

Contents

<i>Preface</i>	<i>page xi</i>
<i>Acknowledgments</i>	<i>xvi</i>
1 The Conundrum: How Much Medical Care Is ‘Enough’?	1
Life Expectancy, Health Status and Health Care Spending	3
Quality and Utilization of Medical Care at the End of Life	7
What is the Goal and How Might We Get There?	15
2 The US Health Care ‘System’: The Good, the Bad, and the Probably Unfixable	17
Health Insurance and Payment – the US ‘System’	18
Sources of Health Insurance Coverage	20
Health Care Payment, Incentives for Overutilization, and Quality of Care	21
Health Care Access and Payment – the Canadian System	24
Health Care Access and Payment – the National Health Service in the United Kingdom	26
Health Care as a Right	28
Informed Consent and End-of-Life Law in the United States	31
Informed Consent and End-of-Life Law in Canada	33
Informed Consent and End-of-Life Law in the United Kingdom	34
Assessing the Possibility of Future Reform	35
3 Autonomy and Informed Consent in the Real World	37
Pathways to Death and Decisional Opportunities	38
Autonomy and Beneficence: Two Fine Words in Search of Meaning	41
Autonomy in the Real World	45
Informed Consent Law and Practice – Papering Over Poor Communication	51
The Reality of Physician-Patient Communication	57

	Yet Another Challenge: Statistics and Innumeracy	65
	The Allure of Hope	68
	The Impact of Race and Racism	69
	‘Doing Everything’ Versus Trying for ‘Just Right’	72
4	The Denial of Death and Its Sequelae	74
	Cultural Indicia of the Fear of Death	78
	The Impact of Death Denial on Life	82
	To Be a Rock and Not to Roll	86
5	Disorders of Consciousness and the Meaning of Life	87
	The Permanent Vegetative State	90
	Theresa Schiavo	92
	Anthony Bland	94
	Hassan Rasouli	96
	Some Comparisons and Observations	98
	Can We Agree to Disagree?	104
6	More Barriers to Good Communication	107
	Communication Avoidance and Its Causes	108
	Physician Professional Culture – the ‘Do Everything’ Mentality	113
	By the Way, a Word About How Physicians Die	116
	Financial Incentives and the Business of Medicine	118
	Liability Fears	123
	Patients Only Die Once	129
7	Palliative and Hospice Care: Misunderstandings and Lost Opportunities	131
	Rates of Utilization	134
	The Benefits of Palliative and Hospice Care	137
	Structural Barriers to Access and Utilization of Palliative Care and Hospice	139
	Once again, Honest Communication Really Matters	142
	A ‘Better’ Death in Britain?	148
	Palliative and Hospice Care are Medical Care	150
8	Rational Apathy and the Role of Uncertainty	153
	Knightian Uncertainty, Clinical Uncertainty, and Cognitive Biases	154
	Rational Patient Apathy	162
	Activist and Passivist Patients and Physicians	165
	Portrait of an Activist	174
	So, What Now?	176

<i>Contents</i>		<i>ix</i>
9	The Crucible: Making Decisions for Incapacitated Patients	178
	The Basics of Surrogate Decision-Making Law and Ethics	180
	Why Surrogate Decision-Making is so Difficult	183
	The Limitations of Advance Directives	187
	The Extra Layers of Clinical and Ethical Uncertainty	193
	Race and Surrogate Decision-Making	198
	With Caring Comes Courage	198
10	Resolving Conflicts at the End of Life	200
	The United States: Hospital Ethics Committees and Judicial Resolution	201
	Canada: Ontario’s Consent and Capacity Board	204
	England and Wales: The Mental Capacity Act	210
	Patient Preferences, With a Dose of Best Interests	213
11	At the End of the Day	215
	The Feasibility of System-Wide Changes	216
	Culture Matters	218
	The Communication Conundrum	219
	Some Promising Developments	228
	Forcing Physicians to have “The Talk”	234
	An Opportunity for Physicians	235
	It’s All Up to Us	238
12	Coda	240
	<i>Index</i>	246