

# The Private Worlds of Dying Children

Myra Bluebond-Langner

# The Private Worlds Of Dying Children

**Jacqueline Mok, Marie-Louise Newell**



## **The Private Worlds Of Dying Children:**

*The Private Worlds of Dying Children* Myra Bluebond-Langner, 1978 The death of a child writes Myra Bluebond Langner poignantly underlines the impact of social and cultural factors on the way that we die and the way that we permit others to die In a moving drama constructed from her observations of leukemic children aged three to nine in a hospital ward she shows how the children come to know they are dying how and why they attempt to conceal this knowledge from their parents and the medical staff and how these adults in turn try to conceal from the children their awareness of the child's impending death

**The Private Worlds of Dying Children** Myra Bluebond-Langner, 2020-05-05 Winner of the Margaret Mead Award A classic moving study of terminally ill children that emphasizes their agency and shows how we can relate to dying children more honestly The death of a child writes Myra Bluebond Langner poignantly underlines the impact of social and cultural factors on the way that we die and the way that we permit others to die In a moving drama constructed from her observations of leukemic children aged three to nine in a hospital ward she shows how the children come to know they are dying how and why they attempt to conceal this knowledge from their parents and the medical staff and how these adults in turn try to conceal from the children their awareness of the child's impending death In contrast to many parents doctors nurses and social scientists who regard the children as passive recipients of adult actions Bluebond Langner emphasizes the children's role in initiating and maintaining the social order Her sensitive and stirring portrait shows the children to be willful purposeful individuals capable of creating their own worlds The result suggests better ways of relating to dying children and enriches our understanding of the ritual behavior surrounding death

**In the Shadow of Illness** Myra Bluebond-Langner, 2020-06-30 A revealing account of how families adapt to living with a chronically ill child What is it like to live with a child who has a chronic life threatening disease What impact does the illness have on well siblings in the family Myra Bluebond Langner suggests that understanding the impact of the illness lies not in identifying deficiencies in the lives of those affected but in appreciating how family members carry on with their lives in the face of the disease's intrusion The Private Worlds of Dying Children Bluebond Langner's previous book now considered a classic in the field explored the world of terminally ill children In her new book she turns her attention to the lives of those who live in the shadow of chronic illness the parents and well siblings of children who have cystic fibrosis Through a series of narrative portraits she draws us into the daily lives of nine families of children at different points in the natural history of the illness from diagnosis through the terminal phase In these portraits as family members talk about their experiences in their own words we see how parents well siblings and the ill children themselves struggle in different ways to contain the intrusion of the disease into their lives Bluebond Langner looks at how parents adjust their priorities and their idea of what constitutes a normal life how they try to balance the needs of other family members while caring for the ill child and how they see the future This context helps us understand how well siblings view the illness and how they relate to their ill sibling and parents Since the issues raised are

not unique to cystic fibrosis but are common to other chronic and life threatening illnesses this book will be of interest to all who study care for or live with the seriously ill      *Drawings from a Dying Child (RLE: Jung)* Judith Bertoia, 2014-07-11 Does a dying child understand death How can we help children who are dying Originally published in 1993 this book concerns a young girl Rachel terminally ill with leukaemia The book describes a series of drawings she made and shows how they reveal her inner experience how she became fully aware that she was dying and even came to accept death The result is a moving and informative story that will be invaluable to caregivers and families with a dying child It provides new understanding of the experience of a dying child and suggests practical strategies for coping      *Healing the World's Children* Cynthia Comacchio, Janet Golden, George Weisz, 2008-06-26 Essays range from historical overviews and historiographic surveys of children's health in various regions of the world to disability and affliction narratives from polio in North America to AIDS orphans in post Apartheid South Africa to interpretations of artistic renderings of sick children that tell us much about medicine family and society at specific times in history      *Children's Palliative Care in Africa* Justin Amery, 2009 Children's palliative care has developed rapidly as a discipline as health care professionals recognise that the principles of adult palliative care may not always be applicable to children at the end of life The unique needs of dying children are particularly evident across Africa where the scale of the problem is overwhelming and the figures so enormous that they are barely comprehensible over 400 000 children in Africa died from AIDS in 2003 and out of the 166 000 children a year diagnosed with cancer 84% of these are in the developing world Despite the enormous need provision of children's palliative care in Africa is almost non-existent with very few health workers trained and confident to provide care for dying children The challenges of providing palliative care in this setting are different to those in more developed countries contending with the shortage of physical and human resources in addition to the vast scope of the care needed Written by a group with wide experience of caring for dying children in Africa this book provides practical realistic guidance on improving access to and delivery of palliative care in this demanding setting It looks at the themes common to palliative care including communication assessment symptom management psychosocial issues ethical dilemmas end of life care and tips for the professional on compassion and conservation of energy but always retains the focus on the particular needs of the health care professional in Africa Whilst containing some theory the emphasis is on practical action throughout It will provide health care professionals working in Africa and other resource poor settings with the confidence knowledge and capacity to improve care for the terminally ill child in constrained and demanding environments      **Children, Theology, and Bioethics** Jessica Bratt Carle, 2024-12-15 Children remain at the periphery when bioethics envisions autonomous adults as normative human beings Children Theology and Bioethics Beyond Autonomy explores the full humanity of children inviting greater recognition of their place in the moral landscape of healthcare Theological insights into vulnerability dependence and agency summon appreciation for the experiences of pediatric patients and reveal what it means to be human at every age Interdisciplinary

dialogue between bioethics childhood studies and pastoral theology is woven throughout with illustrative clinical vignettes from Bratt Carle's experience as a pediatric chaplain and clinical ethicist      Befriending the North Wind Robyn Boeré, 2023

*Befriending the North Wind* is about the moral lives of children and their agency in decisions about death. It examines the dimensions of human meaning children reveal and the new horizons they open to us. It asserts that children can die a good death and that they can and should have a voice in their end of life care      *The Human Rights of Children* Michael Freeman, 2022-03-16

For decades Professor Michael Freeman has without doubt been one of the world's most influential scholars in international children's rights. His scholarship has been at the forefront of the field and has helped shape many of the developments within it. This collection offers the reader a thought provoking snapshot of some of his most seminal essays written and/or published over the past 30 years. Together they highlight above all the interdisciplinary nature of the issues he discusses. Legal doctrinal questions that make the case for recognising that children have rights are of course discussed. But aspects of moral and political philosophy are dealt with as well in addition to among other disciplines history theology psychology and anthropology      Supporting Children with Post Traumatic Stress Disorder David Kinchin, Erica Brown, 2012-10-12

It is estimated that at any one time around 135 000 school children are suffering from post traumatic stress disorder PTSD. They may be survivors of abuse physical emotional or sexual or bullying. Some may have been involved in a road accident an accident at home or any other traumatic event. This book provides teachers support staff and other educational professionals with the information they need to really understand the implications of PTSD and to support and educate a traumatized child. It addresses questions such as what can cause PTSD in young people and understand how PTSD might affect the education of children at school      *On the Death of a Child* Christine Hindmarch, 2018-05-08

The death of a child whether during or following birth through illness through accident or through suicide is one of the greatest challenges families carers friends and the health and social care professionals who support them can face. This book provides professionals with practical advice resources for further support and reading and much needed reassurance that whatever contact they have with the bereaved and however inadequate they may feel to the task they can make a difference. With revised material and an entirely new chapter reflecting recent developments in bereavement theory the third edition of this classic text offers unique insights for professionals with varying levels of experience. From theory and narrative come practical ideas on what to say what to do how to behave how to stay humble in situations where the only real experts are the bereaved themselves and how professionals can look after themselves in what can be particularly traumatic and upsetting circumstances      **HIV Infection in Children** Jacqueline Mok, Marie-Louise Newell, 1995-06-15

As HIV infection in childhood increases concomitant with the spread in adult infection so too is there rapid expansion in our knowledge of the complexities of paediatric infection. Clearly general paediatricians and other members of the multidisciplinary team of carers will increasingly be seeking guidance on management strategies to address a wide range of complex clinical problems. This

very practical and concise volume discusses the epidemiology diagnosis natural history and care of the HIV infected child As the book draws upon an international team of contributors the considerable differences between European treatment strategies and those of North America can be contrasted and evaluated This guide will be of particular interest to paediatricians whether in a hospital specialist unit or community based setting General practitioners obstetricians nurses counsellors and epidemiologists should also benefit from this book *Current Legal Problems 2010* George Letsas, Colm O'Conneide, 2011-01-30 This year's volume covers topics such as military detention English criminal law terrorism democracy human rights civil liberties the media and international law family law child welfare health feminism economic theory corporate law competition regulation contract law biotechnology biodiversity and more *In the Shadow of Illness* Myra Bluebond-Langner, 2000-06-19 A revealing account of how families adapt to living with a chronically ill child What is it like to live with a child who has a chronic life threatening disease What impact does the illness have on well siblings in the family Myra Bluebond Langner suggests that understanding the impact of the illness lies not in identifying deficiencies in the lives of those affected but in appreciating how family members carry on with their lives in the face of the disease's intrusion The Private Worlds of Dying Children Bluebond Langner's previous book now considered a classic in the field explored the world of terminally ill children In her new book she turns her attention to the lives of those who live in the shadow of chronic illness the parents and well siblings of children who have cystic fibrosis Through a series of narrative portraits she draws us into the daily lives of nine families of children at different points in the natural history of the illness from diagnosis through the terminal phase In these portraits as family members talk about their experiences in their own words we see how parents well siblings and the ill children themselves struggle in different ways to contain the intrusion of the disease into their lives Bluebond Langner looks at how parents adjust their priorities and their idea of what constitutes a normal life how they try to balance the needs of other family members while caring for the ill child and how they see the future This context helps us understand how well siblings view the illness and how they relate to their ill sibling and parents Since the issues raised are not unique to cystic fibrosis but are common to other chronic and life threatening illnesses this book will be of interest to all who study care for or live with the seriously ill *Understanding Child and Adolescent Grief* Carrie Arnold, 2017-10-12 *Understanding Child and Adolescent Grief* incorporates theory clinical applications case studies and current research on contemporary models of grief pertaining to children and adolescents The integration of developmental perspectives attachment theory and neurobiological implications provides a thorough summary of the many factors that can affect a child's growth and development and the subsequent influence on grief expression Chapters explore relevant social topics rarely addressed in other texts such as the death of African American men suicide among Aboriginal youth in Canada death suicide among LGBTQ youth and social media's influence Also included are practical tips for helping professionals who want to better understand how grief and loss affect children and teens as well as a meditation guide that provides concrete

opportunities for growth and healing      Maternal-Child Nursing Emily Slone McKinney, MSN, RN, C, Susan R. James, PhD, MSN, RN, Sharon Smith Murray, MSN, RN, C, Kristine Nelson, RN, MN, Jean Ashwill, MSN, RN, 2012-09-24 Ideal for accelerated maternity and pediatrics courses Maternal Child Nursing 4th Edition is filled with user friendly features to help you quickly master essential concepts and skills It offers completely updated content that is easy to read and understand Plus active learning tools give you the chance to practice applying your knowledge and make learning fun Critical Thinking Exercises allow you to apply your knowledge to realistic clinical situations Nursing care plans assist you with applying the nursing process to plan individualized care for the most common maternity and pediatric conditions Critical to Remember boxes summarize and highlight essential need to know information Communication Cues provide practical tips for effective verbal and nonverbal communication with patients and families Clinical Reference sections in pediatric chapters present information relevant to each body system including anatomy and physiology differences in the pediatric patient and related laboratory and diagnostic tests Integrated electronic features match icons in the text so you can use print and electronic resources more effectively together Using Research to Improve Practice boxes help you determine proper care to reinforce best practice Spanish translations are included for phrases commonly encountered with maternity and pediatric patients Improved design makes the text easier to read and up to date photos ensure accuracy      Hospice Care for Children Ann Armstrong-Dailey, Sarah F. Zarbock, 2001 Children with life threatening and terminal illnesses and their families require a unique kind of care to meet a wide variety of needs This book the first edition of which won the 1993 Pediatric Nursing Book of the Year Award provides an authoritative source for the many people involved in caring for dying children It draws together contributions from leading authorities in a comprehensive fully up to date resource with an emphasis on practical topics that can be put to immediate use The book covers the entire range of issues related to the hospice environment and is intended for all those who participate in the hospice care process physicians nurses social workers teachers clergy family therapists parents and community service volunteers      Bioethics in Action Françoise Baylis, Alice Dreger, 2018-05-17 Speaking from and to the growing movement among academics to become involved with socially engaged work this volume presents first person case studies of attempts to fix serious ethical problems in medical practice and research It highlights the critical difference between the pundit approach to bioethics and the interventional approach the talkers and the doers and points to how abused and damaged the doers often end up Chapters cover a diverse set of topics including the troubling influence of for profit businesses on public health policy the politics of exposing histories of unjust medical research the challenges of patient rights work in sexuality and reproduction collaborations between NGOs and academics methods for changing entrenched yet harmful medical practices engaging public policy through educating governmental leaders and whistleblowing The trending interest in the interplay of academia and advocacy and the growing importance of socially engaged work by academics make this a timely and much needed resource      *Oxford Textbook of Palliative Care for*

*Children* Richard Hain, Ann Goldman, Adam Rapoport, Michelle Meiring, 2021 Comprehensive in scope exhaustive in detail and definitive in authority this third edition has been thoroughly updated to cover new practices current epidemiological data and the evolving models that support the delivery of palliative medicine to children This book is an essential resource for anyone who works with children worldwide

**Law and Childhood Studies** Michael D. A. Freeman, 2012-03-08 Offering an insight into the evolving state of law and childhood studies in the modern age the latest volume in the Current Legal Issues series brings together an international and interdisciplinary cast to address the key issues informing current debates



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