potential in exploring matters of faith and belief with a patient. This potential is one that is recognized in some schools of counselling (Lyall 1995), pastoral care (Lake 1986) and psychotherapy (Jung 1933). No psychology of belief, however, can escape the imposing shadow of Freud, who wrote critically about why people hold beliefs. In one sense, Freud suggests that beliefs palliate reality, that they are consoling, may fulfil our (infantile) wishes and may be illusory. At his most critical, Freud held that religious beliefs serve to contradict and compensate for what he understood as the oblivion that follows death. But this conviction underestimates and misrepresents the richness of beliefs concerning death which address such issues as the significance of life, love, sacrifice, change, continuity, suffering and moral value (Bowker 1991).

Despite Freud’s contempt of ‘idolatrous’ beliefs, people depend upon a wide range and level of beliefs in all aspects of life, even in psychotherapy, and the question of their truth endures ongoing debate and revision. In palliative care it is the beliefs not only of patients which are significant but also of caregivers, an area seldom explored. It seems remarkable that in a
field that purports to be comfortable with death, that same field would appear to avoid exploring the beliefs which shape the way death is experienced, understood and cared for.

The ways in which psychological and physiological states are related deserve a brief mention because they provide a perspective on holistic care which can often be left to anecdote or discounted altogether. Psychological variables such as social support, beliefs and concurrent stress can not only influence the way in which patients cope with their illness but also affect their well-being. Psychological factors, as we have noted, also play their part in dying. There are many anecdotes of seriously ill patients surviving to celebrate wedding anniversaries, Christmas or birthdays and then dying. But there is also statistical evidence of significant fluctuations in mortality around the time of significant dates, such as religious festivals (Martin 1997). The findings of one study of three hundred patients cautiously conclude that the beliefs of a religious or spiritual nature are more predictive of clinical outcome in acute illness than the scores of the General Health Questionnaire (King et al. 1994). The proposed correlation between a course of illness and the nature and strength of a person’s beliefs comes with many caveats, but it is a reminder that the process of dying is not just a matter of irreversible pathology and catastrophic biological failure for the individual or for society.

It would seem that no matter which angle we take on dying and death, there is in some inevitable sense a spiritual conjunction and even correlation. This in part is due to the silence of the rational enquiry as it stares at its demythologized death. But it may also be explained by the subjective experience and perception of mortality which takes us beyond death as an objective reality described within particular systems. The end of life may find an explanation in medicine, bereavement in psychology, dying in sociology, but death is not merely the resultant expression of these accounts. Death impacts upon us in the contemplation of our finitude, through our encounters with the dying and in the impress of their death. It therefore becomes a focus for beliefs, values, meaning and life itself. This is what has become in palliative care the category of spirituality, but it is a term that has acquired a putty-like malleability with its convenient gap-filling properties. It is not surprising, therefore, to find spirituality conforming easily to the holistic project such that it is claimed to be indispensable to quality care and ‘the integrating aspect of human wholeness’ (Clark et al. 1991).

This general comprehensiveness, which has become an indelible characteristic of palliative care spirituality, may sustain uncritical acceptance but it can obscure the significance of difference within spirituality both for professional caregivers and for patients. It is tempting, when faced with complexity, to try to circumvent it with some sort of unifying theory. But spirituality is represented and expressed in many different forms, no more so than in what might be called the ‘religious spirituality’ of the world.
faiths. Many of these forms contain concepts and assumptions which are incompatible with one another and cannot be brought together into a single account (Markham 1998). There are also differences within particular traditions apparent in the developments of divergent schools as well as more subtly in individual derivations. Spirituality is also in essence dynamic and easily distorted when reduced to a sketch of certain beliefs, values and practices that become a deterministic caricature – particularly evident in some multicultural approaches to palliative care (Gunaratnam 1997).

Palliative care spirituality can be understood as a collective term representing the assortment of spiritual orientations of patients, but it has also become a reflection of the ‘common’ spirituality that pervades the philosophy of much palliative care and which finds its origins in the modern hospice movement. In this latter sense, spirituality is grounded within a Euro-American context and is significantly influenced by Christianity and the western philosophical traditions. A ‘common’ spirituality should have no pretensions to being either a comprehensive global or a humanitarian account. Therefore spirituality used as a generic term is limited by its necessary abstraction, and limited in its direct application, but its contents may still have a broad significance and validity. A generic spirituality will be provisional, but it must hold some reliability otherwise it will be useless. Here there is a tension between pursuing the greatest degree of generality (simplicity) whilst maintaining what is particular and specific (complexity). But we must be aware also of a complacency that allows spirituality to be maintained as an ethereal mystery which can have the effect of obscuring enquiry, debate and specification.

Spirituality in palliative care must contain sufficient dependable detail and description to enable it to be recognized, understood and studied – the surface of the reality and its knowledge – whilst we remain aware that this will not capture the intimate and inchoate – the depth of the reality and its more profound discernment. Yet, through our underlying humanity and empathetic insight we can appreciate and, at times, comprehend this aspect of human experience in others. There is, however, an incompleteness to any account of spirituality, as in other attempts to portray and analyse human beings, such that:

An immense amount is necessarily left out at both ends of the scale – both the deepest, the most pervasive categories which enter too much into all our experience to be easily detachable from its observation, and at the other end those endlessly shifting, altering views, feelings, reaction, instincts, beliefs which constitute the uniqueness of each individual and . . . the individual flavour, the peculiar pattern of life, of character, of an institution, a mood, and also of an artistic style, an entire culture, an age, a nation, a civilisation.

(Berlins 1996: 19)
It is in this sense that spirituality is short of systematic theory and requires ‘far more sympathy, interest and imagination, as well as experience of life, than the more abstract and disciplined activities of natural scientists’ (Berlins 1996: 20). Although these quotations relate largely to historical theorizing, the argument retains validity for spirituality in that it also deals with the ‘wholes’ of people and their experience which are easily lost in analysis and derivation. It cannot be claimed that the description of someone by a biographer is equivalent to that of social scientist, or that their portrait is equivalent to their X-ray. Each has its use and value, but in each case the former representations are those of insight and acquaintance of the person whereas the latter are observations and the accumulation of particular data.

This presents a further paradox concerning spirituality, and again it is not one that is peculiar to it, for beyond its surface spirituality becomes increasingly unsusceptible to empirical and deductive techniques, although this still leaves a vast territory to explore and describe. The less we depend on assumptions and abstraction, the more we rely upon perception and awareness. It is perhaps not surprising, then, that some of the best language to convey the sense of spirituality is that of poetry, for it is at times necessarily analogical and metaphorical, often conforms only to sufficient grammatical rules to make it ‘legible’, and can by circumlocution and apophasis say much without direct reference to the subject. Poetry is perhaps the language of paradox, and so it is in the poetry of R.S. Thomas that we discover, for example, this simple but penetrating account of the need to pray:

It is this great absence  
that is like a presence, that compels  
me to address it without hope  
of a reply. It is a room I enter  
from which someone has just  
gone, the vestibule for the arrival  
of one who has not yet come . . .


Thomas’s ability to deal with the paradoxes of absence and presence, faith and doubt, provides the means to convey his search for what he believes to be ultimately real. Poetry may give our deepest thoughts, beliefs and experiences words, but it is not a medium which is commonly used in the commerce of logical discourse, and it is certainly not the common parlance of palliative care despite the inclusion of creative arts within the therapeutic context. The language of palliative care spirituality is therefore more often reliant upon second-hand languages that provide an impersonal perspective on a world that is intelligible but often lacks a sense of meaning, reason or value, those things which are often the loci of spirituality in what may be termed a ‘disenchanted’ world. Plainly we need a reliable account of
Understanding spirituality

spirituality, robust enough to be pragmatic and enable useful reflection and enquiry. This is not a mere semantic exercise, but one which requires spirituality to stand in a confident relationship to others who are sifting reality, contemplating being human and who are motivated to care for the dying.

Science, medicine and spirituality

The thought of putting science and spirituality together may at first appear a rather odd conjunction, for science deals in objective realism, and spirituality in the very soul of being. It could be said, therefore, that science looks in from the outside while spirituality looks out from the inside. But both approaches are trying to make sense of life and to respond to the human preoccupation with the nature of reality.

In his exploration of some of the latest scientific theories, George Johnson looks across from the cutting-edge science institutions of New Mexico to the local communities and traditions:

The descendants of the Anasazi dancing in resonance with the seasons, the fundamentalists with their attempts to predict the future through biblical interpretation, and the physicists and biologists with their search for hidden harmonies are battling over the same spiritual ground. All are trying to make sense of life’s overwhelming complexity, to come to terms with the fact that, for all our well-laid plans, we are buffeted about by contingency and chance. Each of these subcultures, in very different ways, is trying to replace randomness with order, to spin webs of ritual and reason, to try and convince itself that if we don’t actually live at the centre of creation, at least we can comprehend it – that there is reason to believe that the human mind can pierce the universal panoply. Each is trying to answer the question of why we are here, as a species, a society, and as individuals. In both science and religion, we seek creation myths, stories that give our lives meaning.

(Johnson 1995: 26)

This generous cosmological interpretation suggests a common purpose in the search for understanding and truth. At its most diplomatic, this inclusive view does not consider science and spirituality to be mutually exclusive. It allows accounts to co-exist because it does not allow for absolute claims to reality. As we shall see, when facing death there are few who would be so bold. However, some of the most powerful critics of this accommodating position come from within the scientific tradition, and particularly modern biology, where claims have been staked for the sole possession of the ‘spiritual ground’. Richard Dawkins considers that natural selection outclasses all explanations of life and believes it to be a blind process with no purpose or meaning other than maximizing DNA survival.
In considering more personal matters, such as suffering, Dawkins is convinced that:

In a universe of blind physical forces and genetic replication, some people are going to get hurt, other people are going to get lucky, and you won’t find rhyme or reason in it, nor any justice. The universe we observe has precisely the properties we should expect if there is, at bottom, no design, no purpose, no evil and no good, nothing but blind, pitiless indifference.

(Dawkins 1995: 133)

A universe of ‘selfish genes’ is a sufficiently complete explanation of life for some; other scientists question just how blind the evolutionary process is and point to its tautological weakness particularly in the circularity of evolutionary arguments. But for many it is hard to believe that an absurd chain of contingencies says all that needs to be said about humanity. The simple point is that science offers its explanations of the physical impersonal world it investigates and that this is not limitless, otherwise we have to concede that science has become omniscient, and that scientism is the order of the day. Scientific reductionism extrapolated to the corners of a multifaceted world also throws up a smokescreen to the questions it cannot answer, the values it has no use for, the purposeful beliefs it occludes with functional utility. We are left therefore with powerful tools and technology and yet as strangers in a cosmological drama in which we now appear in the margins, as one whose divine fiat is surplus to requirement. This is what is referred to as a disenchanted world (Weber), barren of the meaning, experience and understanding that science brands as fiction or fantasy. But that is seldom the personal and embodied world inhabited by human beings who, for example, experience pain and delight in ways that biology or physiology can hardly begin to describe.

Death reduced to an event of medical science was the starting point for the modern hospice counter-movement whose vision combined both the scientific and the spiritual. However, in the desire for credibility and status, palliative care is an uncomfortable position. For as it develops its own specialist clinical science, and returns increasingly to the place from which it departed – acute health care – it may have to abandon some of its distinct philosophy, and as a result the concern for the spiritual may become compromised or even relinquished (Small 1998). But this assumes that this goal is worth achieving and that the progress of science, and more specifically medicine, from which palliative care wishes to benefit, is at least benign and preferably rewarding. And yet as medicine has become more and more ambitious and dominant so too have its discontents and nonconformists.

Illich famously criticized the medical monopoly of health care for undermining people’s ability to face the reality of illness and deal with sickness and death, claiming that the technocracy of medicine was eradicating the
Understanding spirituality

meaning of suffering. Pain for example, Illich argues, has become a term used almost exclusively to refer to bodily pain to be managed by external technique, whereas historically its meaning was cosmic, mythical and an experience as much of the soul as of the body. Therefore, pain was always more than reflex or dysfunction: ‘there could be no source of pain distinct from pain that was suffered’ (Illich 1976: 156). Disquiet with the medicalization of death has been paralleled with growing opposition to the prolongation of life, evident in the drive towards legitimizing euthanasia. Porter, from an historical perspective, recognizes that, for centuries, medicine could achieve little and therefore people had low expectations of it. In the twentieth century, medicine grew in its achievements, its status, cost and therefore its attractiveness to critics. In western society, medicine increasingly faces another plight, and one that will possibly dictate a more ignominious future:

Having conquered many grave diseases and provided relief from suffering, its mandate has become muddled. What are its aims? Where is it to stop? Is its prime duty to keep people alive as long as possible, willy-nilly, whatever the circumstances? Is its charge to make people lead healthy lives? Or is it but a service industry, on tap to fulfil whatever fantasies its clients may frame for their bodies . . .

(Porter 1997: 717)

The relationship between palliative care and medicine is a critical one, not only for the future of palliative care but also for the place of spirituality within it. If palliative care adopts an increasingly reductionist view of terminal illness and dying, it will come to operate with an increasingly impoverished understanding of those for whom it cares as well as those who provide the care. If it can continue to assert its distinctive philosophy and approach it may also continue to embrace a wholeness of human being, suffering and dying that is often obscured or even absent from the sparse view of science. The undoubted effectiveness of medical science must not distract us from its constraints, nor lead us to consign spirituality to a type of epiphenomenon which will eventually be dissolved by cognitive science.

Palliative care is embedded within a wider culture in which science has radically transformed the concept of the self through its relentless materialism and revolutionized our understanding of reality through its reconstruction of the universe. In simple terms this can be traced as a shift from dualism to monism; from a world in which there were physical and spiritual domains to one dominated, to the exclusion of all else, by the purely physical (Wertheim 1999). But for many people this is neither adequate nor sufficient. The spiritual has not ceased to exist because there is no place for it in the scientists’ construction of the world. One perspective cannot provide a comprehensive view of the totality or provide an ‘absolute’ knowledge; however, the fallacy is to assume that anything unaccounted for
The dying soul

in science is simply obsolete, for ‘a methodological limitation does not warrant the conclusion of a corresponding ontological poverty’ (Polkinghorne 1996: 112).

The scientific imagination is the very opposite of impoverished, and through it medicine has transformed our expectations of life. But medicine’s success has been at a cost, and part of that cost has involved a myopic view of illness as pathology, with its damaging consequences for practice. Palliative care, without abandoning scientific developments, has sustained a broader approach and integrated different perspectives that give high regard to the personal and social experience of illness. Perhaps it is because science has relatively little to say in the presence of suffering and death that spirituality still has a place in palliative care. A scientific account, for example, of the cessation of biological life is at best banal and does not capture the profound attitude most people express towards death evident in their response of grief. Again we come across the difference between the causal scientific objective explanation and the human subjective world of meanings and beliefs. This is why medicine and the science upon which it is based can be so alienating, but it may also be why:

Those who seek for meanings may be indifferent to causes, and those who communicate with God through prayer should be no more cut off from him by the knowledge that the world of objects does not contain him, than they are cut off from those they love by the knowledge that words, smiles and gesture are nothing but movements of the flesh.

(Scruton 1996: 107)

Transcendence and the nature of spirituality

A sense of alienation from the world and from one another points us towards the notion of transcendence which is perhaps becoming a significant attribute of spirituality today. Transcendence at its most literal is about going beyond the self, the body, the physical and the mortal. It is a term that can convey a sense of being a part of a greater whole, of connecting with something outside of oneself, or of becoming open to a greater reality that may be in the depths of one’s being, with another person, with the world or with God. Common experiences of transcendence involve the awareness of an ‘other’ beyond the immediate and of losing oneself in its contemplation. Falling in love with another person, taking in a dramatic landscape, viewing a beautiful work of art or listening to music can all be occasions for transcending our selves as well as the object of our consideration. All this can be considered, therefore, in terms of an aesthetic experience or encounter:
For I have learned
To look on nature, not as in the hour
Of thoughtless youth; but hearing oftentimes
The still, sad music of humanity,
Nor harsh, nor grating, though of ample power
To chasten and subdue. And I have felt
A presence that disturbs me with the joy
Of elevated thoughts; a sense sublime
Of something far more deeply interfused,
Whose dwelling is the light of setting suns,
And the round ocean and the living air,
And the blue sky, and in the mind of man:
A motion and a spirit that impels
All thinking things, all object of all thought,
And rolls through all things.

(‘Lines composed a few miles above Tintern Abbey’, Wordsworth)

Wordsworth’s consecration of nature shifts the focus from the self to the other which lies beyond and outside the self but is experienced within. The beauty of nature for Wordsworth has this sublime reality in which ‘we see into the life of things’, something both perceived and revealed:

Enough of Science and of Art;
Close up those barren leaves;
Come forth, and bring with you a heart;
That watches and receives.

(‘The Tables Turned’, Wordsworth)

In going beyond a description of landscape, Wordsworth senses the sacred in nature, that which is of ultimate value. In contemplating humanity, he sees ‘Thou, whose exterior semblance doth belie Thy soul’s immensity’ such that we are not born ‘in entire forgetfulness/And not in utter nakedness/But trailing clouds of glory . . .’: This aesthetic interest, expressed in this case in romantic terms, engages our little world in a wider world of arresting allusion, spiritual significance and morality. And all this through reflecting on the ordinary, material, everyday world. Perhaps here is where the aesthetic and the religious converge in attempting to convey deeper truth:

In the sentiment of beauty we feel purposiveness and intelligibility of everything that surrounds us, while in the sentiment of the sublime we seem to see beyond the world, to something overwhelming and inexpressible in which it is somehow grounded. Neither sentiment can be translated into a reasoned argument . . . All we know is that we can know nothing of the transcendental. But that is not what we feel – and
it is on our feeling for beauty that the content, and even the truth, of religious doctrine is strangely and untranslatably intimated. (Scruton 1998: 29)

Existential uncertainty, dissatisfaction with materialism, the search for meaning and value almost compel transcendence. Thus we attribute awe and wonder, the sacred and the holy, to experiences of transcendence because they give a breadth to the world we inhabit and we become affirmed, consoled, and connected beyond the loneliness of ourselves. This has much in common with an ‘oceanic’ experience (attributed by Freud to the mother/baby relationship) in which a person feels at one with the world in an unbounded union. However, there is a mystical tradition, evident in many religions, that is far from infantile and understands the abdication of the ego as the way to being at one with the universe. Transcendence, therefore, can be understood as the disclosure and realization of significance beyond the particular. For those who hold religious beliefs, transcendence may involve an encounter with the natural through which the supernatural is experienced: a sacramental reality that makes present the ‘ultimate reality’ of God. This endows the world with a telos, or ultimate purpose, according to the religious hermeneutic and faith. Bond declares, however, that ‘[t]heology has lost its object’ such that God ‘has become pluralized into a general spirituality and identified with virtually anything whatsoever’ (Bond 1998: 286). A telos without reference to God, or the supernatural, operates in the noumenal world rather than the empirical world, and transcendence becomes similarly abstract and indeterminate, an aesthetic sublimity without orientation or value. Thus we approach a major question in our understanding of spirituality: can spirituality exist without theology or without religious faith? Can there be a secular spirituality? These are question which, as we shall see, have been debated in palliative care as much as anywhere else.

Spirituality contains a tension, therefore, in that it is expressed and experienced in distinct forms and traditions, whilst also being taken as a unifying, although pluralistic, concept within which all people can be included equally. This patterns to some extent the sociocultural epithets of modernity and postmodernity, the latter suggesting a deregulated spirituality whose authority resides in the individual, rather than in any ‘ultimate’ truth or orthodoxy, with its resultant relativism. It is perhaps of some surprise that the idea of spirituality has survived at all given the claims of secular theories, but the secularization process is losing its confidence and becoming weakened by its limits. Counter-trends have helped to support spirituality, evident in the concern about quality of life and well-being, human rights, ecology and moral values. It is perhaps ironic that contemporary spirituality to some extent finds endorsement within the cultural sphere, and in areas not readily associated with it:
Consumerism, with its emphasis on taste, and the accompanying aestheticisation of social life, along with the new centrality of what might be called a ‘sacred self’; these may signal not only a new appreciation of the symbolic realm but also offer opportunities for considering these ‘religiously’: that is, as evidence of a quest for transcendent meaning.

(Lyon 1996: 20)

The quest for meaning, the questions of existence, are pressing human preoccupations that people are motivated to address in some form or other, both individually and collectively. The survival or continuation of spirituality may need to be thankful to the demythologized and disenchanted views of our world which claim such attention. But this is not to suggest a dichotomy or contradiction that requires a simple choice of alternatives; rather it is to recognize the dynamics of spirituality and its cultural embeddedness. It also reminds us of the enduring and inherent question put before us each morning as we stare at ourselves in the mirror, a question that is perhaps no more urgent than when life is fading: what is the ‘me’ that I see and which lives in this body? To use the more eloquent language of the seventeenth century, which retains relevance for today, ‘what is this quintessence of dust?’ (Hamlet, ii.ii.306). A succinct reply may be found in one of Donne’s Holy Sonnets, ‘I am a little world made cunningly/Of elements and an angelic sprite.’ (V.) And with that we turn to another significant concept for our understanding of spirituality, that of soul.

Soul

The spiritual connotations of soul have not limited its application to matters such as music, friendship and food. Soul denotes something essential, noble and sincere; it is a word of some gravity and much historical significance. Indeed, its etymology takes us back at least to the foundations of western philosophy and theology, and yet its usage persists into contemporary debates about the nature of the self and consciousness (Crabbe 1999). One of the best examples is to be found in the Platonic dialogues of Phaedo (Gallop 1993) which concern Socrates on the day before his execution (399 bce). The dialogues explore the nature not only of death but also of life after death, and presents one strand of an ancient Greek understanding of soul (Greek psyche) that was to have a major influence on Christian theology, and which can be perceived in common notions of soul prevalent today. A few examples will be illustrative:

‘...tell me what it is, by whose presence in a body, that body will be living.’
‘Soul.’
The dying soul

‘And is that always so?’
‘Of course.’
‘The soul, whatever it occupies, always comes to that thing bringing life?’
‘It comes indeed.’

(Gallop 1993: 105 c,d)

‘... And that being dead is this: the body’s having come apart, separated from the soul, alone by itself, and the soul’s being apart, alone by itself, separated from the body? Death can’t be anything else but that, can it?’
‘No, it’s just that.’

(64c)

‘... if these are our conclusions from all that’s been said: soul is most similar to what is divine, immortal, intelligible, uniform, indissoluble, unvarying, and constant in relation to itself; whereas body in its turn, is most similar to what is human, mortal, multiform, non-intelligible, dissoluble, and never constant in relation to itself.’

(80b)

_Phaedo_ does not present a systematic theory of soul, and I am not suggesting that one is read into it, but we can see here the notion of soul as the animating principle (Latin _anima_), in some form of dualistic relationship to the body, and immortal upon the death of the body. However, there are considerable differences with a modern understanding of soul, for the Platonic soul has a prenatal existence, it operates in the mode of reasoning and intellectual function, and has a place in the metaphysical theory of forms which has long been abandoned (Gallop 1993). Despite the historical canyon and the unfamiliar world-view separating us, the Platonic ideas of soul have a remarkable contemporary resonance. Perhaps, dealt with simply, this is not so unexpected, for little has changed in the face of death when a sense of the body being abandoned is felt as much as the cessation of life is observed.

This points us to the thorny philosophical problem of whether or not a person can be subdivided into a collection of ontological ‘components’. Is a person a unity, or is there a ‘ghost’ in the machine? Is the psyche (understood as mind) a product of the brain or an enduring and distinct entity? Cartesian duality has contributed greatly to the success of somatic medicine, but it has also left the door open for ways of reaching the soul. Thus Sacks, reflecting on postencephalitic and Parkinsonian patients, suggests that a practical scientific medicine must be complemented with ‘an utterly beautiful and elemental “existential” medicine’ (Sacks 1982: 241–55) that can deal with the ‘I’ as opposed to the ‘It’ and includes living contact and art. Others have gone a step further, and so in psychoneuroimmunology an
attempt is made to bypass the duality by challenging the psychosomatic fallacy that says either disease is a physical reality or it is all in the mind and therefore ‘imagined’ – in its pejorative sense.

Perhaps the greatest challenge lies in the explanation of the nature of consciousness, the experience of the self, the subject which science attempts to translate into an object by describing it in terms of an epiphenomenon of matter or a cognitive mechanism (LeDoux 1998). In this materialist reduction people are no more than biological creatures, whose self is an erroneous and deceptive illusion. The hypothesis of memes suggests that ‘I’ is a clever trick of evolutionary natural selection which may be more harmful than benign, and that explains ‘why we all live our lives as a lie, and sometimes a desperately unhappy and confused lie’ (Blackmore 1999: ch. 17).

But the autonomous self is self-evident to many people and an immensely powerful notion in the way we think about ourselves, others and mortality. This may be why the language of soul is still in common use even if the elaborate metaphysics of Plato have been forgotten or displaced, for it still represents a significant aspect of personhood. In this sense, soul has associations with the value and dignity of life, its moral agency and its potential. Soul also retains an ethical purchase when entering debates regarding the sanctity of life, euthanasia and abortion. Here the soul symbolizes the core of human life, of intrinsic value to be respected and honoured, whether ‘created’ by a divine or an evolutionary process (Dworkin 1993: ch. 3). Therefore soul is in some sense a reflection of the fundamental values around which life is patterned and which gives life worth and fulfilment. The dynamic in this patterning is evident in the questing after the authentic self, never fully realized but a goal that fascinates and inspires:

The longest journey
Is the journey inwards.
Of him who has chosen his destiny,
Who has started upon his quest
For the source of his being

(Hammarskjöld 1964: 65)

Self-awareness suggests, intuitively at least, an inward gaze that goes beyond the surface persona to an intimacy with the self. This spatial analogy of the journey towards one’s being is evocative of a ‘world within’ and accords with an internalized soul. But soul, as the pattern and goal of the self, may be thought of not as containing but as embracing the person. It is this concept of soul that brings us close to a metaphysics in which immortality and destiny can be contemplated. Transcending our limits may be an hubristic aspiration that can work against our humanity – escape and denial – or it may turn us to attend with more concern to this life, sometimes evident in the spirituality of palliative care. However the soul also provides the possibility of a continuity despite death, a hint of the eternal and
something beyond mortal limits. These immortal longings have been the subject of grand philosophical and theological projects (Kerr 1997), but more simply the idea of soul equips people to look into the oblivion of death, to honour the dead and to afford care to the dying.

The language and symbol of soul clothes a complex of problems and phenomena pointing away from nihilism and towards an expression of being human that is inspiring, profound and transcendent. Perhaps this is why the word has become so embedded in our vocabulary and thinking, receiving the attention not only of certain branches of theology and philosophy (Morea 1997; Swinburne 1997) but also of cognitive science and psychology (Brown et al. 1998). It is a concept that both challenges and fascinates, no more so than when contemplating the end of life, suffering and human destiny. In this sense alone, soul retains an heuristic potential, even if the mythology of soul can be difficult to correlate with other types of discourse and is susceptible to criticism. Soul has historically provided a focus for the human experience of being in the world and a characteristic of life itself. This nexus has intersected for many with spiritual dimensions that enable us to talk about the transcendent capacity we have beyond our fragile and ephemeral bodies. Questions of the existence and place of a human soul, which seem to occupy more the thoughts of scientists than theologians and philosophers, lead to an important question of whether or not we can live and die without soul. It is a critical debate not only about what it means to be human but also about the value and meaning of human life. The importance of soul may therefore reveal itself by its absence in the accounts of humanity that diminish not only the individual self but humanity as a whole:

The denial of the soul leads to loss of the ideal of individual worth; to loss of a sense of the absolute claims of love and truth; to loss of a real sense of moral purpose and the importance of moral striving in the world. If we are really to seek for justice and human freedom and self-realization for all, it is vital to recognize the human soul for what it is – the transcendent subject that is never wholly bound by the material forms in which it is, nevertheless, truly incarnate.

(Ward 1992: 116)

The ethical framework suggested by Ward pivots upon the idea of soul which strives to find fulfilment in responding to absolutes of love, truth and justice – an objective moral basis whose goal is of ultimate value, namely God. This represents a particular theistic spiritual orientation which is influential in palliative care and provides a sense not only of moral dignity but also of moral obligation. The soul has not been left alone by other traditions: claims have been made upon it by other philosophies, and increasingly by science. These varying accounts do not represent equivalent understandings: some attempt to make others redundant, others conflict at
their most elementary level, but to speak of the soul is an attempt to speak of something significant about ourselves and others, about human purpose, destiny and even our place in the life of the universe (Tilby 1992). Debate and disagreement naturally accompany such accounts, for they concern pressing matters, but what is apparent is that the soul is far from receding in the discourse of humankind despite a fading historical importance or any contemporary dissent.

The challenge of spirituality

It is apparent that spirituality has an enormous range of interpretations that include the theistic, non-theistic, atheistic, ascetic, moral, psychological and scientific. They all concern making sense of human existence. This is not the preoccupation of all people: some are content to accept life as it is and go no further. Whether people facing death consider such matters to a greater extent than others is open to speculation, but what is certain is that mortality has occupied an important place in the concepts and expressions of spirituality. If spirituality concerns the significance of life in its diversity, richness, glory and tragedy, then it does so with reference to life defined by death. This is why spirituality should occupy such a prominent place in palliative care, but it is also why spirituality must also be more than a token. For some, spirituality is a relief and detachment from the struggles of existence; others may find through spirituality an affirmation or transfiguration of life in spite of death. This apparently paradoxical stance is nothing more than the reality of existence in its wholeness, which spirituality stands in symbolic relationship to. That language is often inadequate to render the spiritual dimension is evident. Conceptual and abstract words cannot convey the depth of spiritual experience just as the experience of music cannot be adequately described in documented accounts. But spirituality does not need to be abandoned to some ephemeral place appreciated by the gnostics. As with music, spirituality can also be coherently ordered, notated, discussed and developed.

Pursuing spirituality beyond its apprehensibility is a relevant discipline, therefore, for palliative care to be engaged with and, as importantly, to contribute to. Indeed, spirituality is a creative paradigm that should benefit from the wide range of contributors that we have been considering. It is perhaps, therefore, disappointing to discover how limited the involvement of palliative care has been so far. Of equal concern is the occlusion of spirituality from accounts of human experience and from the practice of health care. This is less a result of the abeyance of the spiritual and more a consequence of the loss of confidence in ‘caring’ professions to engage with this deeply human perspective of self and the world. The neglect or negation of spirituality within a particular field results in obscuration within
that field; but, as we explore in the next chapter, spirituality finds alternative expressions and places of validation, or creates new ones.

This chapter began by describing spirituality as something of a conundrum in palliative care. Conundrums become boring after a while, especially when no solution is forthcoming, and thus become neglected or the object of only occasional curiosity. The conundrum challenges palliative care to engage seriously with spirituality and to afford it the same concern as other domains. If spirituality has a place in palliative care, as its philosophy suggests, it should not be treated lightly or dealt with in a cursory fashion. More than that, the challenge is a far broader one concerning how we understand well-being, suffering, life and death: and that is a matter which none of us can avoid, and which shapes our own lives and our relationship with others.

For those for whom the soul is an empty symbol, and spirituality a remnant of a metaphysical world superseded by a plainly physical one, the challenge may still find echoes in moral debates, the impact of suffering, the questions of existence and the contemplation of mortality. The spiritual side of life is a dynamic force that is not only deeply embedded in our thoughts and ideas, but also experienced in our being human. It is this persistent presence which requires addressing both individually and collectively and which constantly challenges our language, symbols and notions. Understanding spirituality is, therefore, a rational intellectual activity, a creative act involving the imagination, a contemplative exercise and a means of grasping the quintessence of life.

Maybe our mind should be sensitive to the vastness that lies behind all reality, should be open to the winds and whispers of infinity, and should be able – by inkling and intuition – to enter the hidden realms of the blazing Tyger, the Robin, the Eagle, the Unicorn, and our mysterious humanity. How can we, in the presence of irreducible being, view life from only one perspective . . . ?

(Okri 1997: 19–20)