

Index

NOTE: Page numbers in *italic type* refer to tables.

- acceptance 135, 144, 145–146, 156
 afterlife 156
 Albert 166, 170
 alternative medicine 29
 altruism 94, 96, 181
 see also protection of others
 anger, at treatment errors 114
 anticipation 4
 of death 107, 115–116
 see also fear; hope; recurrence; remission
 anxiety
 about consultations 33, 48
 about spread 106
 about surgery 55–56
 of family 153–154
 see also fear; shock
 appearance
 control over 80
 disguising 76–77, 155
 self-conscious about 69
 when dying 158
 see also hair loss
 appreciation of life 5, 5, 127–128, 181
 Ash 15, 24–26, 144–147, 169
 autonomy *see* control
 baldness *see* hair loss
 bargaining 157
 Bauman, Z. 123
 Becker, E. 13, 94, 124, 167
 Ben 14
 control 132
 diagnosis 42–44
 lack of support from son 72
 medical consultations 30–32
 place of death 167
 preparations for death 132, 171
 reaction to recurrence 129
 biographical disruption 26
 biopsies 29, 31
 Bob 14
 chemotherapy 74–75
 diagnosis 40–42
 family support 42, 170
 bodily betrayal 180
 bodily breakdown 136
 bodily change, and symptoms 16
 bone marrow test 61
 bone secondaries 20, 22, 99
 brain tumours 110–112
 breast cancer sufferers *see* Gita; Louise;
 Rose; Susan
 Brown, R. 17
 Bury, M. 26
 cancer
 in context of home life 20–22, 50, 60,
 69, 179
 control of 100–103, 131–132
 illness trajectories 2, 177
 impact of 85–87
 perceptions of causes 60–61
 preconceived ideas of 46, 51, 71, 122
 cancer culture 60, 63–64, 83
 see also sufferers
 carers
 as heroes 169
 influence when dying 169–170
 social roles of 168–169
 see also family
 challenge, of illness 57
 Charmaz, K. 77, 121, 172, 173
 chemotherapy
 familiarity with treatment 76
 fear of 76
 Louise's beliefs 90
 for recurrence 125–126, 130–131
 respondent experiences 66–69, 74–75,
 100, 117, 120
 side effects 68–69, 75

188 Index

- chemotherapy clinic observations 75–76
- children
Janet's protection of 161
Laura's leukaemia 22, 46–48
normalisation of home life 108–109,
152–153
parental concern for 170–171
Gerry's 39, 40, 45, 171
Louise's 35, 45, 171
Rose's protection of 104–106, 115,
142, 143–144
Steve's death 151–155, 167, 168
- Clark, D. 9–10, 12
- clinical trials 41
- Clive 14
diagnosis 46
remission and recurrence 116–120
- collapse, at diagnosis 40
- competitiveness 57
- confiding in others 55, 64, 73, 82–84
and protecting family 82
- consultations *see* medical consultations
- contagion, public perceptions of 122
- contamination, feelings of 110
- control
by doctors 91–92
by family and friends 71–72, 87–88
of cancer 131–132
and diet 92, 101, 130–131
Louise's fight for 84, 87–88, 91–93, 131
Louise's loss of 23, 35, 71–72, 85
and normalisation of home life 108–109,
152–153
over appearance 80
preparations for death 105–106, 132,
171
Rose's 115
Susan's fight for 100–103, 131
of treatment 79, 100–103, 131
- Cornwell, J. 128
- Costain Schou, K. 13, 33, 45, 81, 83
- CT scan 61
- Cullen, L.A. 53, 94, 168, 170
- cultural affectations dropped 167
- death and dying 4
acceptance of 135, 144, 145–146, 156
anticipation of 107, 115–116
attitudes to 7, 8, 9–12, 81–82, 126, 176
bodily breakdown 136
changing causes of 8
confronting 1, 49, 135, 177
cultural affectations dropped 167
family present at death 147, 153–154,
162, 164
family reactions 143, 146, 165–167
family support 150–151, 154, 163,
169–170, 174–175
fear of sleep 173
fighting death 119, 144, 145–146
flight or freezing responses 173
humour at time of 144, 148, 156,
171–172
impact of social roles 170–171
management 9
medicalisation 52
narratives
Geoff 162–165
Gita 144–147
Janet 159–162
Jean 155–159
John 147–151
Rose 137–144
Steve 151–155
pain at time of 115, 136–137
perceptions of time 158, 160, 173
place of *see* place of death
postponing death 157, 159, 162, 163,
172
preparations for death 105–106, 132,
171, 174
research on 7–8, 12–13
and social relationships 168
stages of 2–4, 3
see also dying trajectories
death denying 8, 9, 49
Dein, S. 156, 172
Del Vecchio, M.J. 53
delays
in diagnosis 31–32
in seeking medical advice 22, 23–24,
25–26, 27–28, 48
denial 27, 77, 95, 97, 105, 156
see also death denying
departure 3
see also detection of symptoms; diagnosis
destination 4
see also death and dying
detection of symptoms 16–17, 26–28,
48
and emotional work 27
Gerry 17–19
Gita 24–26
Louise 19–24
monitoring during remission 124
recall of 17, 18, 26
in temporal framework 2
diagnosis
Ben 42–44
Bob 40–42

- as complex process 33, 44
 delays in 31–32
 Gerry 36–40
 informing others 37, 58–60, 118, 122
 life changes following 51
 Louise 20, 22, 34–36
 reactions to 22, 24, 46–48, 125, 180
 recall of 35, 41, 44, 45
 of recurrence 96–103, 117–120, 125, 129–130
 social context of 50
 in temporal framework 3
- Diamond, John 76
 diet 92, 101, 130–131
 doctor–patient relationship
 and Louise’s medical knowledge 89–91
 power and control 91–92, 100–101, 113, 131
 support 113
 trust 66, 67, 68, 79, 116
- documentary 94–95, 96, 123
 dying *see* death and dying
 dying behaviour in hospices 164
 dying trajectories 11, 165–167, 178
- Elias, N. 126
 embodied paranoia 65
 embolism 137
 emotional impact of cancer 85–87
 emotional work 27, 56, 127, 178
see also protection of others
- emotions
 confiding in others 73, 82–84
 repression of 27, 55, 56, 64, 82, 119, 126, 127, 152
 revealing to medical staff 55, 64, 116–117
see also fear; hope
- Exley, C.E. 54
 experts *see* specialist medical expertise
- exploration 3
see also tests; treatment
- faith *see* trust
- family
 commitment to 66, 114
 concern for 116
 conveying love to 143
 problems of confiding in 82
 protection of *see* protection of others
 reactions to death 143, 146, 165–167
 reactions to illness 73, 78
 support from 42, 119–120, 169, 170
 during remission 95–96
 lacking 72
 problems of 73, 78, 87–88, 121–122, 127, 139, 169
 when dying 150–151, 154, 163, 169–170
see also children
- family life *see* home life
- fate 24, 25
- fear 180
 on detecting symptoms 17, 19, 26
 of diagnosis 103
 and isolation 78
 of prognosis 78, 107
 rationalisation of 107
 of recurrence 4, 88–89, 105, 106, 116, 118, 124
 of sleep 173
 of treatment 65–66, 76, 118, 119, 120
see also anxiety; shock
- Featherstone, M. 177, 178
- fertility 62–63, 64
- Field, D. 164
- flashbulb memories 17
- flight 173
- Frank, A. 69, 95, 123
- Frankenberg, R. 27
- freezing 173
- friends
 and concepts of remission 95
 support from 71–73, 88, 121–122, 148, 152–153
- funeral arrangements 105, 132
- Geoff, death and dying 162–165, 168, 171
- George, R. 156, 172
- Gergen, K.J. 82
- Gerry 14
 concern for daughter 39, 40, 45, 171
 detection of symptoms 17–19
 diagnosis 36–40
 medical consultations 28–30
 tests 58–63
 treatment 67–70
- Gita
 death of 144–147, 169, 171
 detection of symptoms 24–26
 dying trajectory 166
- Glaser, B.G. 11, 148, 176
- Graham, H. 137
- hair loss 60, 68–69, 76
 disguising 76
- Hassard, J. 66
- Herman, J. 43

190 Index

- heroism 81–82, 177–178
 of carers 8
 characteristics of 4–5, 5
 and confiding in others 82–84
 during remission 93
 Jean's 157
 protecting others 127
- Hewison, J. 13, 33, 45, 81, 83
- Hinduism 24, 25
- holistic care 12
- home, dying at 10, 147–151, 152–155,
 167, 168
- home life
 during remission 84
 illness in context of 20–22, 50, 60, 69,
 179
 normalisation of 108–109, 152–153
- hope 4, 180
 at time of diagnosis 35, 37, 41, 42, 45,
 125
 during remission 124
 and recurrence 125, 138–139, 166
- Hospice Movement 8
 rise of 9–12
- hospices
 choosing to die in 167, 168
 dying behaviour in 164
 Geoff's death 162–165
 Janet's death 159–162
 Jean's death 155–159
 move to single room 146, 168
 nature of 135–136
 philosophy of 12
 volunteer role in xi
- hospitalisation, and loss of autonomy 85
- hospitals
 chemotherapy clinic observations 75–76
 discharge from 121
 dying in 10, 142, 167
 experiences of 52–54
 move to single room 142, 168
 social interaction in 53–54, 120–121
- humour xi, 22
 about hair loss 68, 69
 when dying 144, 148, 156, 171–172
- identity
 maternal 108–109, 139, 155, 161,
 168–169
 and others' perceptions 178
 shift during remission 124
see also appearance; social roles
- illness
 as biographical disruption 26
 as challenge 57
see also cancer
- illness calendar 52–53, 81
- illness trajectories 2, 177
see also dying trajectories
- information
 about prognosis
 and dying trajectory 11
 experience of others 126
 fighting for 104
 given to patients 9, 45, 123, 176
 at time of diagnosis 38
 from other sufferers 120, 129
 preconceived ideas about cancer 46, 51,
 71, 122
 sought following diagnosis 60–61, 63
see also medical knowledge
- informing people
 about hair loss 69
 of diagnosis 37, 58–60, 118, 122
 telling illness story 123
- interview respondents x–xi, 14–15
- interviews ix–x
- introspection 160, 173
- isolation 55, 56, 78, 110
- Janet, death of 159–162, 173
- Jean, death of 155–159, 171
- John, death of 147–151, 167, 168
- knowledge *see* information; medical
 knowledge
- Kubler-Ross, E. 10, 11, 27, 81, 152, 157,
 176
- Kulik, J. 17
- Langley-Evans, A. 171
- Laura 22, 46–48
- Lawton, J. 13, 85, 136
- Leak, W.N. 10
- leukaemia 22, 46–48
- Lichter, I 27, 77
- life changes
 changed appearance 76–77
 following diagnosis 51
- lifespan 116
- Lifton, J. 172
- loneliness *see* isolation
- loss, and end of treatment 120, 121, 122
- Louise 14
 concern for children 35, 45, 171
 confiding in others 82
 contemplating death 1, 78
 daughter's leukaemia 46–48
 detection of symptoms 19–24
 diagnosis 20, 22, 34–36
 fight for control 84, 87–88, 91–93, 130,
 131

- loss of control 23, 35, 71–72, 85
 medical knowledge 89–91
 preparations for death 171
 remission and recurrence 84–93
 support from family and friends 71–72, 87–88, 127, 170
 tests 55–58
 timeline for life 21
- lump
 discovery of 17, 18–19, 22, 25–26
 seeking advice about 28
 surgical removal of 29–30
- Lutfey, K. 37
- lymphoma 36, 38, 60
- macrobiotic diet 101, 130
- Mary 15
 narrative of John's death 147–151, 170, 171
- Maynard, D. 37
- media, and Hospice Movement 8
- medical advice
 decision to seek 18
 delay in seeking 22, 23–24, 25–26, 27–28, 48
- medical consultations
 anxiety about 33
 Ben's 81
 Gerry's 28–30
 Sue-Ellen's 32–33
 supporters at 29, 31, 33–34
- medical control, Louise's loss of 23
- medical domain, patient experiences of 52–54, 180
- medical equipment, for home nursing 149–150
- medical knowledge
 of carers 168–169
 specialist expertise 33, 48
 of sufferers 29, 89–91, 97, 120
see also information
- medical professionals
 disappointment with 2, 31–33, 43, 44, 114, 180
 distancing by 38
 patient relationship with 179–180
 power relationship with 91–92, 100–101, 113, 131
 revealing emotions to 55, 64, 116–117
 social interaction with 53–54
 support from 55, 113, 116–117, 118, 121
 trust in 66, 67, 68, 79, 116
 use of time 36–37
- medical science, trust in 64, 79
- medicalisation of dying 52
- Melbin, M. 36
- Mellor 7–8
- memories, of symptom detection 17, 18, 26
- methodology ix, 13
- mode of restoration 172
- mortality
 changing causes of 8
 confronting 49, 177
see also death and dying
- mothers
 inability to fulfil role 139
 maintaining role 108–109, 155, 161
 problems of support from 73, 87–88, 127, 139, 169
 protection of 24
 responses to illness 73, 77
 support from 170
 suppressing role 168–169
- mutual pretence 148, 149
- Nettleton, S. 79
- Non-Hodgkins Lymphoma 38
- normalisation of home life 108–109, 152–153
- observational research x, xi
- pain
 endurance of 5, 5, 113, 115
 hospice understanding of 12
 when dying 115, 136–137
 pain relief 12, 137, 149–150, 159
- parental role
 concern and protection *see* children
 impact on death and dying 170–171
see also mothers
- passing as healthy 76–77
- past experiences, retreat to 172
- patients
 support network between 109–110, 120–121
see also doctor-patient relationship; sufferers
- Payne, S. 171
- personality structure 38
- Peter, death of 173
- Phillips, M. 54
- physical scars of treatment 113
- place of death 10, 165, 167–168, 174
see also home; hospices; hospitals
- positive outlook on life 5, 5, 127–128, 140, 181
- postponing death 157, 159, 162, 163, 172

192 Index

- power
and doctor-patient relationship 131
and informing others 58–59
see also control
- premature death xi
- Prichard, P. 159
- privacy 26, 157
- prognosis
control after 105–106
estimates of time left 106, 141, 142
hope and fear 78, 124–125
information about
and dying trajectory 11
experience of others 126
fighting for 104
given to patients 9, 45, 123, 176
Steve's 152
protection of others 5, 5, 27, 81, 122, 127, 178, 181
by Louise 24, 36, 56–57
by repressing emotion 27, 55, 56, 64, 127
by Rose 104–106, 110, 111, 112, 115, 143–144, 171
children 104–106, 115, 142, 143–144, 161
when dying 162, 174
- public attitudes
to cancer 46, 51, 71, 122
to death and dying 7, 8, 9–12, 81–82, 126, 176
- public/private anomaly 52, 64, 111, 121
- radiotherapy 65–66, 110, 114, 138
- Radley, A. 17
- rationalisation 39, 57, 107
of symptoms 19, 22, 27, 29, 30
- recurrence 3, 133–134
Ben 129
Clive 117–120
diagnosis of 125
fear of 4, 88–89, 105, 106, 116, 118, 124
Louise's views 88–89, 90–91
Rose 103–116, 129
Susan 94, 96–103, 129–130
treatment for 125–126, 130–131
- relationships *see* social relationships
- religious beliefs
Clive's 118
Gita's 24, 25
and hospice ethos 168
and Janet's death 160
Susan's 99, 100, 101
- remission 3, 132–133
Clive 117
end of treatment 120, 121, 122
Louise 84–85, 87–88
monitoring symptoms 124
Rose 103, 105, 107
shifting roles and identities 123–124
Susan as cancer free 95
repression of emotion 27, 55, 56, 64, 82, 119, 126, 127, 152
- respondents x–xi, 14–15
- responsibility
relinquishing 178
removal of 92–93
for treatment 66
see also control; protection of others
- restitution plot 69
- Richard, death of 173
- Roberts, S.L. 173
- Rose 14
control 131
death and dying 137–144, 167, 171
dying trajectory 165–166
experience of chemotherapy 75
fear of sleep 173
humour 171
problems of family reactions 74, 77
protection of others by 104–106, 110, 111, 112, 115, 143–144, 171
remission and recurrence 103–116, 129
support for 83, 170
- St Christopher's hospice 12
- Saunders, Cicely 12
- Seale, C. 82, 123, 177, 178
- secondaries 97, 129
- self-identity 124, 178
see also appearance; social roles
- shock
of detecting symptoms 17
of recurrence 97–98, 117
and trauma of diagnosis 35, 40, 42, 43, 46–48, 49–50
see also anxiety; fear
- side effects of treatment 75, 138
- Simmel, G. 83
- sleep, fear of 173
- smoking 137
- social events and will to live 139, 140
see also postponing death
- social impact of cancer 85–87, 109
- social interaction
in hospices 156
and medical treatment 53–54, 120–121
- social life *see* home life
- social relationships
at time of death 168
at time of diagnosis 24, 37, 42

- change during treatment 79, 80, 124
 continuing 179
 tension in 126–127, 169–170
see also family; friends; protection of others
- social roles
 of carers at time of death 168
 impact on dying 170–171
 regaining during remission 124
see also identity; mothers; parental role
- social scientific research on death 7–8
 soft palate test 62
 Sontag, S. 122
 Sophie 15, 151–155, 170, 171
 specialist medical expertise 33, 48
 sperm bank 62–63, 64
 Spradley, J.P. 54
 Stacey, J. 89
 sterility 62–63, 64
 Steve's death 151–155, 167, 168
 storytelling 123
 Susan's documentary 94–95, 96, 123
 strangers, confiding in 55, 64, 73, 82–84
 Strauss, A.L. 11, 148, 176
 Sudnow, D. 10
 Sue-Ellen 15, 32–33, 127
 sufferers
 and cancer culture 60, 63
 information from 120, 129
 interview respondents x–xi, 14–15
 support from 60, 63, 83–84, 109–110, 119, 120–121
see also doctor-patient relationship
- support and supporters
 benefits of 179
 cancer support group 97, 98
 confiding in strangers 55, 64, 73, 82–84
 and decision to undergo treatment 67
 during treatment 79, 80
 family *see* family
 fellow sufferers 60, 63, 83–84, 109–110, 119, 120–121
 friends 71–72, 88, 121–122, 148, 152–153
 Gerry's 70
 in hospital environment 120–121
 lacking 72–73
 at medical consultations 29, 31, 33–34, 40, 97
 medical staff 55, 113, 116–117, 118, 121
 problems of 71–72, 73, 78, 87–88, 121–122, 127, 139, 169, 178–179
 Vera's 67
 when dying 150–151, 154, 163, 169–170, 174–175
- when recurrence diagnosed 97, 98–100
 when symptoms detected 28, 48
- surgery
 anxiety about 55–56
 problems following 114
 removal of lump 29–30
- survival
 control of diet 101, 130–131
 fight for 119, 144, 145–146
see also control; will to live
- Susan 15
 control 131
 in documentary 94–95, 96, 123
 loneliness 78
 remission and recurrence 94–103, 129–130
 support 72–74
- symptoms
 detection of 16–17, 26–28, 48
 and emotional work 27
 Gerry 17–19
 Gita 24–26
 Louise 19–24
 monitoring during remission 124
 recall of 17, 18, 26
 in temporal framework 2
 rationalisation of 19, 22, 27, 29, 30
 syringe driver 159
- telling illness story 123
 telling others 37, 58–60, 69, 118, 122
- temporal framework 2–4, 3
 illness calendar 52–53, 81
see also dying trajectories; illness trajectories; time frames
- test results *see* diagnosis
- tests
 anticipation of 29
 Gerry's 58–63
 Louise's 55–58
- time
 and medical regime 52–53, 142
 medical staff's use of 36–37
 perceptions of after diagnosis 54–55
 perceptions of when dying 158, 160, 173
 retreat to past experiences 172
 territorial dimensions of 33
see also temporal framework
- time of death, postponing 157, 159, 162, 163, 172
- time frames
 for recovery 138
 when dying 141, 142
see also prognosis; temporal framework
- timeline, Louise's 21
 total pain 12

194 Index

- trauma
of diagnosis 35, 40, 42, 43, 46–48, 49–50
see also anxiety; fear; shock
- treatment 3
appearance after 69, 76–77, 80
chemotherapy clinic observations 75–76
clinical trials 41
control of 79, 100–103, 131
decision to undergo 66, 67, 79
errors in 2, 31–33, 43, 44, 114, 180
fear of 65–66, 76, 118, 119, 120
Gerry's 67–70
loss and end of 120, 121, 122
Louise's beliefs 90–91
period following *see* remission
positive response to 74–75
for recurrence 125–126, 130–131
respondent approaches to 71
scars from 113
side effects 75, 138
and social interaction 53–54, 120–121
social relationships during 79, 80, 124
time frame 52–53, 81
- Vera's 65–67
see also chemotherapy; radiotherapy; surgery
- treatment regimes 52–53
- trust, in medical profession 66, 67, 68, 79, 116
- truth telling 177
- Vera 15
dying trajectory 166
fear 78
support from family 170
treatment 65–67
volunteering at hospices xi
- Walter, T. 165
- Weisman, A. 49
- will to live 139, 140
and fear of sleep 173
postponing death 157, 159, 162, 163, 172
see also survival
- wills 106
- withdrawal 160, 173
- Young, M. 53, 94, 168, 170
- Zerubavel, E. 33, 37, 52, 73