

End of Life Choices for Cancer Patients

There have been impressive improvements in the diagnosis and treatment of cancer in recent decades. In economically advantaged countries with well-developed healthcare systems, over 50% of all cancer patients achieve long-term survival and are probably cured. Not only has survival improved radically for cancer patients but also there has been an increasing focus on the quality of patients' lives, on improving the patient experience of care and on developing effective support for the very many cancer survivors.

Despite the progress in cancer treatment, unfortunately a substantial number of cancer patients will still ultimately die of their disease. For many this will follow periods of successful treatment which resulted in good remissions and good quality of life. Helping patients to make the right choices about their care towards the end of their lives is one of the greatest and most challenging responsibilities of all healthcare professionals.

Legal change on the provision of assisted dying by healthcare professionals has occurred in a substantial number of jurisdictions. This work brings together contributions on end of life choices from experienced professionals from oncology disciplines, palliative care, law, nursing and professions allied to medicine. The goals are:

- To better inform members of the Association of Cancer Physicians and the wider community about developments in choices in end of life care for cancer patients internationally.
- To better answer questions from patients and respond to their requests, including questions about and requests for assisted dying in countries where it is legal.
- To have a balanced and well-informed dialogue about choices available to patients, without developing a formal policy position on change in law.
- To provide a basis of information for future educational activities.

CONTENTS: Introduction and summary – An oncology perspective on choices at the end of life for cancer patients – How do permissive regimes regulate assisted dying? – Patients, physicians and law at the end of life in England and Wales – Assisted dying in Canada: lessons from the first 3 years – Provision of palliative care in the UK: how does the research evidence compare with current practice? – A palliative care perspective on choices for end of life care for cancer patients – Conclusions.

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End of Life Choices for Cancer Patients

An International Perspective

RUTH E BOARD, MICHAEL I BENNETT,
PENNEY LEWIS, JOHN WAGSTAFF,
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BOARD ET AL.

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Ruth E. Board, Michael Bennett, Penney Lewis, John Wagstaff, Peter Selby, Editors

Association of Cancer Physicians

The 'Problem Solving' series of cancer-related books are developed and prepared by the Association of Cancer Physicians (ACP), often in partnership with one or more other specialist medical organisations. As the representative body for medical oncologists in the UK, the ACP has a broad set of aims, including education for our own members and for non-members, including interested clinicians, healthcare professionals and the public. The Problem Solving series is a planned sequence of publications that derive from a programme of annual scientific workshops initiated in 2014 with *Problem Solving in Acute Oncology* followed by *Problem Solving in Older Cancer Patients*, *Problem Solving through Precision Oncology*, *Problem Solving in Patient-Centred and Integrated Cancer Care* and *Problem Solving in Immunotherapy*. *Problem Solving in Acute Oncology 2nd Edition* is the latest in this series.

The publication involves considerable work from members and other contributors and this work is done without remuneration as an educational service. We have been delighted with the standard of the publications and they have been well received. The BMA prize for Best Oncology Book of the Year was awarded to *Problem Solving in Older Cancer Patients* in 2016, *Problem Solving in Precision Oncology* in 2017 and *Problem Solving in Patient-Centred and Integrated Cancer Care* in 2018.

The ACP wishes to thank all of the contributors to this book, our previous publications and those which are yet to come.

*David Cunningham, Chairman, Association of Cancer Physicians
Peter Selby, President, Association of Cancer Physicians*

Chapter 1: Introduction and Summary

Ruth E. Board, Michael I. Bennett, Penney Lewis, Peter Selby

There have been impressive improvements in the diagnosis and treatment of cancer in recent decades. In economically advantaged countries with well-developed healthcare systems, over 50% of all cancer patients achieve long-term survival and are probably cured.¹ This much-improved outcome may be compared with a figure of only 25% in the latter half of the 20th century in these countries.¹ Not only has survival improved radically for cancer patients but also there has been an increasing focus on the quality of patients' lives, on improving the patient experience of care and on developing effective support for the very many cancer survivors.¹

Major scientific and technological developments are continuing and the practice of oncology is becoming more precise and with more accurate patient selection for appropriate treatment.² In addition to surgery, radiotherapy and chemotherapy, there are important developing and successful new modalities of treatment, including immunotherapy³ and interventions that can destroy tumours using heat, cold, electricity, radio waves and ultrasound without major surgical procedures. There still remain many challenges to be addressed if we are to continue to improve cancer therapy and its outcome. Not only must we vigorously pursue the scientific and technical advances that are providing improvements but we must also ensure that care for cancer patients is well organized with timely access to the appropriate diagnosis and treatment.¹ We must provide high-quality and timely support for patients who have acute medical problems and complications from cancer.⁴ We must recognize that cancer is most commonly a disease of elderly people and adjust our approaches to make them feasible and acceptable for all patients.⁵

Despite the progress outlined above, a substantial number of cancer patients will still ultimately die of their disease. For many this will follow periods of successful treatment that resulted in good remissions and good quality of life. However, when patients relapse, the disease may become resistant to available treatment. Helping patients to make the right choices about their care towards the end of their lives is one of the greatest and most challenging responsibilities of all healthcare professionals. Choosing treatments to relieve symptoms is often difficult. Decisions on the continuation of specific anticancer treatments to prolong life or relieve symptoms are complex and uncertain and depend greatly on our ability to elicit the patient's needs and preferences. The involvement of partners, family and friends is often important but must be achieved without overshadowing the patient's own views. Oncology and palliative care professionals from many disciplines work together in teams in order to provide the best possible help for their patients.

There is currently an added dimension that we feel needs to be considered. Legal change on the provision of assisted dying by healthcare professionals has occurred in a substantial number of jurisdictions. There is some pressure for change in UK law and some UK patients travel to other jurisdictions to access assisted dying.

The Association of Cancer Physicians' workshop

The workshop of the Association of Cancer Physicians (ACP) 'End of life choices for cancer patients: an international perspective' was held in Leeds in May 2019 and brought together

colleagues from oncology disciplines, palliative care, law, nursing and professions allied to medicine. The goals were to allow an exchange of information through formal presentations and discussion:

- to better inform ACP members and the wider community about developments in choices in end of life care for cancer patients in the UK and internationally;
- to be better able to answer questions from patients and respond to their requests, including questions about and requests for assisted dying in countries outside the UK;
- to have a balanced and well-informed dialogue about choices available to patients in the UK and internationally, without developing a formal ACP position on change in UK law;
- to provide a basis of information for future educational activities.

Definitions

The topic of assisted dying involves a wide range of terms and definitions that are constantly changing. In the ACP workshop and publication we have used the terminologies shown in Box 1.1 below.

Box 1.1 Definitions.

- **Euthanasia:** An intervention undertaken with the intention of ending a life to relieve suffering. In the Dutch and Belgian contexts, the term euthanasia refers only to the termination of life upon request.

Some common (and often confusing) modifiers of euthanasia are:

- **Active:** A deliberate intervention to end life.
- **Passive:** Withdrawal/withholding of life-sustaining treatment.
- **Voluntary:** At the request of the person killed.
- **Involuntary:** In the absence of a request by the person killed, although that person is competent.
- **Non-voluntary:** In the absence of a request by the person killed, when that person is not competent and has not made an advance request for euthanasia.
- **Assisted suicide:** Any act that intentionally helps another person to commit suicide, for example by providing him or her with the means to do so. In the Netherlands, assisted suicide is often included in the term euthanasia. Legal regimes often permit only physician-assisted suicide.
- **Assisted dying:** (Voluntary, active) euthanasia and assisted suicide.
- **Physician-assisted death:** This includes physician-administered voluntary euthanasia and physician-assisted suicide.
- **Medical assistance in dying (MAID):** Used most recently in Canada and includes physician-assisted suicide and clinician-administered voluntary euthanasia.

The legal debate on assisted dying in the UK

As we will discuss in Chapter 4, assisted dying, whether in the form of assisted suicide or voluntary euthanasia, is illegal in the UK in all jurisdictions. However, in any year several dozen people from the UK travel abroad for assistance in suicide or euthanasia. Doubts and uncertainties about the role of family members in helping them do so cause considerable anxiety. However, in February 2010, the Director of Public Prosecutions set out the factors to be considered when deciding whether a prosecution in an assisted suicide case is in the public interest (the policy is discussed in Chapter 4). The policy suggests that it is unlikely to be in the public interest for a loved one who has provided assistance to be prosecuted if the person who travelled to another jurisdiction for assistance with suicide had reached a voluntary, clear, settled and informed decision to do so, and the loved one who had helped them was motivated by compassion.

In the UK there have been attempts to change the law on assisted dying since 1931, when a voluntary euthanasia bill was proposed. The Voluntary Euthanasia Society was formed in 1935. This society is now known as Dignity in Dying. Another attempt at legal reform was made in 1936, and again in the House of Lords in 1969 and 1976. An assisted dying bill was introduced into the Commons in 1997 but was defeated. Lord Joffe introduced bills between 2003 and 2006 without success. Lord Falconer introduced an assisted dying bill into the House of Lords in 2014, proposing that patients with a life expectancy of less than 6 months should have the choice of a medically assisted death, but it did not succeed. In 2015, the MP Rob Marris brought forward a private member's bill proposing assisted suicide, which was substantially based on Lord Falconer's proposals. The bill was defeated in the House of Commons in September 2015. In 2016, Lord Hayward introduced an assisted dying bill in the Lords, but it did not progress.

The law in Scotland is of course different from the law of England and Wales. Most recently, in 2015, a proposal to change the law was defeated in the Scottish Parliament. In February 2019, a group was formed in the Scottish Parliament seeking to attempt to reform assisted dying law in Scotland. There have been no recent efforts to change the law in Northern Ireland.

Among Crown dependencies and overseas territories, the Falkland Islands' representatives voted in July 2018 to allow assisted dying for the terminally ill subject to safeguards, in principle indicating a willingness to change their law if the UK did so. On the other hand, also in 2018, representatives in Guernsey voted against a change in the law to allow access to assisted dying. Currently there is an ongoing debate in Jersey, in response to a petition, and Jersey's health minister has called for laws banning assisted dying to be reviewed.

Among Commonwealth countries, Canada has recently changed its law following a successful constitutional challenge (discussed in Chapter 5). The Australian state of Victoria's Voluntary Assisted Dying Act came into effect on 19 June 2019.⁶ A similar law in Western Australia was passed by the state legislature in December 2019 and is likely to come into force in 2021.⁷ The New Zealand Parliament has recently debated and approved an approach to the provision of assisted dying in New Zealand and is placing its proposed detailed legislation before the citizens of New Zealand in a referendum.⁸ In Chapters 3 and 5 we will describe the approaches to choices at the end of life that have been developed in other countries and in particular focus on the recent experience in Canada over the last 3 years. The international situation remains dynamic.

Against such a complex background we have sought in our workshop and this publication to provide an informative and balanced review of international experience and current UK relevant healthcare practice for healthcare professionals and those considering a change in the law in the UK.

Summary of the workshop and this edited collection

Dr Ruth E. Board gave an oncology and patient-centred overview of the choices faced by cancer patients, which is presented in Chapter 2. She introduced the debate on assisted dying and reported recent survey evidence of the attitudes of UK clinicians to possible changes in legislation. The recent survey evidence from the Royal College of Physicians and the Royal College of Radiologists indicates a change in attitudes among oncologists. The professionals surveyed are, according to these data, broadly neutral in their attitude to a change in legislation governing choices at the end of life. However, importantly, as discussed in more detail by Professor Rob George and Dr Amy Proffitt in Chapter 7, palliative care physicians are broadly against any change in UK law. Professor John Wagstaff described his experience as a medical oncologist working in the Netherlands during the early years of the introduction of lawful assisted dying for patients.

There was a consensus in the workshop that the decisions about changing legislation should be influenced most by social, legal and political opinion and should not be heavily influenced by those of healthcare professionals. The views of healthcare professionals are important, not because they should guide or shape public opinion but because these professionals are closely involved in the provision of good-quality care for patients at the end of life and will continue to be so. Any legislative change will have an impact on the patterns and quality of clinical practice and communication with patients.

Professor Penney Lewis and Dr Isra Black laid out for clinical colleagues the law that governs choices at the end of life in jurisdictions around the world. These are presented in Chapters 3 and 4. How the law was changed in the Netherlands, Belgium, Luxembourg, Switzerland, nine US states, Columbia and, more recently, Canada was described for these jurisdictions, which have in recent decades changed their law to permit, variously, assisted suicide and/or euthanasia. Important definitions were set out (summarized in Box 1.1). Professor Lewis summarized features of permissive assisted dying regimes, their oversight and reporting and the frequency of different end of life decisions. Dr Black described the law as it applies in England and Wales and illustrated how the law applied to current practice in the care of cancer patients covering refusal of life-prolonging treatments, advance decisions, stopping eating and drinking, withholding or withdrawing life-prolonging treatment, euthanasia and assisted suicide.

The most recent experience of a significant change in the choices available to patients at the end of life comes from Canada. This was explained to us by Professor Gary Rodin at the workshop and together with Dr Gilla Shapiro, Dr Joshua Wales and Dr Madeline Li, he summarises his presentation in Chapter 5. The law in Canada changed when the Supreme Court of Canada ruled that the criminal prohibition of assisted suicide was unconstitutional. Professor Rodin described the experience of implementing MAID across Canada in the last 3 years. Broadly, Professor Rodin and his colleagues concluded that the introduction of MAID has been possible, has affected a relatively small proportion of patients, and while creating debate and some tension within healthcare circles has not been associated with any evidence of deterioration in the quality of care in a country with good access to palliative care. Further developments that will address important subgroups, including older children and some vulnerable adults, are under discussion in Canada.

Professor Michael Bennett summarized palliative care services in the UK and what they are achieving for patients. He and Dr Andrew Page present their summary in Chapter 6. Professor Bennett described how palliative care in the UK was among the best in the world and evidence showed its efficacy in many cases. However, the duration of palliative care for cancer patients remained relatively short and there was evidence of inequitable access. Professor Rob George

described the rational basis of palliative care and end of life choices and he and Dr Amy Proffitt present this and the views of palliative care professionals in Chapter 7. They agreed that decisions about change in the law must be seen as a wide social, legal and political development but felt professionals should express their views on how changes could be implemented while ensuring we continued to maintain the best in healthcare services. Their conclusion, importantly, was that if there were to be changes in the law then implementation of assisted suicide or euthanasia should be kept separate from the provision of palliative care for cancer patients and other patients at the end of life.

In Chapter 8, the editors draw out some broad conclusions from the discussions in the workshop and from the contributions of their colleagues.

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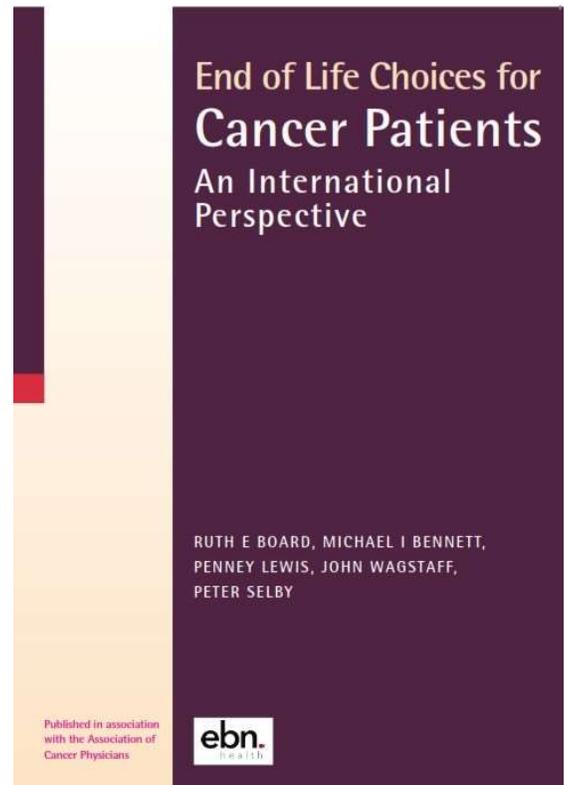
An International Perspective

Edited by Ruth E Board, Michael I Bennett, Penney Lewis, John Wagstaff, Peter Selby

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Legal change on the provision of assisted dying by healthcare professionals has occurred in a substantial number of jurisdictions. This work brings together contributions on end of life choices from experienced professionals from oncology disciplines, palliative care, law, nursing and professions allied to medicine. The goals are:

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