

Introduction to the Second Edition

The twentieth century witnessed fundamental changes in attitudes to death and the care of dying people. Although many suggested that discussion about death was taboo in the same ways as sex had been for Victorian Britain, death became a subject for debate opened up primarily by Phillipe Ariès, the French philosopher. This book like others presents the reader with an opportunity to make up his or her own mind about a range of contested topics in this field. There are different vantage points, for example one which suggests that the traditional public rituals surrounding death have all but disappeared, others might suggest that, evidenced by the public reaction to the death of national figures, be they football stars or princesses, ritual is alive and well. This book demonstrates that despite the so-called trend to minimize expressing our grief and emotions in general, as a society we remain fascinated by death.

The ways in which we handle death and dying at the beginning of the twenty-first century is indisputably different from how this was done a hundred years ago. Most people in the UK die in institutional settings, for example hospitals, residential care and hospices. The principal carers are paid professionals not family members and they manage our 'dying trajectories'. Once dead, the funeral industry moves in to provide our families and friends with a range of packages from which to choose; these are marketed like other consumer products. Thus in contrast to a hundred years ago the management of both dying and death is removed from the home and from bereaved people. However the British picture is much more complex because of the influence of the palliative care and hospice movements which strive to give dying people and bereaved people control over events. This movement which indirectly led to the publication of this book has sought to revolutionize the experiences of dying.

Although academic study of death and dying really took off during the latter part of the twentieth century, prior to this there was no dearth of literature, music and theological treatises on this subject. Different theological and religious traditions have handed down oral and written directives on how to treat dying people and dispose of bodies. Novelists, poets and biographers have been at pains to convey the distress as well as the joy heroes experienced as they approached death since the ancient civilizations of Egypt and Greece. Yet until 50 years ago, professionals working with death and dying had little empirical or even qualitative research upon which to base their practice. And until the emergence of multidisciplinary teams, the hallmark of the palliative care movement, there was little interchange between the fields of cancer care, psychology, sociology, ethics, history and medicine. Only with the widespread availability of internet facilities has information about palliative care become accessible to non-physicians.

The purpose of both editions of this book was to provide a fairly comprehensive text for the growing numbers of paid professionals, lay carers, friends, volunteers, researchers and academicians involved in caring for dying and bereaved people. It also serves as a general source book. After all, death is universal and concerns each one of us and cannot and should not be pigeonholed into any particular discipline. Thus this collection of over 60 contributions ranges from literature, penetrating first-person accounts and poetry to historical information and practically applicable research findings. We have endeavoured not only to provide beauty and intellectual stimulation, but information useful for formal and informal practice particularly in relation to communicating with dying people, understanding debates about the ethics of euthanasia and do-not-resuscitate decisions and theories of bereavement.

The structure of the book does not separate concepts, ideas or forms of contributions. It follows a certain logic in so far as Part 1 looks at ways in which history has interpreted the human struggle to understand loss and dying; Part 2 focuses on some of the practical issues entailed in addressing the needs and concerns of dying people; Part 3 presents debates in medical ethics about end of life decisions faced by dying people themselves, their informal and professional carers; and Part 4 explores the impact of different kinds of bereavement for those residing in twenty-first century Britain which consists of a multi-ethnic, non-traditional society.

The first contribution describes death rituals in an Edwardian English fishing village. This contrasts with contemporary practices in an increasingly secular British society but accounts of immigrant cultural rituals, such as those of Firth, identify similarities with earlier British traditions. Part 1 provides the backdrop to the book illustrating the enormous changes not only in ritual but attitudes towards and ways of caring for dying people. This is illustrated not only by Clive Seale's and Christina Victor's factual accounts but by the powerful poetry of Donne and Thomas. Tolstoy's spiritual quest provides a powerful finale to this part.

Part 2 links humane communication practices with the wide-ranging procedures at the centre of palliative care, including those derived from palliative medicine, complementary therapies and contemporary perspectives on holistic care. Debates are aired about the applicability of palliative care to non-malignant conditions. But the underlying theme is the centrality of good communication, openness and honesty. These are exemplified by academic contributions from Robert Buckman and Dorothy Judd and personal accounts about dying from internationally best-selling authors John Diamond and Mitch Albom. These identify the range of emotions as well as practical difficulties experienced by dying people and their carers.

In Part 3 we see the impact that high-technology medicine has had on sustaining life. Withdrawing hydration and feeding represents one set of moral dilemmas while assisted death and advance directives present others. The harrowing but deeply moving account from Tolstoy's *Death of Ivan Ilyich* provides a literary counterbalance and first-person accounts such as that from Clare Williams add a personal note here, as in other parts.

The final part focuses on bereavement and grief and how the pain of mourning can be understood and addressed. Contributions include responses to the hitherto unacknowledged grief of learning disabled people or following the death of stillborn children and gay partners. Douglas Dunn's contemporary poem concludes the book with the unsolved mysteries of living and dying.

Although this book has proved most popular amongst those training to work with dying and bereaved people, namely nurses and doctors in different settings, other health professionals and counsellors, emergency services, police and funeral directors, it also appeals to those already established in the field as well as the general reader. With such a diverse readership it seemed appropriate to include far more contributions than is common in other academic Readers. Unfortunately this meant editing down articles: we hope readers will seek unedited versions for further study.

The first edition of this book was the accompanying set book for the Open University course *Death and Dying* which was first presented in 1993. The editors who conceptualized the course and put together this text (with the help of the rest of the course team), were the then Dean of the School of Health and Social Welfare, Professor Malcolm Johnson, and the Chair of the Death and Dying development and production course team, Dr Donna Dickenson. As over 50 per cent of the original selection has either been retained as is, or updated, their original philosophy has been respected and sustained in this new edition.

The original production of the *Death and Dying* course was funded by the Department of Health as an acknowledgement of the enormous contribution of

the hospice and palliative care movements and in recognition that this area needed both academic study as well as practical application. Dr Gillian Ford and Professor Norman McKensie were influential in ensuring that The Open University was able to meet this need and we are immensely grateful for their endeavours. Recognition is due to the roles played by Professor Malcolm Johnson and Dr Donna Dickenson in preparing the original manuscript, other members of the original course team who commissioned, selected and edited contributions were Alyson Peberdy, Dr Jeanne Katz and Dr Moyra Sidell. Margaret Allott as course manager and Rae Smyth as secretary co-ordinated this complex undertaking.

The *Death and Dying* course is very successful, with annual figures at over 1,000 students. This second edition of the reader accompanies the remake of that course and reflects the changes in this field that occurred in the last decade of the century. I have had the privilege to chair the remake of the course and edit the new edition of this reader. Thanks are due to Alyson Peberdy and Dr Moyra Sidell who have continued their academic involvement in the course, and to Carol Komaromy who joined the course team. Particular thanks are also due to Dr Louise de Raeve, Dr Stephen Wilkinson and Eve Garrard who, as consultants to the course component which relates to Part 3 of this Reader, thoughtfully selected most of the new contributions for this part. Without the remarkable efficiency of Claire Edwards the course manager and our secretary Val O'Connor, who have had the unenviable task of piecing together newly selected and commissioned articles as well as making sense of those articles that have been updated from the first edition, the task would have been almost impossible. Giles Clark of The Open University Co-publication unit and Karen Phillips of Sage have continued to provide valued support throughout the production of both these editions and I express my gratitude to them both.

I should like to acknowledge academic colleagues from other institutions, practitioners in the field and those who wrote first-person accounts for generously agreeing to write specially commissioned articles for both editions of this book, and particularly to those who agreed to update what they wrote eight years ago. Their commitment to the field and willingness to share their experiences has ensured that this book remains one of the most comprehensive collections of articles on this subject.

Jeanne Samson Katz

LIFE AND DEATH

Introduction

Addressing the eternal questions of life and death presents a daunting prospect. World literature, philosophy, religion and history provide us with an endless source of material which is necessarily inconclusive. Fortunately our task is not to present our readers with a digest of this vast body of work. It is more focused and instrumental. So this first part offers a selection of contributions which contextualize the *contemporary* experience of dying and death. It provides powerful sketches of the awesome struggle humankind has with the reality of mortality, whilst concentrating on the ways in which the past and the present influence the attitudes, rituals and practices which operate in modern societies at the end of life.

David Clark's beautifully observed anthropological account of death in Staithes at the turn of the century provides an evocation to add to the current debate about 'the world we have lost'. Its precise descriptions of the complex religious, metaphysical and folk beliefs about death and the associated rituals, public and private, are not confined to a seaside town in the staunchly traditional north-east of England. It offers a universal picture of the interweaving of fear, hope, respect, celebration, mourning, ceremonial and petty concerns which have surrounded death everywhere and in every age. As an opening piece it stimulates many of the questions and debates which follow in the rest of the book.

From the local and the particular we move to the great canvas of history addressed by Phillipe Ariès in his monumental survey of death. Here we can only offer a taster of a huge scholarly work which has excited much controversy and debate since it was first published in French in 1977. In a characteristically Gallic review Ariès does not hesitate to interpret history or to make judgements. The passage reproduced here propounds the view that modern societies are death-denying societies which are unwilling to face the inescapable facts of death. He argues that this attitude explains the professionalizing of death and its sanitization by the funeral industry.

Tony Walter, Jane Littlewood and Michael Pickering's article picks up several themes from Ariès. In subjecting the question of public invigilation of private emotion to critical scrutiny, they note the powerful position of journalists in constructing the images of bereaved people. One significant change not alluded to in the first articles of this book is the increasing ethnic and religious diversity to be found in the United Kingdom. Shirley Firth addresses an important dimension of this newly acknowledged mix, as she examines the religious, cultural and family patterns of Sikh and Hindu

communities in Britain. Attention is drawn to the distinctive attitudes to health, illness and dying which require reactions from health professionals quite different from those predominant in the host culture. The need of Hindus to die lying on the floor, in the midst of their family, to the accompaniment of ritual chanting is juxtaposed with the clinical atmosphere of typical hospital wards.

The next group of chapters are of a much more practical nature, exploring the demographic reasons for the dramatic changes in the contemporary experience of death and ways in which society provides services for dying people. Clive Seale, in a specially written article, demonstrates how the dramatic rise of life expectancy and the shift from infectious diseases to degenerative diseases during the twentieth century changed experiences of dying. Drawing on official statistics as well as national surveys he demonstrates contrasts in gender in both the experiences of old age and dying. Also in a specially written and updated article Christina Victor provides further demographic data, taking a macro view of mortality rates and the causes of death, placing them in the broad context of social policy and provision. She identifies a range of challenges to health and social care systems, if they are to provide an adequate response to the needs of dying people.

Taking the particular case of sudden death by suicide, Stella Ridley continues the practical approach by mapping the incidence of self-inflicted death and the limited services which relate to it. But she also raises more philosophical questions about the meaning and the taking of life which are treated more fully in Part 3. In a similar vein, Mary Bradbury's questioning of what constitutes a good or a bad death combines anthropological and theological considerations with observations about the medical management of terminal illness. These two updated specially commissioned pieces act as valuable links between the global subjects at the start of this part and much of the rest of the book.

The selection of poetry and prose in this part reflects the ideas, concerns, practices and beliefs uncovered by the preceding articles. The extracts from the mid-Victorian *Child's Own Magazine* portray a middle-class Christian version of death designed to comfort children and likely to incur the wrath of Ariès. John Donne, Philip Larkin and Dylan Thomas, however, have no illusions about death, although they respond to it in characteristically different ways: Donne with a comforting romanticism, Larkin with clinical realism and Thomas with exuberant defiance – such a contrast with Kahlil Gibran's calm spirituality.

Jane Martin's brief but arresting personal story of the experience of someone else's death reminds us of the emotional strength that professional carers need if they are to work well in the midst of dying and grief. At the close of this part we explore the meanings of life and death. Alyson Peberdy's specially rewritten article considers what we mean by spirituality and the need for spiritual care of dying people. She examines some of the philosophical questions that people ask themselves and also ways in which

carers can 'accompany the person going through the journey of dying'. This resonates with the earlier statements by Martin which reflect the same, universal concerns which captured the imagination of the great Russian writer Leo Tolstoy, whom we present twice in this volume. The mixture of philosophical reflection and literary anguish he displays in this first piece is a marked contrast in style and analysis.