Introduction
Monika Renz, Mark Kyburz, and John Peck
in Dying: A Transition
Publisher: Columbia University Press
doi: 10.7312/columbia/9780231170888.003.0001
Despite the elusive nature of the final mystery, understanding what happens spiritually and psychically near death improves therapeutic-spiritual end-of-life care. The methods used in the underlying study “Dying is a Transition” (N=80, N=600) (Renz et.al. 2013b), is introduced: participant observation, Interpretative Phenomenological Analysis (IPA), and limitations.

Speaking for the Dying
Susan P. Shapiro
Publisher: University of Chicago Press
doi: 10.7208/chicago/9780226615882.001.0001
Seventy percent of Americans age 60 or over requiring decisions about medical treatment in the final days of life lack capacity to make these decisions. The biggest life-and-death decisions of their lives—literally—had to be made by someone else. Yet despite their critical role, we know remarkably little about these surrogate decision makers, the process they follow, the criteria they consider, the choices they make, and the challenges they face. Drawing on observations of two diverse intensive care units, day after day, for more than two years, this book exposes how and why surrogates navigate this grueling role and the impact of the course they fashion. Readers will learn how decision makers are selected, the interventions they weigh in on, the information they seek and evaluate, the values and memories they draw on, the criteria they weigh, the outcomes they choose, the conflicts they become embroiled in, and the challenges they face. Observations also provide insight into why some decision makers authorize one aggressive intervention
after the next while others do not—even on behalf of patients with similar problems and prospects. And they expose the limited role of advance directives in structuring the process decision makers follow or the outcomes that result. These findings provide important lessons to future patients, their loved ones and surrogates; those who serve, counsel, or care for those as they near life’s end and their families (physicians, nurses, chaplains, social workers, and lawyers); and scholars, bioethicists, and health policy makers as well.

Return migration in later life
John Percival
Published in print: 2013 Published Online: January 2014
DOI: 10.1332/policypress/9781447301226.001.0001
Item type: book

The main objective of this edited volume is to explore the motivations, decision making processes, and consequences, when older people consider or accomplish return migration to their place of origin; and also to raise the public policy profile of this increasingly important subject. The book examines in detail a range of themes affecting return migrations, including: family ties, obligations and their emotive strengths; comparative quality, and cost, of health and welfare provision in host and home countries; older age transitions and cultural affinity with homeland; and psychological adjustment, belonging and attachment to place. The wide ranging collection covers refugee, political, heritage, life-style, or family-oriented return. There is varying emphasis on permanent return, non-permanent returns, and visits to place of origin, which reflects variety in strategic approaches to return migrations and mobilities in later life. The book is unique in bringing this breadth and depth of exploration to bear on older people's return movements, providing a focused synthesis that allows a neglected subject to receive due attention in an era of ageing and more mobile societies. Chapters reflect a variety of quantitative, qualitative and ethnographic methods of enquiry, by researchers from different disciplines, including social gerontology, anthropology, migration and human geography perspectives. The book will be of use and interest to public service providers, government departments, agencies working with and for older people, policy developers, research bodies, and commercial organizations with interest and experience in travel and tourism.
Using an intersectional lifecourse approach to understand the migration of the highly skilled

Melissa Kelly

in Researching the lifecourse: Critical reflections from the social sciences

Published in print: 2015 Published Online: January 2016
Item type: chapter

This chapter combines an intersectional approach with a lifecourse perspective in order to understand the migration of the highly skilled. An intersectional lifecourse approach contextualizes migration processes, considers the role of both structure and agency, and the macro and micro factors underlying peoples’ moves. These theoretical ambitions are best furthered, the chapter argues, in conjunction with a methodology that draws on multiple types of data sources. In order to illustrate how such a project might be carried out, the chapter draws on a study conducted with people of Iranian origin who first moved to Sweden, and then moved again to London or Toronto. Findings suggest that for these highly mobile people, deciding to make multiple migrations was based on a variety of factors. While employment opportunities were an important aspect of the decision making process so too, were a number of non-economic factors. Overall, the chapter critically identifies, evaluates and aims to address some of the challenges that often arise in migration research.

Financial elder abuse

Mary Gilhooly, Deborah Kinnear, Miranda Davies, Kenneth Gilhooly, and Priscilla Harries

in The New Dynamics of Ageing Volume 2

Published in print: 2018 Published Online: January 2019
Item type: chapter

This chapter examines the possibilities of the ‘bystander intervention model’ to explore the decision making of health and social care professionals when detecting and attempting to prevent financial elder abuse. It is often suggested that the cases that come to the attention of professionals represent the ‘tip of the iceberg’. If this is the case, argue M Gilhooly, Cairns, Davies, K Gilhooly and Harries, at various points in the decision making process professionals must be deciding not to intervene. Although this UK study goes some way to explaining why professionals
find it difficult to detect financial elder abuse, or fail to act when they suspect such abuse, the study also revealed that many professionals do play safe and act even when in doubt. The finding that ‘mental capacity’ was a key determinant of both certainty that abuse was taking place, and likelihood of intervention, is concerning. Prevention requires that such abuse is detected well before an older person loses mental capacity.

**Legal capacity for people with dementia: a human rights approach**

Eilionóir Flynn

in *Dementia and Human Rights*

Published in print: 2018 Published Online: September 2018


This chapter explores the right to legal capacity for people with dementia. The analysis focuses on General Comment 1 of the UN Committee on the rights of persons with disabilities. The chapter also provides some examples of law reform around the world on the issue of legal capacity and considers how these reforms may impact on people with dementia. Finally the chapter considers how the right to legal capacity may be framed in any new UN Convention on the rights of older persons. The chapter argues that legal capacity is a critical human rights issue in the context of dementia and that Article 12 (CRPD) and the general comment 1 provide a strong base for respecting the autonomy and self determination of people with dementia.

**Decision-Making with Planning**

Amy Ziettlow and Naomi Cahn

in *Homeward Bound: Modern Families, Elder Care, and Loss*

Published in print: 2017 Published Online: April 2017


Chapter 4 explores how family members assumed responsibilities as the primary decision-maker when the parent engaged in formal planning in advance. The primary decision-maker acts as a complement to, and may be the same person as, the primary caregiver, but not always. It catalogs the different advance planning resources available, and highlights the ones used by study participants. Specifically, it looks at the roles played by Do Not Resuscitate (DNR) orders and powers of attorney.
in offering guidance to a grown child and in resolving conflicts within different family structures. Few study participants, however, reported that a parent had engaged in such advance planning. As this chapter shows, even when the parents’ efforts provided guidance, they did not necessarily prevent all conflicts.

Decision-Making without Planning
Amy Ziettlow and Naomi Cahn

in Homeward Bound: Modern Families, Elder Care, and Loss
Published in print: 2017 Published Online: April 2017
Publisher: Oxford University Press
DOI: 10.1093/acprof:oso/9780190261092.003.0006
Item type: chapter

Chapter 5 explores the surrogate decision-making experience in the absence of advance directives. It explains the legal and pragmatic default rules for appointing a decision-maker and the guiding principles for that decision-maker, such as substitutive judgment or best interests. Finally, it explores how decisions were actually made, and what role family structure played to complicate or simplify the experience, especially in the decision to “pull the plug.”

Improvising Plans for the Future
Phyllis Moen

in Encore Adulthood: Boomers on the Edge of Risk, Renewal, and Purpose
Published in print: 2016 Published Online: May 2016
Publisher: Oxford University Press
DOI: 10.1093/acprof:oso/9780199357277.003.0004
Item type: chapter

This chapter is about Boomers’ decisions in the unsettled period of encore adulthood. A confluence of forces is opening a window of risk but also of potential prime time, a new life stage coming after career- and family-building and prior to old age. Boomers are having to make their own plans and develop their own expectations. The chapter describes decision-making under uncertainty and the elusiveness of choice for some, as well as offering an institutional framing of the ways plans and structures reproduce the gendered life course. Decisions are constrained or opened up by historical, cultural, and organizational environments. When laid off, insecure, burnt-out, well-heeled, or enterprising Boomers seek what’s next in the face of ageism and essentially two institutionalized choices, full-time work or full-time retirement, the encore adult years become an improvisational work in
progress. Concluding sections address whether couples plan together, along with singles’ plans and possibilities.

Actors
Susan P. Shapiro

This chapter introduces health care providers in the ICU, patients, and especially their significant others. It depicts the misfortunes that brought patients to the ICU, their impact on patients’ decision-making capacity, and how capacity determinations are made. The chapter traces the worlds from which patients traveled and their very diverse backgrounds (age, race/ethnicity, marital status, religion, health insurance, affluence of residence). It shows the arrangements patients made in advance to plan for medical decision making on their behalf—including preparation of advance directives—and what happens when, as is usually the case, they made no preparations. The chapter introduces the friends and family who visit, interact with health care providers, and maintain the occasional vigil at the bedside. It describes their characteristics, the complex tangled family trees from which some travel, family dynamics, and the sometimes challenging or contentious struggles to determine who gets to speak on behalf of the patient. The chapter examines the relationship of surrogate decision makers to the patient and how the former come to understand their role and responsibilities. Finally, ICU health care professionals’ characteristics and bedside manner are described.

Decision-Making Scripts
Susan P. Shapiro

This chapter considers the role of law in the ICU and presents the legal and bioethical scripts for surrogate decision making. It describes legal provisions for advance directives that specify the patient’s wishes and/or decision maker and the criteria for the selection of a default
surrogate when no decision maker was appointed. The chapter reviews the bioethical standards which surrogates should follow when deciding for another—beginning with the patient’s explicit instructions and, when they are unknown, substituted judgments of the patient’s wishes, followed by the patient’s best interests—as well as the evidentiary rules to guide surrogate judgments. Surrogates encounter many difficulties following these scripts in the real world, even as so many families and health care providers don’t even know that they exist. One of those difficulties results from the impossibility of truly knowing another’s wishes, another from conflicts of interest at the bedside which are inevitable when loved ones, with the most to gain or lose, are entrusted with life-and-death decisions. Yet another reflects the heuristic and cognitive biases that compromise the judgments of physicians and decision makers alike. The chapter concludes by reviewing the challenges of implementing law at the bedside.