

# Contents

<b>1</b>	<b>The Contemporary Challenges of Caregiving.....</b>	<b>1</b>
1.1	Introduction.....	1
1.1.1	Trends Shaping Future Caregiving.....	1
1.1.2	Caregiving Defined.....	5
1.1.3	Changing Families and Changing Caregiving Needs.....	6
1.1.4	Formal Caregiving.....	7
1.1.5	Informal Caregiving.....	7
1.1.6	Role Theory and Caregiving.....	8
1.1.7	Life Span Development and Intergenerational Caregiving.....	9
1.2	New and Continuing Challenges.....	11
1.3	Summary.....	11
1.4	Questions for Discussion.....	12
	References.....	12
<b>2</b>	<b>Social Change and Caregiving.....</b>	<b>15</b>
2.1	Introduction.....	15
2.2	Trends in Caregiving.....	15
2.3	An Aging Society and Caregiving.....	17
2.3.1	The Effects of Gender, Rights and Equality Issues on Caregiving.....	19
2.3.2	The Household Economy Model.....	20
2.3.3	The Male Breadwinner/Female Caregiver Model.....	22
2.3.4	The Dual Breadwinner/Female Caregiver Model.....	23
2.4	Effects of Changes in Disease Types and Lifestyles on Caregiving.....	25
2.5	Social Change and Risk Factors for Disease.....	27
2.6	Implications for Caregiving.....	28
2.7	Summary.....	29
2.8	Questions for Discussion.....	30
	References.....	31

<b>3</b>	<b>The Life Course Perspective .....</b>	<b>33</b>
3.1	Caregiving and the Life Course .....	41
3.2	Summary .....	42
3.3	Questions for Discussion.....	44
	References .....	44
<b>4</b>	<b>Caregiving Children with Special Healthcare Needs.....</b>	<b>47</b>
4.1	Introduction.....	47
4.2	Estimates of Prevalence of Children with Special Needs .....	47
4.3	Caregiving Concerns.....	49
4.4	Finances of Caregiving Special Needs Children.....	53
4.5	Summary .....	58
4.6	Questions for Discussion.....	58
	References.....	59
<b>5</b>	<b>Caregiving Adolescents and Young Adults with Disabilities .....</b>	<b>61</b>
5.1	Introduction.....	61
5.2	Service Issues .....	62
5.3	Transition to Adulthood.....	63
5.4	Negotiating Autonomy .....	64
5.5	Transition Satisfaction.....	66
5.6	Summary .....	67
5.7	Questions for Discussion.....	68
	References.....	68
<b>6</b>	<b>Caregiving at Life's Transitions: The Senior Years .....</b>	<b>69</b>
6.1	Introduction.....	69
6.2	"Normal" Aging .....	70
6.2.1	Joann's Longevity .....	70
6.2.2	Definition and the Realities of the Senior Years.....	71
6.3	Empowerment as a Process.....	71
6.4	Successful Aging.....	73
6.4.1	Autonomy and Control .....	74
6.4.2	Social Support and Social Networks .....	74
6.5	Insights into Long, Happy Lives: The Results of the Harvard Grant Men Study.....	75
6.6	Summary .....	76
6.7	Questions for Discussion.....	77
	References .....	77
<b>7</b>	<b>Socioeconomic Status and Caregiving.....</b>	<b>79</b>
7.1	Introduction.....	79
7.2	Socioeconomic Status and Aging.....	79
7.3	The Socioeconomic Context of Caregiving .....	84

7.4	Summary .....	93
7.5	Questions for Discussion.....	94
	References .....	94
<b>8</b>	<b>Ethnic Variations in Caregiving .....</b>	<b>97</b>
8.1	Introduction.....	97
8.1.1	Growing Ethnic Diversity.....	97
8.1.2	A Norm of Family Caregiving & Filial Piety .....	100
8.1.3	Variations in the Details of Context.....	105
8.1.4	The Stress Process Model.....	108
8.2	Summary .....	118
8.3	Questions for Discussion.....	119
	References .....	119
<b>9</b>	<b>Outsourced and Specialized Caregiving .....</b>	<b>123</b>
9.1	Introduction.....	123
9.2	Caring from a Distance .....	123
9.2.1	Long Distance Defined.....	124
9.2.2	Long-Distance Caregiving.....	124
9.2.3	Long-Distance Care of a Family Member with Dementia ....	125
9.3	What To Do About Aunt Mary? .....	126
9.4	Level of Burden Index .....	131
9.5	Caregiving Structures: Levels of Specialized Care.....	132
9.5.1	Contracts .....	132
9.5.2	Levels of Specialized Care .....	133
9.6	Emotional and Financial Costs of Long-term Care for Caregivers.....	133
9.6.1	Financial Costs.....	135
9.6.2	Emotional Costs.....	135
9.7	Summary .....	136
9.8	Questions for Discussion.....	137
	References .....	137
<b>10</b>	<b>Caregiving at the End of Life.....</b>	<b>139</b>
10.1	Introduction.....	139
10.2	Definitions.....	141
10.2.1	Palliative Care and Hospice Care .....	141
10.2.2	End-of-Life and End-of-Life-Care .....	141
10.3	Where We Die .....	143
10.4	The Trajectories of Dying .....	144
10.5	Men as Caregivers.....	145
10.5.1	Men as Caregivers at the End-of-Life .....	146
10.6	Impact of End-of-life Care on Caregivers.....	147
10.7	Preventing Caregiver Burnout.....	147
10.8	After Death Care for Caregivers .....	148

10.9	Summary .....	149
10.10	Questions for Discussion.....	150
	References.....	150
<b>11</b>	<b>The Health of Caregivers.....</b>	<b>153</b>
11.1	Introduction .....	153
11.1.1	Caregiving as a Job.....	153
11.1.2	Caregivers' Coping and the Positive and Negative Effects of Caregiving.....	154
11.1.3	Multiple Roles .....	155
11.2	Social Support as a Moderator of Caregiving Stress.....	156
11.3	The Roles, Dynamics, and Outcomes of Caregiving and Receiving .....	157
11.3.1	Role Initiation .....	158
11.3.2	Role Performance .....	158
11.3.3	Role Outcomes .....	160
11.4	Predicting Caregiver Health Effects and Mortality.....	161
11.4.1	Health Effects .....	161
11.4.2	Mortality .....	162
11.5	The Quality of the Caregiver-Recipient Relationship as a Predictor of Caregiver and Recipient Health .....	163
11.6	Summary .....	164
11.7	Questions for Discussion.....	164
	References.....	165
<b>12</b>	<b>Legal and Ethical Issues in Caregiving.....</b>	<b>169</b>
12.1	Introduction.....	169
12.2	Planning for Incapacity: Legal Issues of Caregiving .....	170
12.2.1	Decision-Making .....	170
12.3	Advance Directives .....	171
12.4	Attitudes Toward and Effects of Advance Directives .....	172
12.5	The Role and Scope of Surrogates in Advance Directives.....	173
12.6	Physician Aid-in-Dying.....	174
12.7	Crucial Conversations .....	175
12.8	Elder Abuse, Neglect and Exploitation in Caregiving .....	177
12.8.1	Definition.....	177
12.8.2	Prevalence/Incidence of Maltreatment .....	177
12.8.3	Risk Factors vs. Protective Factors and Elder Maltreatment .....	178
12.9	Elder Maltreatment in Institutional Settings .....	179
12.10	Summary .....	181
12.11	Questions for Discussion.....	182
	References.....	182

<b>13 National Caregiving Policy Initiatives.....</b>	<b>185</b>
13.1 Introduction.....	185
13.1.1 Caregiving Principles and National Health Policy .....	186
13.2 National Initiatives in Caregiving .....	188
13.2.1 The National Family Caregiver Support Program (NFCSP) (2000) Under the Older Americans Act Title ITTE .....	188
13.2.2 The Affordable Care Act of 2010 (P.L. 111–148).....	189
13.2.3 Caregivers and Veteran Omnibus Health Services Act of 2010 (P.L. 111–163) .....	193
13.3 Family and Medical Leave Act of 1993 (FMLA) (P.L. 103–3).....	194
13.4 Lifespan Respite Care Act of 2006 (P.L. 109–442) .....	194
13.5 New Models of Caregiving .....	196
13.6 Summary .....	197
13.7 Questions for Discussion.....	197
References.....	197
<b>14 Caregivers' Utilization of Social Networks and Social Media .....</b>	<b>201</b>
14.1 Introduction.....	201
14.1.1 Definitions .....	202
14.1.2 Scope of Internet Use .....	203
14.2 The Support Role of Social Networks and Social Media.....	204
14.3 Network Disruptions: A Predictor of Caregiver Distress.....	205
14.4 Telephone Networks.....	206
14.5 Interventions to Moderate Family Caregiver Burden and Stress.....	207
14.6 Summary .....	207
14.7 Questions for Discussion.....	208
References.....	208
<b>Index.....</b>	<b>211</b>