Index

- acute hospital setting, palliative nursing care in
  accident and emergency (A&E) units, 56
- barriers, 55–7
- best practices
  in assessing pain and symptoms, 60–62
  continuous subcutaneous infusion, 62–3
- causes of deaths in hospitals, 53–5
- decision making and advance directives, 67–8
- end of life care
  diagnosis of dying, 64
  failure to recognise dying patient, 65
- LCP team approach, 65–7
- intensive care units (ICUs), 56–7
- referral criteria, 58–9
- role of specialist nurses, 57–60
- advance care planning
  in COPD, 126
  dementia, 152–3
  ESRD, 206, 214
  hospice team, 109
- advanced directives, 136
- akathisa (restlessness), 190
- Alder Centre, 265
- American College of Chest Physicians, 126
- amyotrophic lateral sclerosis (ALS), 167
- anaemia, 211
- analgesia, 150, 213
- anorexia, 212
- antibiotics, 24
- anticholinergics, 131
- antiemetics, 121, 131
- antimuscarinic bronchodilator treatment, 133
- antipsychotics, 159
- antiretroviral therapy (ART), 243–5
- anxiety, 191
- artificial feeding, 161
- artificial hydration, 24
- artificial nutrition, 24
- augmented feeding, 170
- baclofen, 179
- Because Cowards Get Cancer Too (John Diamond), 44
- Before I Say Goodbye (Ruth Picardie), 44
- benzodiazepines, 131, 134, 213
- bereavement care, 28–9, 126
  children’s hospices, 282–3
  hospital palliative care, 107–8
  Huntington’s disease (HD), 163
  motor neurone disease (MND), 174–5
- beta agonists, 133
- bioethical principles in palliative care
  autonomy, 38–40
  idea of beneficence, 40–42
  social and distributive justice, 42–4
- biomedical model, of care, 23
- Body mass index, airflow Obstruction, Dyspnœa, Exercise capacity index (BODE), 130
- bronchial pneumonia, 158
- bronchodilator therapy, 133
cancer, advanced, 22–3  
breast  
incidence, 223  
pain, 224–6  
psychosocial support and communication issues, 228  
related fatigue, 226–7  
skeletal complications, 227–8  
symptoms, 224  
treatments, 224  
as a chronic disease, 221–3  
experiences of women, 43  
haematological approaches to care, 229–32  
common clinical problems, 232–3  
overview, 229  
specific issues at the end of life, 233–4  
hospice care, 45  
incidence rate, 221  
life-limiting aspects of, 42–3  
lung, 234–6  
types, 220  
Cancer Plan, 74  
cardiopulmonary resuscitation, 24  
CCR5 inhibitors, 244  
CD4 cells, 244–5  
chemotherapy, 24, 31  
chorea, 159–60  
chronic kidney disease, 205  
chronic obstructive pulmonary disease (COPD) and palliative care  
burden of disease, 125–6  
end of life care, 135–6  
ethical practice, 129–30  
symptom management  
  anxiety, fear and depression, 134–5  
  breathlessness, 131–3  
  sputum and secretions, 134  
  therapeutic communication, 126–8  
chronic pulmonary disease, 31  
citalopram, 134  
co-danthramer, 120  
cognitive impairment, 160, 172  
Combivent™, 133  
Community Nurse Specialist (CNS), in palliative care, 106  
community palliative care delivery  
  advanced planning and coordination of services, 81–2  
  care pathways, 81–3  
  centres, 73–4  
  and impact of demographic change, 74  
  provision  
    attitude towards information giving, 77–8  
    good communication, 76–7  
    psychological support, 79–80  
    rights of dignity and respect, 75–6  
    symptom control, 78–9  
constipation, 22  
continuous subcutaneous infusion (CSCI), 62–3, 121, 213  
cyctizine, 128  
day care provisions, in hospitals, 103–5  
Deadman Writing (Jonathan Wilson), 44  
death and dying  
  in A&E units, 56  
  causes, 6  
  diagnosis of dying, 64–7  
  due to COPD, 125–6  
  due to heart failure, 116  
  good, 91  
  at home, 53–4  
  in a hospital ward, 55–6  
  Huntington’s disease (HD), 157–8  
  in ICUs, 56–7  
  Jewish tale, 37  
  society’s exposure to, 23
temporal predictions of dying trajectories, 90
dementia, 31
carer support, 151–2
challenge for nurses with patients of, 146
communication strategies for assessment of patients, 146–7
definition, 143
end of life care, 152–3
epidemiology, 143
ethical issues in treating, 153
HIV, 247–8
holistic care, 145–8
management of pain and distress, 148–50
needs assessment, 145
palliative care, 144
prognosis, 143
Dementia Reconsidered (Tom Kitwood), 145
depression, 191
diamorphine, 128
Diana nurses (England), 286
diazepam, 128, 134
disenfranchised people. See marginalised people
diuretics, 120, 211
Dominica, Sister Francis, 278
‘Do not Resuscitate’ (DNR) orders, 208
dysarthria, 160
dyskinesia, 190
dysphagia, 160, 191
dyspnoea, 22, 117
dystonia, 160
End of Life Care (EoLC) Programme, 20, 54, 121
End of Life Care Strategy, 12
end-stage renal disease
CKD patients, 204–5
stages, 206
end of life care, 213
international perspective, 208–9
palliative care
need for, 205
renal supportive care services (RSCS), 206
prevalence, 204
psychological care, 213–14
social support, 214–15
symptom management
anaemia, 211
anorexia, 212
fatigue and lethargy, 212
fluid overload, 211–12
insomnia, 212
nausea and vomiting, 212
pain, 210
pruritis (itch), 211
terminal phase, 215–16
withdrawal and withholding of dialysis, 206–8
European Association for Palliative Care (EAPC), 294
fatigue, 22, 212
feedbacks, 68
fluid overload, 211–12
formoterol, 128, 133
forward planning, in palliative care, 24
frusemide, 211
fusion inhibitors (FI), 244
gabapentin, 179
Garnier, Madame Jeanne, 6
gastrostomy, 171
glomerular filtration rates, 205
glutamate release antagonist, 168
glycopyrronium, 128, 133
Gneszidlov, Andrei, 8
Gold Standards Framework (GSF), 11, 81–2, 121, 135–6, 163, 169
‘Go Wish Card Game,’ 136
Great Ormond Street Hospital, 265
hallucinations, 191
haloperidol, 128, 212
heart failure and palliative care
end of life care, 121–2
impact on quality of life, 117
indication for referrals, 119
physical problems associated with heart failure, 117
prevalence of heart failure, 116
referral criteria, 119
heart failure and palliative care (Cont.)
specific symptoms
  constipation, 120–21
  nausea and vomiting, 121
  pain, 120
SUPPORT study, 117
symptoms management, 117–18
Helen House, 278, 283
highly active anti-retroviral therapy (HAART), 244
HIV/AIDS
case study, 249–50
challenge of palliative care, 245–46
depression and complex co-morbidities, 248
drug therapy, 243–5
HIV dementia, 247–8
international impact, 242–3
nursing services, 248–9
pain and symptom management, 246–7
prevalence, 243
HM Prison Barlinnie, 36
Hodgkin’s lymphoma, 246
holistic care, 60
home care service, 9
Hospice and Palliative Care Directory, 9
‘hospice at home’ services, 107
hospital palliative care. See acute hospital setting, palliative nursing care in
benefits, 105
bereavement care, 107–8
day care provisions, 103–5
evolution, 99–101
holistic patient-centred care, 102
‘hospice at home’ services, 107
modern times, 100
multidisciplinary team, 108–10
nursing, 101–3
provision of specialist services, 105–6
referral to, 104
Huntington’s disease (HD)
bereavement, 163
care planning, 164
carers, 163
clinical features, 157–8
dietary intake, 161
effect on families, 158–9
end of life care, 162–3
mortality rate, 157
oral problems, 161
palliative care issues, 159–62
prevalence, 157
psychiatric issues, 158, 162
role of generic testing, 157
specialist palliative care units, 163–4
spiritual issues, 162
symptoms, 157
weight loss problems, 161
hydromorphone, 63
hyoscine hydrobromide, 128, 133
hypnotics, 212
immobility, 172
Impact of Event Scale, 215
infective exacerbations, 133
infusion site, selection, 63
insomnia, 212
integrase inhibitors, 244
International Society for Nurses in Cancer Care (ISNCC), 294
ipratropium bromide, 128
Kaposi’s sarcoma, 246
Kearney, Michael, 8
King’s College Hospital, London, 169
Kubler-Ross, Elizabeth, 8
L’Association des Dames du Calvaire, 6
lethargy, 212
leukaemia, 45
levomeprazine, 128
levomepromazine, 212
Lewy Body disease, 143
liquid paraffin plus magnesium hydroxide, 121
Liverpool Care of the Dying Pathway (LCP), 11, 117, 121, 135–6, 163
for the dying patient, 65–7
for the hospital setting, 66–7
for the Rapid Discharge Home of the Dying Patient, 67–8
long-term oxygen therapy (LTOT), 130–31
lorazepam, 128, 134
Macmillan Cancer Support, 12
marginalised people
after and secondary cancer, 43
chronic obstructive pulmonary disease, 43
dementia, 43
HIV positive individuals, 39, 43, 45
homeless men, 39
idea, 36–7
mental health problems, 39
non-malignant long-term illness, 43–4
prisoners, 39
self-inflicted individuals, 46–7
severe language and communication disability, 41
Marie Curie Cancer Care, 12
Marie Curie Memorial Foundation, 6
Martin House, 283
Memorial Pain Assessment Card, 61
Mental Capacity Act (2005), 180
Merseyside and Cheshire guidelines, for referrals, 119
midazolam, 128, 134, 213
mirtazepine, 134
Modified Early Warning System, 61
morphine, 63, 120, 128, 131
Motor Neurone Disease Association, 175
motor neurone disease (MND)
bereavement support, 174–5
case management, 169
clinical nurse specialist role, 168
diagnosis, 166–8
El Escorial criteria, 167–8
drug therapy, 168
end of life care, 174
epidemiology, 165–6
forms of, 167
nature of, 165
problems
bowel and bladder issues, 172
cognitive dysfunction, 172
respiratory systems, 171–2
speech and swallowing, 169–70
psychological, social and spiritual impact, 172–3
specialist palliative care, 173–4
mucolytic therapy, 133
multiple sclerosis (MS), 31
life experiences with, 177–8
physical aspects of, 176
role of palliative care, 178
survival and prognosis, 176–7
myocardial infarction, 56
National Health Service Knowledge and Skills Framework, 300–302
National Institute of Clinical Excellence, 54–5
Supportive Care Guidance, 135
National Service Framework for Long-Term Conditions, 101
nausea, 22, 212
nebulised opioids, 131
new opportunity fund (NOF), 285
NHS and Community Care Act, 1990, 87
NHS e-portfolios, 303–4
NHS-funded palliative care services, 9
non-invasive ventilation (NIV), 132, 171
non-malignant palliative care, 43–4
non-nucleoside analogue reverse transcriptase inhibitors (NNRTIs), 244
NSAIDs, 213
nucleoside analogues, 244
nursing care, palliative
commissioned study on constraints and challenges, 89–92
implications for end of life care, 93–5
implications for personal and professional development of carers, 95–6
implications for training needs of care workers, 92–3
end of life care policy, 88
impact of demographic changes, 86–7
policy, 87–9
state of death in care homes, 88
nursing education, in palliative care continuing professional development, 299–304
core curriculum for, 294–6
Index

nursing education (Cont.)
higher levels of nursing practice
advanced nursing practice, 305–6
clinical nurse specialist (CNS), 306
community matron’s role, 306–7
educators or researchers, 308–9
nurse consultant, 307–8
specialist practitioner qualification, 304–5
levels of knowledge and skill, 297–9
undergraduate curriculum, 292–3

occupational therapy assessment, 160
ondansetron, 211
opioids, 63, 131
opportunistic infections (OIs), 244
Our Health, Our Care, Our Say
(Department of Health), 73
Our Lady’s Hospice, Dublin, 6
oxycodone, 63

paediatric palliative care
challenges and emerging ideas, 266–7
children’s hospice movement, 260–62
community nurses, 286
in community setting, 283–6
education and dying child, 264–5
ethos of, 266
focus, 257–8
history, 258–60
hospital settings
care planning, 270–74
challenges, 274–5
issues with, 269–70
medical conditions requiring, 262–4
oncology outreach, 286
psychosocial issues, 265–6
pain assessment and management of
demented patients, 148–50
pain management, 210
HIV, 246–7
palliative care aims
attitude towards dying, 23–5
helping dying patients to remain active, 27–8
helping families cope with death, 28–9
integration of psychological and
spiritual aspects of care, 25–7
promotion of quality of life, 30–31
relief from pain, 22–3
support for other therapies, 31
team approach in caring, 29–30
clinical and restorative, 46–8
community-based approaches, 47–8
contemporary issues and future challenges, 11–13
cost-effective care, 40–42
definitions and terminology, 17–21
National Institute of Clinical Excellence (NICE), 18–19, 54
WHO, 18
and financial and social resource, 38–40
modern development of, 8–9
and modern hospice movement, 7–8
origin, 5–7
physical symptom management in, 22
recognition, 9–10
role of practitioners, 45–6
standards, 9–10
palliative medicine, 58
palliative rehabilitation, 27
panoptical prison building, concept of, 90
paracetamol, 213
parenteral opioids, 131
Parkinson’s disease
advanced co-morbidity, 187–8
complexity, 186–7
diagnosis, 183
idiopathic, 182
maintenance, 184–5
palliative care
with other chronic conditions, 189–90
patient education, 191–2
physical symptom control, 190–91
psychological needs, 191
psychosocial needs, 192–3
spiritual needs, 193
through the disease trajectory, 188–9
prevalence, 182
prognosis, 182–3
stages, 183–8
symptoms, 183
patch administration, 150
percutaneous endoscopic gastrostomy, 171, 180
performativity, notion of, 91
Post-registration Education and Practice standards, 302
PQRST model, of symptom assessment, 61
Preferred Place of Care (PPC), 121, 135, 206
document, 174
‘Preferred priorities of care’ document, 11
prognostication, in COPD, 126, 135
progressive bulbar palsy (PBL), 167
progressive muscular atrophy (PMA), 167
pruritis (itch), 211
psychological well-being, 25–6
quality of life, 24
Rachel House, 279
radiotherapy, 31
recombinant human erythropoietin therapy, 211
rehabilitation, in palliative care, 27–8
renal supportive care services (RSCS), 206
research, in contemporary palliative care barriers and challenges, 317–20
cultural and practical barriers, 317–18
ethical issues, 318–19
evidences, 315–17
future directions, 320–21
journals, 313
methodological challenges, 319–20
NCRI study, 313–14
need, 312–13
organisational issues, 320
rigidity management, 160
Riluzole, 168
salbutamol, 128
salmeterol, 128, 133
Saunders, Dame Cicely, 5, 7, 21–2, 73, 100, 108
Scotland managed clinical network for palliative care education, 295, 298–9
Scottish Centre of Technology for Communication Impaired (SCTCI), 170
Scottish Huntington’s Association, 164
selective serotonin reuptake inhibitors (SSRIs), 134
self-acceptance, 25
Senn 2 tablets, 121
Sere tide, 128, 133
sertraline, 134
sialorrhoea, 171
SIGN guidelines, 146
Society for the Prevention and Relief of Cancer, 8
Specialist Palliative Care Team, 30
spiritual care, in palliative care, 26–7
spirituality, 26
St Christopher’s Hospice, London, 7, 10, 12
St Joseph’s Hospice, London, 6, 99–100
stretching regimes, 179
stroke, 56
St Thomas’s Hospital, London, 7
swallowing disorder, 160
management, 170
Symbicort, 128, 133
Tasma, David, 7
temazepam, 212
terbutaline, 128
thalidomideamine, 211
theophyllines, 128
tiotropium, 128
tricyclic antidepressants, 134
tuberculosis, 249
uræmia, 212
vascular dementia, 143
vomiting, 22, 212
West Lothian Dementia Palliative Care Project, 142, 145, 149
Winston’s Wish, 265
Woman’s Hour (BBC Radio 4), 43
zidovudine, 243
zinc deficiency, 212
zinc, oral, 212
zolpidem, 212
Zorza, Victor, 8