Continuous Sedation at the End of Life

Continuous sedation until death (sometimes referred to as terminal sedation or palliative sedation) is an increasingly common practice in end-of-life care. However, it raises numerous medical, ethical, emotional and legal concerns, such as reducing or removing of consciousness (and thus potentially causing 'subjective death'), the withholding of artificial nutrition and hydration, the proportionality of the sedation to the symptoms, its adequacy in actually relieving symptoms rather than simply giving onlookers the impression that the patient is undergoing a painless 'natural' death, and the perception that it may be functionally equivalent to euthanasia.

This book brings together contributions from clinicians, ethicists, lawyers and social scientists, and discusses guidelines as well as clinical, emotional and legal aspects of the practice. The chapters shine a critical spotlight on areas of concern and on the validity of the justifications given for the practice, including in particular the doctrine of double effect.

SIGRID STERCKX is a professor of ethics at Ghent University and at the Vrije Universiteit Brussel (VUB) in Belgium.

KASPER RAUS is a postdoctoral researcher at Ghent University, Belgium.

FREDDY MORTIER is a professor of ethics at Ghent University, Belgium.

Cambridge Bioethics and Law

This series of books was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law's complex and troubled relationship with medicine across both the developed and the developing world. Since the early 1990s, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and the failures of modern medicine, while international organisations such as the WHO and UNESCO now regularly address issues of medical law.

It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. The series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy debates in the UK, Europe and the international community involve a strong medical law dimension. With that in mind, we seek to address how legal analysis might have a trans-jurisdictional and international relevance. Organ retention, embryonic stem cell research, physician assisted suicide and the allocation of resources to fund health care are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and health care.

Series Editors

Professor Margaret Brazier,
University of Manchester

Professor Graeme Laurie,
University of Edinburgh

Professor Richard Ashcroft,
Queen Mary, University of London

Professor Eric M. Meslin,
Indiana University

A list of books in the series can be found at the end of this volume.

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

Continuous Sedation at the End of Life

Ethical, Clinical and Legal Perspectives

Edited by
Sigrid Sterckx, Kasper Raus and Freddy Mortier

CAMBRIDGE
UNIVERSITY PRESS

© in this web service Cambridge University Press

CAMBRIDGE
UNIVERSITY PRESS

University Printing House, Cambridge CB2 8BS, United Kingdom

Published in the United States of America by Cambridge University Press, New York

Cambridge University Press is part of the University of Cambridge.

It furthers the University's mission by disseminating knowledge in the pursuit of education, learning and research at the highest international levels of excellence.

www.cambridge.org
Information on this title: www.cambridge.org/9781107039216

© Cambridge University Press 2013

This publication is in copyright. Subject to statutory exception and to the provisions of relevant collective licensing agreements, no reproduction of any part may take place without the written permission of Cambridge University Press.

First published 2013

Printed in the United Kingdom by MPG Printgroup Ltd, Cambridge

A catalogue record for this publication is available from the British Library

Library of Congress Cataloguing in Publication data
Continuous sedation at the end of life : ethical, clinical, and legal perspectives / edited by Sigrid Sterckx, Kasper Raus, Freddy Mortier.
pages cm. – (Cambridge bioethics and law)
Includes bibliographical references and index.
ISBN 978-1-107-03921-6 (hardback)
1. Terminal sedation. 2. Terminal care – Law and legislation.
3. Terminally ill – Psychology. I. Sterckx, Sigrid, editor of compilation. II. Raus, Kasper, editor of compilation.
III. Mortier, Freddy, editor of compilation.
R726.C6725 2013
616.02′9–dc23 2013009518

ISBN 978-1-107-03921-6 Hardback

Cambridge University Press has no responsibility for the persistence or accuracy of URLs for external or third-party internet websites referred to in this publication, and does not guarantee that any content on such websites is, or will remain, accurate or appropriate.

Contents

© in this web service Cambridge University Press www.cambridge.org

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

© in this web service Cambridge University Press

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

Figures

© in this web service Cambridge University Press www.cambridge.org

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

Contributors

MARGARET P. BATTIN is a professor of philosophy and medical ethics at the University of Utah, USA. She has authored, co-authored, edited, or co-edited some twenty books, including works on philosophical issues in suicide, case-puzzles in aesthetics, ethical issues in organised religion and various topics in bioethics. She has published two collections of essays on end of life issues, *The Least Worst Death* and *Ending Life*, and has been the lead for two multi-authored projects, *Drugs and Justice* and *The Patient as Victim and Vector: Ethics and Infectious Disease*. In 1997, Professor Battin won the University of Utah's Distinguished Research award, and in 2000, she received the Rosenblatt Prize, the University's most prestigious award. Her current projects include a comprehensive historical sourcebook on ethical issues in suicide, a volume of puzzle cases about issues in disability and a book on large-scale reproductive problems of the globe, including population growth and decline, teen pregnancy, abortion and male roles in contraception.

SOPHIE M. BRUINSMA works as a doctoral researcher at the Department of Public Health of Erasmus Medical Centre, Erasmus University Rotterdam, The Netherlands. She is a sociologist and epidemiologist by training. She is involved in an international study (the UNBIASED study) that explores the perspectives of clinical staff and bereaved informal caregivers on the use of continuous sedation until death for cancer patients. Her Ph.D. research specifically focuses on the experiences of relatives with continuous sedation at the end of life.

THOMAS CARROLL, MD, Ph.D., was educated at: Nazareth College, Rochester, New York (BS in Biochemistry); the University of Connecticut, Farmington, Connecticut (MD/Ph.D. Medical-Scientist Training Program); and the University of Rochester, Rochester, New York (Internal Medicine Internship and Residency, Chief Resident Internal Medicine and Fellow in Hospice and Palliative Medicine).

© in this web service Cambridge University Press

CAMBRIDGE

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

He will be staying on at the University of Rochester as faculty with appointments in the divisions of General Medicine and Palliative Care.

EVELIEN DELBEKE specialises in healthcare law in the broad sense of the word (e.g. medical liability, medical disciplinary rules, professional legal advice, bioethical regulations, patient rights, and the like). From 2006 to 2011, she worked as a doctoral researcher in the field of health law at the Faculty of Law of the University of Antwerp, Belgium. In 2011, she obtained the degree of Doctor of Law with a dissertation on the legal aspects of end-of-life care, in which she examined the legal aspects of the various medical end-of-life decisions (euthanasia, ending of life without request, assisted suicide, alleviation of pain and symptoms with a possible life-shortening effect, continuous deep sedation at the end of life, and the withholding or withdrawing of life-sustaining treatment). She compared Belgian law with the laws of The Netherlands, France, Luxembourg, Switzerland, the USA and the UK. She was awarded the prize André Prims for her work. Dr Delbeke is a frequently invited lecturer on these topics. Since 2012, she has been an attorney-at-law with Monard-D'Hulst, a law firm specialising in health law.

CLAUDIA GONZALEZ was born in Mexico City. She received her medical degree from the Universidad Autonoma de Gaudalaja and completed her Internal Medicine residency at Unity Health System, Rochester, New York. Currently she is doing her Hospice and Palliative Care fellowship at the University of Rochester in Rochester, New York.

TIMOTHY HOLAHAN attended medical school at the Lake Erie College of Osteopathic Medicine in Erie, Pennsylvania and graduated with a Doctor of Osteopathic Medicine degree in 2009. He then completed his residency in Internal Medicine at the University at Buffalo in Buffalo, New York in 2012. Currently he is completing a combined fellowship in palliative care and geriatrics at the University of Rochester in Rochester, New York. During his residency training, he developed a strong interest in the field of palliative care. He was a co-author for a case series with Dr Kerr and Dr Robert Milch that was published in the *Journal of Palliative Medicine* in 2011, entitled 'The use of ketamine in severe cases of refractory pain syndromes in the palliative care setting'. Another case series he has contributed to, together with Dr Kerr and Dr Debra Luczkiewcz, describes the use of pentobarbital in the restoration of sleep-wake cycles in refractory delirium. This study is pending publication. He has also spent

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

six months as Chief Medical Resident in the University at Buffalo Internal Medicine program.

SØREN HOLM is a medical doctor and philosopher who generally holds conservative views in relation to euthanasia, physician-assisted suicide and other forms of assisted dying. He is a professor of bioethics and medical ethics. Professor Holm directs the Centre for Social Ethics and Policy at the University of Manchester, UK, and holds permanent visiting chairs at the University of Oslo, Norway and the University of Aalborg, Denmark. He is the former Editor in Chief of the *Journal of Medical Ethics* and the current Editor in Chief of the journal *Clinical Ethics*.

RUTH HORN is an Ethics and Society Wellcome Trust Fellow at the Ethox Centre, University of Oxford, UK. She was awarded a BA in Sociology from Ludwig-Maximilian University Munich (2002), an MA in Sociology from Paris Diderot University (2003) and a Master of Research (2004) and Ph.D. (2009) from the Ecole des Hautes Etudes en Sciences Sociales, Paris. Her doctoral thesis examined the euthanasia debates and end-of-life practices in France and Germany. After conducting postdoctoral research about advance decision-making and discontinuation of life-sustaining treatments in France (funded by the French National Cancer League) at the Ecole Nationale Supérieure in Paris, Dr Horn completed a postdoctoral research project on advance directives in England and France (funded by the European Commission) at the University of Bristol. Her general research interest lies in exploring ethical questions raised by medical practices at the end of life, particularly regarding the tensions between respect for patient autonomy and physicians' duty to protect life. She is interested in understanding in which contexts (legal, cultural, socio-historical) these questions emerge in the public space, and how they are treated in the debates in specific countries (UK, France, Germany).

RICHARD HUXTABLE is Reader in Medical Ethics & Law and Deputy Director of the Centre for Ethics in Medicine, in the School of Social and Community Medicine at the University of Bristol. Qualified in law and socio-legal studies, his research primarily concerns end-of-life decision-making and surgical ethics, and he has published widely in medical, legal and bioethical journals, as well as engaging with the international media. Richard is the author of *Euthanasia, Ethics and the Law: From Conflict to Compromise* (2007) and *Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat?* (2012). He is also co-author, with Dickenson and Parker, of *The Cambridge Medical*

© in this web service Cambridge University Press

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

Ethics Workbook (2010, Cambridge University Press). He is currently working on *All That Matters: Euthanasia*, which is due to be published in 2013. A long-standing participant in clinical ethics support, Richard is also a trustee of the National Council for Palliative Care, and Chair of its Ethics Forum.

DAVID ALBERT JONES is Director of the Anscombe Bioethics Centre in Oxford. He is also Research Fellow in Bioethics at Blackfriars Hall, Oxford and Visiting Professor in the Centre for Bioethics and Emerging Technologies, St Mary's University College, Twickenham. Professor Jones read Natural Sciences and Philosophy at Cambridge (1984–7), and Theology at Oxford (1992–2000). His book *The Soul of the Embryo* was short-listed for the Michael Ramsey Prize 2007. His doctorate was published in 2007 as *Approaching the End: a theological exploration of death and dying*. Professor Jones also contributed to *The Mental Capacity Act: A practical guide* and *A Practical Guide to The Spiritual Care of the Dying Person*. He is Vice-chair of the Ministry of Defence Research Ethics Committee, examiner for the Diploma in the Philosophy of Medicine run by the Society of Apothecaries, is on the National Reference Group of the Liverpool Care Pathway for the Dying Patient and was on a working party of the General Medical Council which helped draft its 2010 guidance on *Treatment and Care towards the End of Life*. His most recent book, co-edited with Calum MacKellar, is *Chimera's Children: Ethical, Philosophical and Religious Perspectives on Human-Nonhuman Experimentation*.

JOHAN LEGEMAATE is a professor of health law at the Academic Medical Centre at the University of Amsterdam. Over the past twenty years he has been closely involved with legislation and policy concerning medical decisions at the end of life. He has published several national and international papers concerning euthanasia and related topics. Until 2010 he was the Chief Legal Counsel for the Royal Dutch Medical Association. In 2011–12 he was a member of the research team that carried out the evaluation of the Dutch Euthanasia Act.

FREDDY MORTIER is a professor of ethics at Ghent University. He lectures on courses in Bioethics, Philosophy of Religion, and Moral and Faith Education. His current research focuses on the ethics of medical decision-making surrounding the end of life and on the epistemology of religious thought. He has (co-)authored numerous book chapters as well as journal articles. He is also a member of several advisory boards and commissions, including the Belgian Advisory Committee on Bioethics and the Ethics Committee of Ghent University Hospital.

© in this web service Cambridge University Press

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

DAVID ORENTLICHER is a professor of bioethics and law at Indiana University Robert H. McKinney School of Law and Indiana University School of Medicine. A graduate of Harvard Medical School and Harvard Law School, he has authored *Matters of Life and Death* (2001), and he is co-author of *Bioethics and Public Health Law* (3rd edn. 2013). Before coming to Indiana University, he directed the American Medical Association's division of medical ethics and helped draft the Association's policies on end of life decisions. Between 2002 and 2008, he served in the Indiana House of Representatives.

JOSEP PORTA-SALES studied medicine at the University of Barcelona (1975–82). He specialised in Internal Medicine and trained in Palliative Care at St Christopher's Hospice (London). He obtained an MA in Palliative Care from the University of Barcelona (1998) and an MA in Bioethics from the Autonomous University of Barcelona (1999). Since 1987 he has been working as a palliative care consultant in various hospitals. Dr Porta-Sales is currently Head of Research and Teaching at the Palliative Care Service of the Catalan Institute of Oncology, and Senior Lecturer in Palliative Medicine at the International University of Catalonia. He has authored many national and international articles and textbooks. His main areas of interest and research are palliative sedation, opioids in cancer pain and the organisation of palliative care in acute hospitals.

TIMOTHY E. QUILL is a professor of medicine, psychiatry and medical humanities at the University of Rochester School of Medicine and Dentistry. He is also Director of the Palliative Care Program in the Department of Medicine. Dr Quill has published and lectured widely about various aspects of the doctor–patient relationship, with special focus on end-of-life decision-making, including delivering bad news, non-abandonment, discussing palliative care earlier and exploring last-resort options. He is the author of several books on end of life, including *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (2004), *Caring for Patients at the End of Life: Facing an Uncertain Future Together* (2001) and *A Midwife Through the Dying Process: Stories of Healing and Hard Choices at the End of Life* (1996), as well as numerous articles published in major medical journals. Dr Quill was the lead physician plaintiff in the New York State legal case challenging the law prohibiting physician-assisted death that was heard in 1997 by the US Supreme Court (*Vacco* v. *Quill*). Dr Quill received his undergraduate degree from Amherst College (1971), and his MD from the University of Rochester (1976). He completed his Internal Medicine residency in 1979 and a Fellowship

CAMBRIDGE

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

in Medicine/Psychiatry Liaison in 1981, both from the University of Rochester School of Medicine and Dentistry. Dr Quill is a Fellow in the American College of Physicians, an ABMS certified palliative care consultant, and the immediate past-President of the American Academy of Hospice and Palliative Medicine.

KASPER RAUS holds an MA in Philosophy (Ghent University, 2008) and a Ph.D. in Philosophy (Ghent University, 2013). His current research focuses on the ethical issues surrounding end-of-life decisions in general, and continuous sedation at the end of life in particular. He has published various articles on this topic in international journals. Together with researchers from the End-of-Life Care Research Group of the Vrije Universiteit Brussel he is involved in an international qualitative research study on the experiences and attitudes of physicians, nurses and relatives concerning continuous sedation at the end of life. Broader aspects, for example the possible justifications of sedation in end-of-life care, are also being addressed by this study. This research is being conducted by a multidisciplinary team of researchers in Belgium, The Netherlands and the UK.

JUDITH A.C. RIETJENS works as an assistant professor at the Department of Public Health of Erasmus Medical Centre, Erasmus University Rotterdam, The Netherlands, and as a part-time professor at the End-of-Life Care Research Group of Ghent University and Vrije Universiteit Brussel, Belgium. She is a health scientist by training and completed her Ph.D. on end-of-life decision-making in 2006. She is involved in several local, national and international studies concerning end-of-life decision-making. She was awarded a VENI grant (Innovative Research Incentives for Academic Excellence) and an EUR fellowship. She coordinates the UNBIASED study, an empirical and ethical evaluation of the practice of continuous sedation at the end of life in The Netherlands, Belgium and the UK. Her other research interests include different perspectives on end-of-life decision-making (e.g. international comparisons; comparisons of perspectives of patients, relatives and healthcare professionals) and media representations of end-of-life decisions. In 2010 she was a visiting researcher at the Department of Geriatrics of Yale School of Medicine, New Haven, USA. Judith was selected to participate in the Erasmus MC Female Career Development Program. In 2010, she was granted the Young Investigator Award (2nd prize) of the European Association of Palliative Care, and in 2012 the UNESCO/L'Oréal For Women in Science fellowship.

© in this web service Cambridge University Press www.cambridge.org

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

JANE SEYMOUR is head of the Sue Ryder Care Centre for Palliative and End of Life Studies and Director of Research at the School of Nursing, Midwifery and Physiotherapy, the University of Nottingham. The Centre's programme of research has particular focus on older people's needs for palliative and end-of-life care and the improvement of care in resource-poor contexts. It collaborates with a wide range of partners in the UK and internationally and has had graduates from its Ph.D. programme from Jordan, Kenya, India, Thailand and Saudi Arabia, as well as the UK. Jane is a nurse and a social scientist, and has been involved in palliative care research and education since the early 1990s. She has published widely in the palliative care, social science and nursing press. She co-led (with Dr. Katherine Froggatt, Lancaster University) a programme of research related to older people and end-of-life care within one of the UK's two national supportive and palliative care collaboratives: the 'Cancer Experiences Collaborative'. Professor Seymour was the principal investigator in a project examining the use of sedation in end-of-life care in the UK, funded by the Economic and Social Research Council. This study was run in parallel with studies in Belgium and The Netherlands.

SIGRID STERCKX is a professor of ethics at Ghent University and at the Vrije Universiteit Brussel (VUB) in Belgium. She lectures on courses in Theoretical Ethics, Methods in Ethics, Contemporary Continental Ethics, Global Ethics and Environmental Ethics. Her current research focuses on: ethical aspects of medical decisions at the end of life; ethical aspects of biobanking, organ transplantation and patenting of human body material (particularly genes and stem cells); ethical issues regarding human enhancement; patent law (especially in Europe and the USA); and environmental ethics and governance, focusing inter alia on climate change, global and intertemporal justice. Sigrid has (co-)authored numerous book chapters as well as journal articles. She serves on various advisory boards and commissions, including the Belgian Advisory Committee on Bioethics, and works as an ethics consultant for several EU research projects. She is also a member of the Steering Group for the UNBIASED study, an interview study exploring the perspectives of physicians, nurses and bereaved informal caregivers on the use of continuous sedation until death for cancer patients in the UK, The Netherlands and Belgium.

NIGEL P. SYKES is Medical Director and Consultant in Palliative Medicine at St Christopher's Hospice in London, UK, where he has been since 1991. St Christopher's, founded in 1967 by Dame Cicely

CAMBRIDGE

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

Saunders, is often regarded as the birthplace of the hospice movement and the specialty of palliative care. It has both inpatient and community palliative care services, and looks after about 2,000 terminally ill people each year. Dr. Sykes' principal research interests concern gastrointestinal and end-of-life symptom management in palliative care, subjects on which he has written extensively. He is a past winner of the Evans Prize for Research in Palliative Medicine. He also teaches widely both in the UK and abroad. Previously a member of the Executive and Ethics committees of the Association of Palliative Medicine of Great Britain and Ireland, Dr. Sykes is currently a member of the Neurological Diseases Strategy Group of the UK National Council for Palliative Care. He set up the first clinical ethics committee to be located in a hospice and has spoken on television and radio, and made presentations to British parliamentary committees, on ethical issues relating to palliative care.

JOHANNES J.M. VAN DELDEN is a professor of medical ethics at the Julius Centre for Health Sciences of the medical school of Utrecht University, The Netherlands. Ever since he worked as a house officer on an intensive care ward, he has been highly interested in medical ethics. He wrote his doctoral thesis on the medical and ethical aspects of 'do not resuscitate' orders. He served as one of the principal researchers for the study of medical decisions concerning the end of life for the Remmelink committee in The Netherlands. Following his education as a nursing home physician, he has worked in several nursing homes for 15 years (until May 2011). His particular areas of interest are: research ethics, ethical problems concerning the end of life and ethical problems in the care of the elderly.

AGNES VAN DER HEIDE, MD, Ph.D., is a professor of medical care and decision-making in the last stage of life, at the Department of Public Health of Erasmus Medical Centre, Erasmus University Rotterdam, The Netherlands. She has coordinated many collaborative research projects on a national and international scale. Her research focuses on epidemiological, clinical and ethical aspects of euthanasia and other end-of-life decisions. She has conducted quantitative and qualitative studies on continuous sedation in the last phase of life. Her research group was the first to demonstrate that the Liverpool Care Pathway for the Dying Patient improves the quality of care in the last days of life.

ELEANOR WILSON is a research fellow with a background in social science and an MSc in Medical Social Anthropology. She is an

© in this web service Cambridge University Press www.cambridge.org

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

experienced qualitative researcher working in the Division of Nursing at the Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care of the University of Nottingham since 2000. In that time she has worked on a range of projects focusing on palliative and end-of-life care by investigating patient and family experiences of illness, staff roles and service evaluations. Eleanor is the lead researcher at the Nottingham site for work funded by Marie Curie Cancer Care on 'Nurses' roles in the use of anticipatory prescriptions'. This study is ongoing and is due to be completed by September 2013. Another element of Eleanor's work particularly focuses on the provision of care for those affected by neurological conditions. Her work can be found in several journals and as a chapter in *Palliative Care in Neurological Disease: A Team Approach* (2009) by Byrne et al. This is linked to her doctoral study exploring the needs of those affected by Huntington's disease and the healthcare staff who provide their care.

© in this web service Cambridge University Press

Acknowledgements

First and foremost, the editors would like to express their heartfelt gratitude to Julian Cockbain, who has not only done a superb job regarding the language editing of the entire manuscript, but has also spent enormous amounts of time double checking and completing literature references, compiling a single reference list for all the chapters, sharing comments and ideas on many of the topics discussed in the book, and lots of other little and big things. Julian, this book owes so much to you that we cannot possibly thank you enough!

Obviously, we also want to thank all the contributors to this volume for writing their insightful chapters, for the positive and constructive attitude they have shown throughout the editorial process, and for never complaining about the tight deadlines that we sometimes imposed on them. Being able to bring together so many fascinating analyses and ideas from so many reputable experts on the topic, from so many different disciplinary and geographical backgrounds, has been a truly exciting intellectual adventure for us.

Sigrid Sterckx would like to thank her parents Marie-Louise and Wilfried, as well as her twin brother Wouter and his partner Fabienne, for their continuous encouragement and moral support.

Kasper Raus is grateful to his family, especially to his wife Leonie Krekels, for providing loving support and understanding for all the days and nights he spent working on this volume. He also owes a great debt of gratitude to his daughter, Martha. Though she may not yet realise it, she has helped him greatly by providing a smile whenever he needed one.

Freddy Mortier especially wishes to thank his wife Annemie Schotanus for enduring his seemingly endless periods of absence and nevertheless continuing to surround him with TLC.

The editors would also like to express their gratitude to Finola O'Sullivan, Juliet Binns and Richard Woodham from Cambridge

© in this web service Cambridge University Press www.cambridge.org

Cambridge University Press
978-1-107-03921-6 - Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives
Edited by Sigrid Sterckx, Kasper Raus and Freddy Mortier
Frontmatter
More information

University Press, for their skilful assistance, advice and encouragement throughout the journey that led to this manuscript. We are also very grateful to the anonymous referees who provided helpful comments on the initial book proposal.

© in this web service Cambridge University Press