

# Index

- activities of daily living (ADLs)  
   device deactivation criteria and, 42–3  
   prognostication and, 23  
 actuarial judgment, 22–3  
 acute stroke settings, palliative care protocols in, 57–9  
 adult day care, for Parkinson's disease patients, 90  
 advance care directives  
   advanced Parkinson's disease patients, 82–3  
   conflicting goals, preferences and, 9–10  
   discussion of prognosis in, 21–5  
   enteral feeding decisions and, 62–4  
   family estrangement and, 138–41  
   goals of palliative care and, 127–9  
   multiple sclerosis and importance of, 156–7, 158–9, 161–4  
   progressive Parkinson's disease and, 88–9  
   shared decision-making and, 72–3  
   stroke in young patients and lack of, 55  
   surrogate decision-making in  
     absence of instruction, 134–6  
     temporary noninvasive ventilation, do-not-intubate patients, 49–50  
   utilization of prognosis in, 24–5  
 amantadine, guidelines for using, 85–6  
 ambulation function, epidural spinal cord compression case study, 27  
 amphetamine treatment, cognitive enhancement and, 17, 18–19  
 amputation for pain management, 118–19  
 amyotrophic lateral sclerosis (ALS)  
   noninvasive positive pressure ventilation with, 102–3  
   palliative care evaluation, 76  
   symptom management prior to ventilator weaning, 105–7  
 anticonvulsants  
   for post-stroke pain, 66–7  
   seizure management and, 130–3  
 antidepressants, for post-stroke pain, 66–7  
 anxiety  
   management in terminal patients, 106  
   neuromyelitis optica spectrum disorder, 168–9  
 attention deficit hyperactivity disorder (ADHD), amphetamine treatment for, 17  
 autoimmune neurology, palliative care evaluation, 153  
 autonomy, non-maleficence and, 18–19  
 average volume assured pressure support (AVAPS) settings, home ventilators, 102–3  
 basilar artery occlusion, time-limited trial for, 60–1  
 belief systems, spiritual aspects of palliative care and, 39–40  
 bereavement counseling  
   risk screening, 30–1, 34–5  
   in spousal death, 30–3  
   sudden death and, 34–7  
 Besbris, Jessica, 105–7, 142–3  
 bi-level positive airway pressure (BPAP), 102–3  
 bladder distention, in dementia patients, 110–12  
 brain tumors  
   hospice care in management of, 44–6  
   palliative care evaluation, 113  
   survival predictions for, 23–4  
 Buddhist faith, patients with, spiritual aspects of palliative care for, 52  
 Capgras syndrome, 86–7  
 caregiver burden  
   dementia patients' caregivers, 90–1  
   with pediatric patients, 99–101  
   support services, 96–8  
   surrogate decision-making in  
     absence of instruction, 134–6  
 Carver, Alan, 124–9  
 central post-stroke pain (CPSP), management of, 66–7  
 cerebrovascular disease  
   palliative care and, 47  
   temporary noninvasive ventilation, do-not-intubate patients, 49–50  
 Chasteen, Kristen, 130–3  
 chemotherapy  
   peripheral neuropathy with, 121–2  
   stem-cell transplant with, 115–17  
   surrogate decision-making in  
     absence of instruction and, 134–6  
 Cheshire, William P., 13–19  
 children, palliative care for, 99–101  
 Chow, Kimberly, 115–17, 121–2  
 clinical judgment, 22–3  
 clinical trials  
   basilar artery occlusion, 60–1  
   neuro-palliative care and, 3  
   NPPV mask in, 49–50  
 clinician's predictions of survival (CPS), 22–3  
   survival predictions and, 23–4  
 clozapine, guidelines for using, 85–7, 90  
 CNS lymphoma, physical management guidelines for, 115–17  
 cognitive behavioral therapy,  
   prolonged grief counseling and, 31  
 cognitive decline, in Parkinson's disease, 85–7  
 cognitive enhancement  
   ethical and legal issues in requests for, 17–19  
   for Parkinson's disease patients, 86–7  
 communication in palliative care  
   consults  
     acute stroke settings, 57–9  
     common challenges in, 8–11  
     conflicting goals, preferences and values, 9–10  
     deliberative model of, 3–4  
     discussion of nonmedical topics, 4  
     discussion of prognosis, 4–5, 23–4  
     emotional impairment of  
       understanding and judgment and, 9  
   hospice care communications with  
     patient and family, 45–6  
   misunderstanding of prognosis and, 8–9  
   negotiating goals of care and, 5–6  
   in neuro-palliative care, 3–7

## Index

- communication in palliative (cont.)  
 in palliative care, 3–4  
 physician discomfort with sensitive topics and, 9  
 on sensitive topics, physician discomfort with, 9  
 Serious Illness Communication Checklist, 6–7  
 sudden death and bereavement screening, 35–6  
 summary of medical situation, 4  
 unrealistic/impossible patient/family expectations, 10  
 concurrent care programs, for pediatric patients, 100–1
- concussive symptoms  
 management of, 17–19  
 pharmacologic vs. non-pharmacologic treatment of, 19
- confusion assessment method, 111
- connections with the deceased, prolonged grief interventions and, 31–2
- constipation with Parkinson's disease, 92–3
- consult in palliative care  
 guidelines for, 3–6  
 Serious Illness Communication Checklist, 6–7
- continuous positive airway pressure (CPAP), 102–3
- Creutzfeldt, Claire J., 57–61
- cultural aspects of palliative care, 94–5  
 chemotherapy-induced peripheral neuropathy, 121–2  
 language barriers and, 52–3  
 spiritual aspects of palliative care and, 39–40  
 “culture of cure,” goals of care and, 128
- decompressive hemicraniotomy, stroke in young patients and, 54–6
- deliberative communication model, whole-person approach to patients and, 3–4
- delirium, in dementia patients, 110–12
- Delirium Symptom Interview, 111
- DeLuca, Gabriele C., 158–9
- dementia  
 delirium and bladder distention in patients with, 110–12  
 palliative care evaluation, 75–6  
 in Parkinson's disease patients, 82–4, 85–7
- psychosis and caregiver strain for families with dementia patients, 90–1
- demyelinating diseases, palliative care evaluation, 153
- depression  
 management in terminal patients, 106  
 neuromyelitis optica spectrum disorder, 168–9
- device deactivation, case study and criteria for, 41–3
- discharge planning, prognostication and, 25–6
- donepezil, guidelines for using, 19, 86–7
- do-not-intubate patients, temporary noninvasive ventilation for, 49–50
- do not resuscitate (DNR) status  
 ethical and legal aspects of, 14  
 goals of palliative care and, 127–9
- Dopamine Agonist Withdrawal Syndrome, 85–6
- emotions  
 communication of, 5–6  
 compassionate Parkinson disease diagnosis and, 79–81  
 impaired understanding and judgment with, 9
- end-of-life care  
 for advanced Parkinson's disease patients, 83–4  
 cultural issues in, 94–5  
 device deactivation case study, 42–3  
 hospice admission and, 44–6, 96–8  
 pediatric patients, 146  
 prolonged grief and bereavement risk screening, 31  
 seizure management with, 130–3  
 sudden death and bereavement screening, 35–6  
 surrogate decisions in absence of instruction about, 134–6  
 transition to, 127–9
- end stage heart failure  
 device deactivation with, 41–3  
 stroke and, 52–3
- enhancement, therapy vs., 18
- enteral feeding, advanced care directives and, 62–4, 134–6
- epidural spinal cord compression (ESCC)  
 bone metastases and, 27–8  
 outcomes and treatment, 28
- Erikson, Erik, 39–40
- ethical domain in palliative care, 14  
 autonomy and information requirements, 14–15
- cognitive enhancement requests, 17–19
- enteral feeding options and, 62–4
- neuro-oncology patients, 115–17
- pediatric patients, 146
- physical and psychological aspects of care and, 18
- poor patient compliance, 154–5
- shared decision-making and, 70–3
- surrogate decision-making in absence of instruction, 134–6
- temporary noninvasive ventilation, do-not-intubate patients, 49–50
- time-limited trials, 60
- withdrawal of care decisions and, 13–16
- expanded disability scale score (EDSS), 154
- faith development, stages of, 39–40
- families of patients  
 advanced Parkinson's disease patients, 82–4  
 burden of Parkinson's disease patients for, 88–9  
 clinical trial decisions for young patients and, 60–1  
 cognitive decline in Parkinson's patients and, 85–7  
 compassionate Parkinson disease diagnosis and, 79–81  
 enteral feeding decisions and, 62–4  
 estrangement of family members and, 138–41  
 ethical and legal aspects of palliative care and, 14  
 hospice care communications with, 45–6  
 neuro-oncology patients, 115–17  
 nonmedical topics in discussions with, 4  
 pediatric palliative care and, 99–101  
 prolonged grief and bereavement risk counseling, 31  
 psychosis and caregiver strain, in Parkinson's disease patient families, 90–1  
 sudden death, bereavement risk screening and, 34–5  
 surrogate decision-making for stroke patients by, 57–9  
 symptom management and goals of care decisions and, 105–7  
 unrealistic/impossible expectations of, 10
- Fatabhoy, Karishma, 130–3
- fentanyl, guidelines for using, 108–9

- FOLFOX regimen, 121–2  
 Fowler, James, 39–40  
 Fugate, Jennifer E., 49–50  
 functional outcomes, epidural spinal cord compression case study, 28
- gabapentin, guidelines for using, 65–7, 116, 118–19, 121–2  
 Glare, Paul, 21–9  
 glioblastoma multiforme, 8, 10–12, 21–6, 124–6, 134–6  
 gliomas  
   palliative care evaluation, 113  
   seizure management with, 130–3  
 goals of palliative care  
   advanced Parkinson's disease patients, 82–4  
   changes in, 127–9  
   communication in acute setting of, 57–9  
   conflicting goals, preferences and values, 9–10  
   in multiple sclerosis patients, 156–7, 158–9, 161–4  
   negotiation of, 5–6  
   physical and psychological aspects of, 18  
   progressive Parkinson's disease, evolution in, 88–9  
   shared decision-making and, 70–3  
   stroke in young patients and, 54–6  
   ventilator management and, 105–7  
 grief counseling  
   after spousal death, 30–3  
   compassionate Parkinson disease diagnosis and, 79–81  
   pre-loss and anticipatory grief, 97–8
- Health Care Power of Attorney (HC-POA), shared decision-making and, 72–3  
 health care proxies  
   enteral feeding decisions and, 62–4  
   family estrangement and, 138–41  
 Higginson, Irene, 157  
 high-level cervical spinal cord injuries case study, 13–16  
   ethics of palliative care and, 14–15  
   quality of life issues, 15–16  
 home care  
   burden on families with, 82–4  
   cultural issues and, 94–5  
   NIPPV procedures and, 102–3  
   progression of Parkinson's disease and, 88–9  
   travel and pain management for, 142–3  
 hospice care  
   admission criteria for, 44–6  
   for advanced Parkinson's disease patients, 83–4  
   bereavement outcomes and, 32–3  
   delirium and bladder distention management in, 110–12  
   family transition to, 31, 32–3, 96–8  
   for pediatric patients, 100–1, 146–7  
   prognostication and eligibility for, 25–6  
   seizure management in, 127–9, 130–3  
   transition to, 127–9  
   treatment protocols in, 45–6  
 hospital protocol  
   amputation for pain management, 118–19  
   clinical trials for young patients, 60–1  
   cultural aspects of palliative care and, 52–3  
   enteral feeding decisions and, 63  
   epidural spinal cord compression case study, 28–9  
   individualized care plans and, 69–70, 71  
   MCA ischemic stroke management, 58  
   metastatic melanoma, 138–41  
   multiple sclerosis management, 165  
   NPPV therapy, do-not-intubate patients, 50  
   pain management for travel, 142–3  
   palliative care and, 15  
   prognostication and, 25–6  
   spiritual aspects of palliative care and, 38–9  
   stem cell transplantation, 117  
   stroke in young patients and, 55  
   symptom management and ventilator weaning, 106–7  
   transition to hospice and, 128  
 Howick, Priscilla H., 38–40  
 Hutchinson, Joseph J., 158–60  
 hydrocephalic patients, pediatric  
   palliative care for, 146–8  
 hypertension, intracerebral hemorrhage and, 65–7
- imminent death, care guidelines for, 99–101  
 implanted pacemaker/cardiac defibrillator (ICD), deactivation of, 41–3  
 individualized care plans, for stroke patients, 69–73  
 information  
   autonomy and overwhelming aspects of, 14–15  
   sudden death and re-visiting of, 35–6  
 intracerebral hemorrhage (ICH)  
   pain management and, 65–7  
   palliative care evaluation, 47  
 intrathecal baclofen, guidelines for using, 149–52  
 ischemic stroke, palliative care evaluation, 47
- Kaplan Meier survival curves, 23–4  
 Karnofsky Performance Scale, 23  
 Kluger, Benzi, 79–84  
 Kolberg, Lawrence, 39–40  
 Kramer, Neha M., 65–73
- language barriers in palliative care, 52–3  
 left ventricular assist device (LVAD)  
   deactivation criteria and, 41–3  
   risk factors in use of, 42–3  
 legal domain in palliative care, 14  
   cognitive enhancement requests, 17–19  
   enteral feeding options and, 62–4  
   neuro-oncology patients, 115–17  
   pediatric patients, 146  
   poor patient compliance, 154–5  
   shared decision-making and, 70–3  
   surrogate decision-making in absence of instruction, 134–6  
   time-limited trials, 60  
   withdrawal of care decisions and, 13–16  
 letters of condolence, as end-of-life care component, 32–3  
 levodopa, guidelines for using, 80, 82–4, 85–7, 90  
 lifestyle choices, cognitive performance and, 18  
 limb girdle muscular dystrophy 21 (LGMD21), 99–101  
 limb pain, in post-stroke patients, 66–7  
 living will  
   shared decision-making and, 72–3  
   stroke in young patients and lack of, 55  
 Lopez Chiriboga, Alfonso Sebastian, 165–70  
 lorazepam, guidelines for using, 111–12
- Medical Orders for Scope of Treatment (MOST), 82–3  
 medical situation, summarization with patients of, 4  
 medications for post-stroke pain, 66–7  
 memantine, guidelines for using, 86–7  
 Memorial Delirium Assessment Scale, 111

## Index

- metastatic melanoma, 138–41  
 methadone, guidelines for using, 118–19  
 middle cerebral artery (MCA) ischemic stroke, palliative care for, 57–9  
 Miyasaki, Janis M., 85–95  
 Montreal Cognitive Assessment (MOCA) Scale, 79, 82, 85–6, 90, 92  
 Morris, Sue E., 30–7  
 motor neuron diseases, palliative care evaluation, 76  
 movement disorders, palliative care evaluation, 75  
 multiple sclerosis  
   advance care directives for patients with, 156–7, 158–9, 161–4  
   neuropsychological disturbances, 165–7  
   palliative care evaluation, 153  
   in young patients, 154–5  
 Multiple System Atrophy, 75  
 muscular dystrophies, palliative care evaluation, 76
- National Consensus Project for Quality Palliative Care, 31, 35–6  
 neurodegenerative disease, palliative care evaluation, 75–6  
 neurological examination  
   advanced Parkinson's disease, 82  
   basilar artery occlusion, 60  
   end stage heart failure, 52  
   left ventricular assist device (LVAD) case study, 41  
   middle cerebral artery (MCA) ischemic stroke, 57  
   Parkinson disease diagnosis, 79, 85–6  
   spinal cord compression, 27  
   stroke in young patients and, 54  
 neuromuscular disease, palliative care evaluation, 76, 145  
   pediatric neurology, 99–101, 145  
 neuromyelitis optica spectrum disorder (NMOSD), 168–9  
 neuro-oncology, palliative care evaluation, 113  
 neuropathic pain, amputation for, 118–19  
 neuropsychology, multiple sclerosis and, 165–7  
 Nevel, Kathryn, 124–9  
 Ng, Lauren K., 52–6  
 non-invasive positive pressure ventilation (NIPPV)  
   do-not-intubate patients, 49–50  
   in neuromuscular disease, 102–3  
   for pediatric patients, 99–101
- nonmaleficence, patient autonomy and, 18–19  
 nonmedical topics, discussion with patients and family of, 4  
 Nonmotor Symptoms Questionnaire, 86  
 non-pharmacologic palliation, 18–19  
 NURSE model for communicating emotion, 5–6
- objective prognostication, 22–3  
 Oliver, David J., 154–7  
 outcome predictions  
   bereavement outcomes, hospice care and, 32–3  
   functional outcomes, 28  
   prognostication, 27–9  
   stroke in young patients and, 54–6  
   SUPPORT protocol, 24–5  
 outpatient care, 18  
 oxycodone, guidelines for using, 118–19
- PAINAD scores, pain management and, 108–9  
 pain management  
   in ALS patients, 105  
   chemotherapy-induced peripheral neuropathy, 121–2  
   in dementia patients, 108–9  
   neuromyelitis optica spectrum disorder, 168–9  
   in neuro-oncology patients, 115–17  
   palliative amputation for, 118–19  
   palliative protocols for, 65–7  
   patient travel and, 142–3  
 palliative care  
   domains of, 1, 14  
   ethical and legal aspects of, 14  
   five Ds of, 27  
   prolonged grief and bereavement risk screening, 31  
   role of consult in, 3–6  
   spiritual aspects of, 38–40  
   sudden death and bereavement risk screening, 35–6  
   utilization of prognosis in, 24–5  
 Palliative Performance Score (PPS), 23  
 Parkinson's disease  
   advanced disease, family and patient care during, 82–4  
   cognitive decline in, 85–7  
   compassionate diagnosis in young patients, 79–81  
   constipation with, 92–3  
   evolving goals of care in progression of, 88–9  
   palliative care evaluation, 75  
 Partain, Daniel K., 3–11
- patient  
   conflicting goals, preferences and values of, 9–10  
   discussion of prognosis with, 4–5  
   ethical and legal aspects of palliative care and, 14  
   hospice care communications with, 45–6  
   misunderstanding of prognosis by, 8–9  
   negotiating goals of care with, 5–6  
   nonmedical topics in discussions with, 4  
   summary of medical situation with, 4  
   unrealistic/impossible expectations of, 10  
   whole-person approach to, 3–4  
 Patient-Controlled Analgesia (PCA) pump, 115–17, 119  
 pediatric neurology, palliative care and, 145  
   hydrocephalic patients, 146–8  
   neuromuscular disease, 99–101  
   severe spasticity, intrathecal baclofen for, 149–52  
 peripheral neuropathy, chemotherapy and, 121–2  
 Phillips, Joel, 99–104  
 physical aspects of palliative care  
   amputation for pain management, 118–19  
   cerebrovascular disease, 49–50  
   chemotherapy-induced peripheral neuropathy, 121–2  
   constipation with Parkinson's disease, 92–3  
   dyspnea and fatigue, in ALS patients, 102–3  
   goals of, 18  
   neuromyelitis optica spectrum disorder, 168–9  
   for neuro-oncology patients, 115–17  
   neuropsychological aspects of multiple sclerosis, 165–7  
   pain management, 65–7, 108–9, 142–3  
   for pediatric neuromuscular disease patients, 99–101  
   seizure management, 127–9, 130–3  
   spasticity management, 149–52  
 physicians  
   discomfort with discussion of sensitive topics among, 9  
   prognostication guidelines for, 21–5  
 Piaget, Jean, 39–40  
 pimavanserin, guidelines for using, 86–7, 90

- polyethylene glycol (PEG 3350), 92  
 pramipexole, guidelines for using, 85–7  
 primary palliative care, 161  
 prognostication  
   communication of, 4–5, 23–4  
   compassionate diagnosis in  
     Parkinson disease patients and, 80–1  
   guidelines for physicians, 21–5  
   hospital protocol for, 25–6  
   patient's misunderstanding of, 8–9, 44–6, 124–6  
   spinal cord compression case study, 27–9  
   stroke in young patients and, 54–6  
   survival prediction and, 21–6  
   for young patients, clinical trials and, 54–6, 60–1  
 Progressive Supranuclear Palsy, 75, 94–5, 96–8  
 prolonged grief disorder (PGD)  
   criteria for, 30–1  
   physical and mental risks of, 32–3  
 psycho-educational framework, prolonged grief interventions, 31–2  
 psychological aspects of palliative care, 18  
   amputation for pain management, 118–19  
   cognitive decline in Parkinson's disease patients, 85–7  
   compassionate diagnosis of Parkinson disease, 79–81  
   delirium in dementia patients, 110–12  
   depression and anxiety in terminal patients, 106, 154–5  
   family estrangement and advanced care directives, 138–41  
   neuromyelitis optica spectrum disorder, 168–9  
   for neuro-oncology patients, 115–17  
   neuropsychological aspects of multiple sclerosis, 165–7  
   prolonged grief interventions, 31–2  
   psychosis and caregiver strain, 90–1  
   sudden death and bereavement counseling, 36  
 psychology of faith, spiritual aspects of palliative care and, 39–40  
 psychosis in Parkinson's patients, 85–7, 90–1  
 pulmonary function testing, 102  
 quality of life issues  
   multiple sclerosis patients, 158–9, 161–4  
   palliative care and, 154–5  
   shared decision-making and, 72–3  
 quetiapine, guidelines for using, 90, 111–12  
 religion  
   faith development and, 39–40  
   pain management and, 142–3  
 Rich, Shayna, 41–6, 149–52  
 risk assessment, bereavement risk screening, 30–1, 34–5  
 rivastigmine, guidelines for using, 86–7  
 R-MVP regimen, guidelines for, 115–17  
 Robinson, Maisha T., 38–46, 62–4, 96–8, 134–41, 149–51  
 Roche-Green, Alva, 146–8  
 'role reversal,' bereavement in families and, 34–5  
 ropinirole, guidelines for using, 85–6  
 safety issues, advanced Parkinson's disease patients, 82–4  
 secondary palliative care, 161  
 seizure management  
   in glioma patients, 130–3  
   transition to hospice and, 127–9  
 self-care activities, prolonged grief interventions, 31–2  
 Sener, Ugur, 134–41  
 sensitive topics, physician discomfort with discussion of, 9  
 Serious Illness Communication Checklist, 6–7  
 shared decision-making, for stroke patients, 69–73  
 Shariff, Imran, 108–14  
 Sinnaraha, Aynharan, 161–4  
 "slow medicine" protocol, progressive Parkinson's disease and, 89  
 social aspects of care  
   amputation for pain management, 118–19  
   caregiver support, 96–8  
   chemotherapy-induced peripheral neuropathy, 121–2  
   neuro-oncology patients, 115–17  
   neuropsychological aspects of multiple sclerosis, 165–7  
   prolonged grief and, 31–2  
   psychosis and caregiver strain, 90–1  
   stroke in young patients and, 55  
   spasticity in pediatric patients, intrathecal baclofen for, 149–52  
 SPIKES communication tool, 4, 79–80  
 spinal cord compression, prognostication in case study of, 27–9  
 spinal drug delivery, guidelines for, 151–2  
 spiritual aspects of palliative care, 38–40  
   amputation for pain management, 118–19  
   stroke and end stage heart failure, 52–3  
 spiritual distress crisis, 39–40  
 spousal death, prolonged grief following, 30–3  
 stem cell transplant, emotional issues surrounding, 115–17  
 Strand, Jacob J., 3–11  
 stroke  
   end stage heart failure with, 52–3  
   pain management following, 65–7  
   palliative concepts relating to, 47  
   shared decision-making for patients with, 69–73  
   surrogate decision-making for patients with, 57–9  
   in young patients, 54–6  
 structure and process of palliative care  
   advanced Parkinson's disease patients, 82–4  
   communication in acute setting and goal of, 57–9  
   in multiple sclerosis patients, 156–7, 158–9, 161–4  
   pediatric patients, 99–101, 146–7  
   prognosis and trajectory of care discussions, 96–8, 124–6  
   progressive Parkinson's disease, evolution in, 88–9  
   survival prediction and, 21–6  
 Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), 24–5  
 subarachnoid hemorrhage case study, 13–14  
 subjective prognostication, 22–3  
 sudden death, bereavement counseling following, 34–7  
 suicide, palliative care and, 154–5  
 surprise question (SQ), in subjective prognostication, 23  
 surrogate decision-making  
   absence of instruction and burden of, 134–6  
   enteral feeding decisions and, 62–4, 134–6  
   shared decision-making and, 72–3  
   for stroke patients, 57–9



Index

- survival predictions
  - communication of prognosis and, 23–4
  - epidural spinal cord compression, 28
  - five Ds of palliative care and, 27–9
  - prognostication structure and process, 21–6
- symptom management
  - constipation with Parkinson’s disease, 92–3
  - in neuro-oncology patients, 115–17
  - pediatric palliative care and, 99–101
- systemic lupus erythematosus (SLE), palliative care with, 168–9
- systemic mastocytosis with associated clonal hematological non-mast cell lineage disease (SM-AHNMD) case study, 3
- Taylor, Breana L., 57–61
- temporary noninvasive ventilation, do-not-intubate patients, 49–50
- tertiary palliative care, 161
- therapy, enhancement *vs.*, 18
- time of diagnosis
  - cerebrovascular disease, 47
  - compassionate diagnosis in Parkinson disease patients, 79–81
  - palliative care principles at, 1–2
  - seizure management at, 132
- Tokashui score, epidural spinal cord compression, 28
- Tomita score, epidural spinal cord compression, 28
- tracheostomy, for ALS patients, 105–7
- Tramadol, guidelines for using, 122
- travel by terminal patients, pain management and, 142–3
- unrealistic/impossible expectations, management of, 10
- Vanopdenbosch, Judo J., 154–7
- ventilation procedures. *See also* non-invasive positive pressure ventilation (NIPPV)
  - weaning procedures, 105–7
- ventriculoperitoneal (VP) shunt, failure of, 146–8
- vertebral metastases, epidural spinal cord compression and, 27–8
- “waiting for the miracle” perspective, spiritual aspects of palliative care and, 39–40
- Walbert, Tobias, 130–3
- wish/worry statement, 9–10
- withdrawal of care
  - case study and guidelines for, 13–16
  - device deactivation, 41–3
  - ethical and legal aspects of, 14
  - hospital protocol for, 15
  - spiritual beliefs and resistance to, 38–9
- wound care, 94
- young patients. *See also* children
  - multiple sclerosis in, 165–7
  - multiple sclerosis management in, 154–5
  - palliative care for, 54–6
  - Parkinson disease diagnosis in, 79–81
  - time-limited trials for, 60–1
- Zarit Caregiver Burden Inventory, 88–9