Improving Care at the End of Life for Residents in Long-Term Care

CHRISTOPHER A. JONES, MD, MBA, HMDC, FAAHPM
CO-DIRECTOR, HOSPITAL OF THE UNIVERSITY OF PENNSYLVANIA INPATIENT PALLIATIVE CARE CONSULT SERVICE
ASSISTANT PROFESSOR OF CLINICAL MEDICINE, PERELMAN SOM
12/12/18

Disclosure

- Neither I nor any family members have relationships with industry relevant to this presentation.
- I will not discuss off-label or investigative use of products or devices.
- I will certainly discuss off-label use of medications since that's most of what we do in PalCare.

The Story of John

Agenda

1. List patients' 3 most important aspects of high quality end of life (EOL) care.
2. Describe common barriers to family and staff satisfaction with EOL care in nursing homes.
3. Personalize anticipatory guidance language around symptoms common throughout the dying process.
4. Consider potential solutions to eleven common physical and psychological symptoms and signs at EOL.

What do people want at EOL?

ORIGINAL CONTRIBUTION

Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers

Karen E. Steinhauser, PhD
Nicholas A. Christakis, MD, PhD, MPH
Elizabeth C. Clipp, PhD, MS, RN
Maya McNeilly, PhD
Lauren McIntyre, PhD
James A. Tulsky, MD

Context A clear understanding of what patients, families, and health care practitioners view as important at the end of life is integral to the success of improving care of dying patients. Empirical evidence defining such factors, however, is lacking.

Objective To determine the factors considered important at the end of life by patients, their families, physicians, and other care providers.

Design and Setting Cross-sectional, stratified random national survey conducted in March-August 1999.

Participants Seriously ill patients (n = 340), recently bereaved family (n = 332), physicians (n = 361), and other care providers (nurses, social workers, chaplains, and hospice volunteers; n = 429).

Main Outcome Measures Importance of 44 attributes of quality at the end of life (5-point scale) and rankings of 9 major attributes, compared in the 4 groups.

DYING PATIENTS CONFRONT complex and unique challenges that threaten their physical, emotional, and

JAMA. 2000;284(19):2476-2482.

Rank these for yourself. Top 3?

- Mentally aware
- Treatment choices followed
- Freedom from pain
- Presence of family
- Feel life was meaningful
- Resolve conflicts
- Finances in order
- At peace with God
- Die at home

Table 5. Mean Rank Scores of 9 Preselected Attributes*

Attributes	Patients	Bereaved Family Members	Physicians	Other Care Providers
Freedom from pain	3.07 (1)	2.99 (1)	2.36 (1)	2.83 (1)
At peace with God	3.16 (2)	3.11 (2)	4.82 (3)	3.71 (3)
Presence of family	3.93 (3)	3.30 (3)	3.06 (2)	2.90 (2)
Mentally aware	4.58 (4)	5.41 (5)	6.12 (7)	5.91 (7)
Treatment choices followed	5.51 (5)	5.27 (4)	5.15 (5)	5.14 (5)
Finances in order	5.60 (6)	6.12 (7)	6.35 (8)	7.41 (9)
Feel life was meaningful	5.88 (7)	5.63 (6)	5.02 (4)	4.58 (4)
Resolve conflicts	6.23 (8)	6.33 (8)	5.31 (6)	5.38 (6)
Die at home	7.03 (9)	6.89 (9)	6.78 (9)	7.14 (8)

*Attributes are listed in the mean rank order based on patient response. Numbers in parentheses are mean rank order, with lowest rank score (1) indicating most important attribute and highest rank score (9) indicating least important. Friedman tests were significant at $P<.001$, suggesting that rankings by each group were different than would be expected by chance alone.

Differences of opinion

Table 3. Attributes Rated as Important by More Than 70% of Patients But Not Physicians*

Attributes	Participants Who Agreed That Attribute Is Very Important at End of Life, %	
	Patients	Physicians
Be mentally aware	92	65
Be at peace with God	89	65
Not be a burden to family	89	58
Be able to help others	88	44
Pray	85	55
Have funeral arrangements planned	82	58
Not be a burden to society	81	44
Feel one's life is complete	80	68

*$P<.001$ for all comparisons.

What increases bereaved family members' dissatisfaction with EOL care in a skilled nursing facility (SNF)?

- Receiving **confusing information** from nursing staff about the resident's care, including medical treatments
- Receiving **inadequate information** from nursing staff
- Feeling that EOL care was **different** than they had expected

J Gerontol Nurs. 2012 Oct;38(10):49-60.

Staff Needs

198 Journal of Pain and Symptom Management Vol. 53 No. 2 February 2017

Original Article

Caring for Dying Patients in the Nursing Home: Voices From Frontline Nursing Home Staff

John G. Cagle, PhD, MSW, Kathleen T. Unroe, MD, MHA, Morgan Bunting, BS, Brittany L. Bernard, BS, and Susan C. Miller, PhD, MBA

University of Maryland (J.G.C., M.B.), Baltimore, Maryland; Indiana University Center for Aging Research (K.T.U., B.L.B.), Indianapolis, Indiana; Regenstrief Institute, Inc. (K.T.U., B.L.B.), Indianapolis, Indiana; Brown University School of Public Health (S.C.M.), Providence, Rhode Island, USA

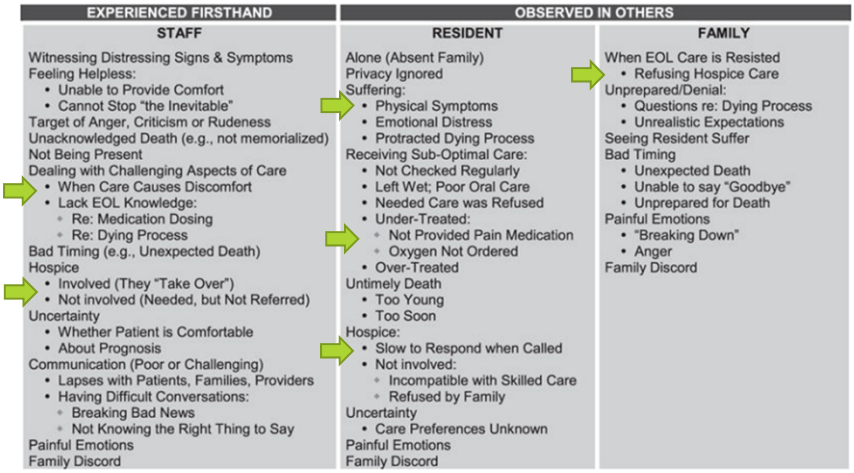
- www.pubmed.com
- Type most of the title and hit enter
- Click on this article in the topmost box
- Click PMC Full Text at the top right

It was the best of times...

EXPERIENCED FIRSTHAND	OBSERVED IN OTHERS	
STAFF	**RESIDENT**	**FAMILY**
Honored to Provide EOL Care Created a Close Bond ("like family") Learned Something & Gained Perspective Received Appreciation from: • Resident • Family members Made a Difference by: • Going the "Extra Mile" • Responding to care/support needs • Listening • Physical touch/presence Hospice Involved • Shared workload • Provided EOL expertise • Managed post-death details Prepared • Accepted Dying/Death • Knew what to expect • Strength & meaning from faith Good Communication	Received Good Care: • Physically Comfortable • Pain Managed • "At Peace" • Clean, well-groomed • Repositioned regularly • Dignity Preserved • Maintained Autonomy • Peaceful Surroundings/Environment • Kept Safe & Secure Not Alone Suffering Ended with Death Hospice Involved: • Pain & Symptoms Managed Prepared: • Accepted Death (no anxiety) • Aware of Dying • Gave/Received Forgiveness • Customs Honored (e.g., Last Rites) • Being able to say "Goodbye" • Giving/Getting Forgiveness • Crying (Cathartic; Healing)	Supported: • Emotionally • Decisions Family Involved: • Increased visits • Present at death/said "goodbye" Knowing Loved One is Free of Pain Acknowledged Personhood/Humanity by: • Sharing stories • Smiling/Laughing Hospice Involved • Educated (re: dying process; meds) • Grief counseling provided • Chaplain support Being Prepared • Accepted Death (no anxiety) • Informed (re: prognosis; treatment) • Spiritual preferences honored

Fig. 1.
Qualitative themes: nursing home staff's reports of positive experiences caring for dying patients. EOL = end-of-life.

It was the worst of times...



EXPERIENCED FIRSTHAND	OBSERVED IN OTHERS	
STAFF	**RESIDENT**	**FAMILY**
Witnessing Distressing Signs & Symptoms Feeling Helpless: • Unable to Provide Comfort • Cannot Stop "the Inevitable" Target of Anger, Criticism or Rudeness Unacknowledged Death (e.g., not memorialized) Not Being Present Dealing with Challenging Aspects of Care • When Care Causes Discomfort • Lack EOL Knowledge: ◦ Re: Medication Dosing ◦ Re: Dying Process Bad Timing (e.g., Unexpected Death) Hospice • Involved (They "Take Over") • Not involved (Needed, but Not Referred) Uncertainty • Whether Patient is Comfortable • About Prognosis Communication (Poor or Challenging) • Lapses with Patients, Families, Providers • Having Difficult Conversations: ◦ Breaking Bad News ◦ Not Knowing the Right Thing to Say Painful Emotions Family Discord	Alone (Absent Family) Privacy Ignored Suffering: • Physical Symptoms • Emotional Distress • Protracted Dying Process Receiving Sub-Optimal Care: • Not Checked Regularly • Left Wet; Poor Oral Care • Needed Care was Refused • Under-Treated: ◦ Not Provided Pain Medication ◦ Oxygen Not Ordered • Over-Treated Untimely Death • Too Young • Too Soon Hospice: • Slow to Respond when Called • Not involved: ◦ Incompatible with Skilled Care ◦ Refused by Family Uncertainty • Care Preferences Unknown Painful Emotions Family Discord	When EOL Care is Resisted • Refusing Hospice Care Unprepared/Denial: • Questions re: Dying Process • Unrealistic Expectations Seeing Resident Suffer Bad Timing • Unexpected Death • Unable to say "Goodbye" • Unprepared for Death Painful Emotions • "Breaking Down" • Anger Family Discord

Fig. 2.
Qualitative themes: nursing home staff's reports of negative experiences caring for dying patients. EOL = end-of-life.

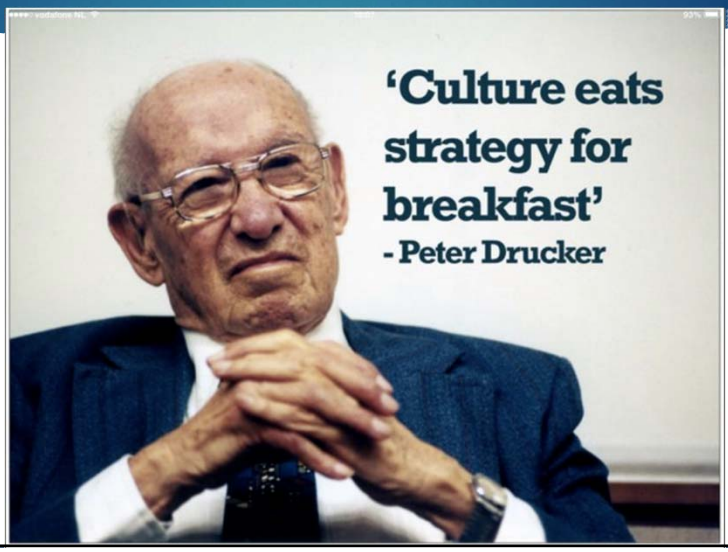
When do CNAs do better after a resident's death?

- Certified nursing assistant (CAN) is older and a longer tenure in the job
- Perceived the resident as in pain
- Perceived that the resident was aware he/she was dying
- Turned to their coworkers for support in the last weeks of the resident's life
- Resident died on hospice and CNA viewed the hospice involvement as positive

Van Riesenbeck et.al. J Pain Symptom Manage. 2015 July; 50(1): 9–16.

Bringing Care to the Nursing Home

Working in the Nursing Home



Humble PalCare Partnership

- Find the facility's power center (usually DON or NHA)
- What keeps that person up at night? (regulatory/quality of care, readmissions, resident symptoms, staff distress/turnover)
- "How can my team and I partner with you to improve _____?" (partnership, not mergers and acquisitions)
- Pilot care with 1-3 patients then meet to reassess (what can we do different or better?)

https://www.healthcareitnews.com/sponsored-content/solving-healthcare-value-equation-0

Barriers to High-Quality EOL Care in Skilled Nursing Facilities

- Limited skill set around palliative best practices
- Varied comfort level among SNF physicians and nursing staff treating symptoms
- Some commonly used medications at EOL face regulatory hurdles
- Hospice services are based on prognosis and we are terrible at prognostication
- Financial incentive to perform rehab in the dying
- Reimbursement for palliative care services is typically inadequate to cover program costs
- Variable hospice usage compared to the average population

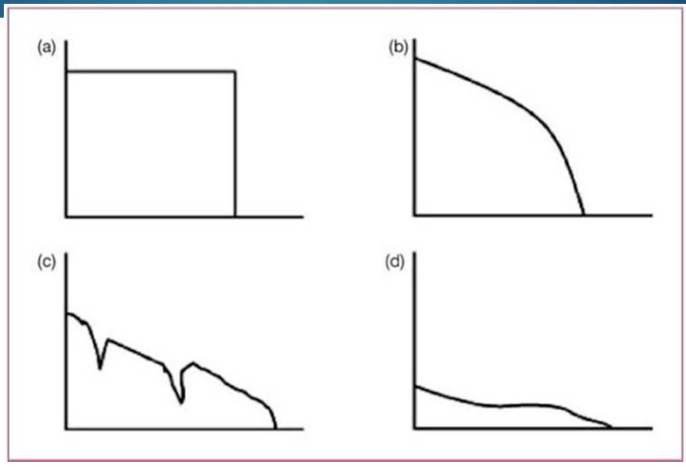
J Am Med Dir Assoc. 2018 Sep 24. pii: S1525-8610(18)30418-3.
Gerontologist. 2013 Oct;53(5):817-27.
Ann Palliat Med. 2016 Jan;5(1):22-9.

How does the money work?

- MediCARE (and many private insurers) pay for hospice care in any setting but not SNF room and board if not doing rehab
- MediCAID or the resident/family pay for room and board in the nursing home ($200-600/day)
- Hospice "get a lot, give up a bit too". Give up disease-focused care. Palliative Care can happen at any stage of a serious illness ALONG WITH curative therapies.
- Veterans Affairs supports "Concurrent Hospice" (can get hospice along with curative chemo/radiation)

www.getpalliativecare.org
Health Aff (Millwood). 2017 Jul 1;36(7):1274-1282.

4 Trajectories of Dying



Sudden

Cancer

Organ Failure

Neuro

Rand Corp. 2003.

Shifting gears to Clinical Care

Brink of Death Care

- Normalize the normal
- Modify the distressing
- Neither speed nor hasten death

Discussing Prognosis

- Emotional vs Intellectual Question
  - Intellectual question – data (logistics)
  - Emotional question – explore data needs
- No absolutes. "I'm worried…"
- If families ask, offer prognosis in a range (hours to a day, days to weeks, etc.). For one-way extubations, offer a prognosis whether they ask or not (minutes to weeks) to minimize second-guessing later on.

Talking about dying

- Death is a process, not an event
- Anticipatory guidance
  - Sleepiness/Lethargy
  - Oral Secretions
  - Cool Extremities
  - Non-Verbal Pain
  - Breathing Pattern Changes
  - Anorexia

Words that work (for me)

- Dying:
  - I am seeing some physical changes that make me worried he's beginning to die.
- Anticipatory Guidance:
  - Lethargy: Most people with his level of illness get sleepier each day as they get closer to dying. Our medications shouldn't worsen that.
  - Oral Secretions: Have you heard of a frog in the throat? She has a tiny bit of saliva in her voice box that's rattling around when she breathes. She isn't choking or she would cough. It is more like a snore. We can try some medicine to decrease the sound.

Words that work (for me)

- Anticipatory Guidance
  - Cool Extremities: As her body pools its resources to the center, the feet and hands can get cool. It isn't painful but can be surprising to families.
  - Non-verbal Pain: When people can't tell us ouch, things we look for to show pain include a wrinkled forehead, tightly clenched fists, rolling in the bed, and moaning and groaning. It's almost always a combination of those and not just one.

Words that work (for me)

- Anticipatory Guidance
  - Breathing Changes: During dying, people's breathing can look like anything. There's no pattern that shows pain; it is just the body responding to acid in the blood. We can use medicine to keep the breathing from getting too fast.
  - Anorexia: Imagine the sickest you ever were and what your appetite was then. The way the body protects against nausea/vomiting is by dropping the appetite. Offer food and liquids frequently and let her appetite guide when to stop. Too much will make her vomit. As long as she is full, she's eating enough.

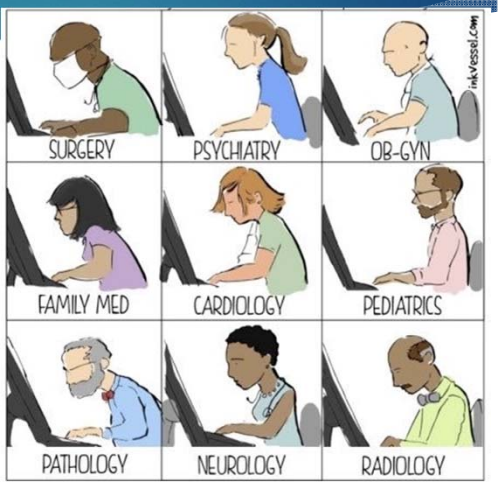
Care of the Dying – Common Symptoms at EOL

- Delirium
- Anxiety
- Anorexia
- Fatigue
- Secretions
- Pain
- Dyspnea
- Fevers
- Nausea
- Constipation
- Pressure ulcers

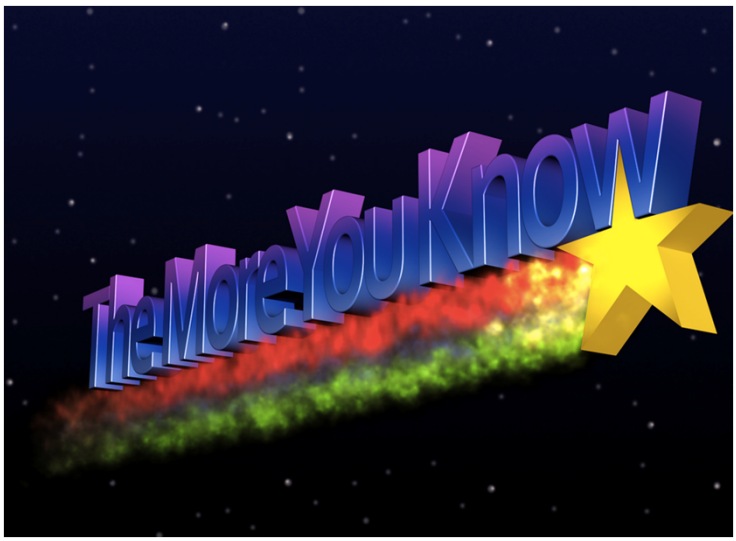
Fildes. *The Doctor.* 1891

Care of the Dying – Common Symptoms at EOL

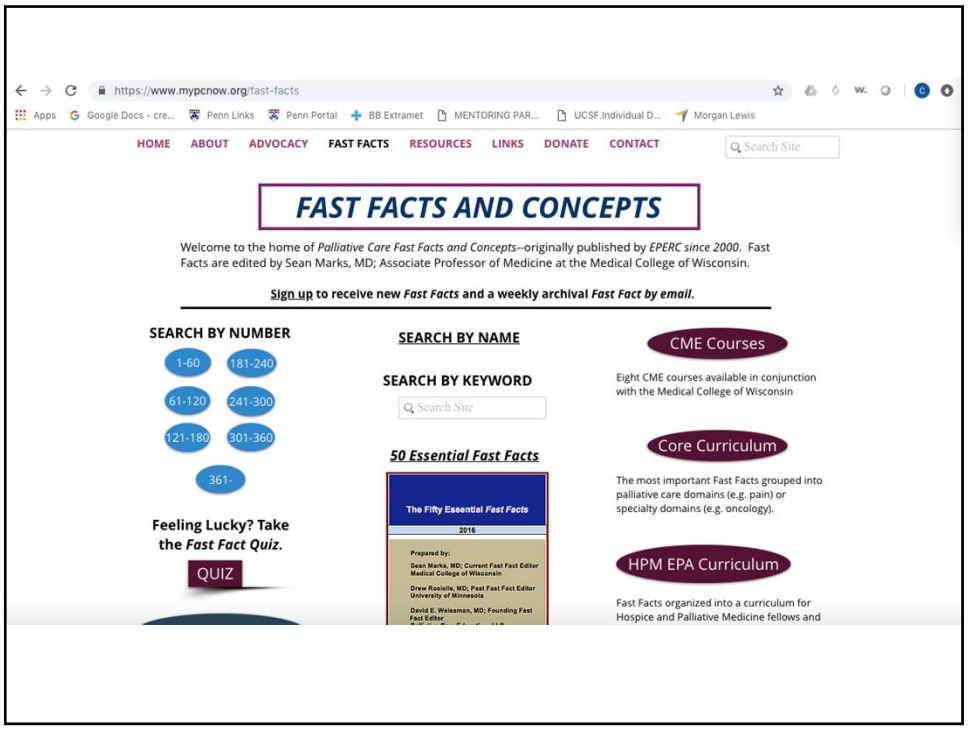
- Delirium
- Anxiety
- Anorexia
- Fatigue
- Secretions
- Pain
- Dyspnea
- Fevers
- Respiratory pattern
- Nausea
- Bowel obstruction
- Pressure ulcers



Gray. *The Doctor.* 2018



www.mypcnow.org



FAST FACTS AND CONCEPTS
Core Curriculum

The Core Curriculum contains the most important Fast Facts within a particular palliative care domain or speciality area. These can be used to supplement a Generalists Palliative Care training initiative, for on-boarding new palliative care specialists, for health professional trainees working in hospice and palliative medicine or for "just in time" education to meet a clinical problem.

Palliative Care Domains

- Cancer Syndromes
- Communication Skills
- Ethics
- Hospice
- Non-Pain Symptoms
- Nutrition / Hydration
- Opioid Ordering
- Opioid Products
- Opioid Toxicity
- Pain-Misc. Topics
- Prognosis
- Psycho-Social
- Substance Abuse
- Wounds / Oral Care

Specialty Domains

- Cardiac
- Emerg Med
- GI
- Hospitalist
- Neurology
- Oncology
- Pulmonary
- PC Teams
- Psychiatry
- Renal

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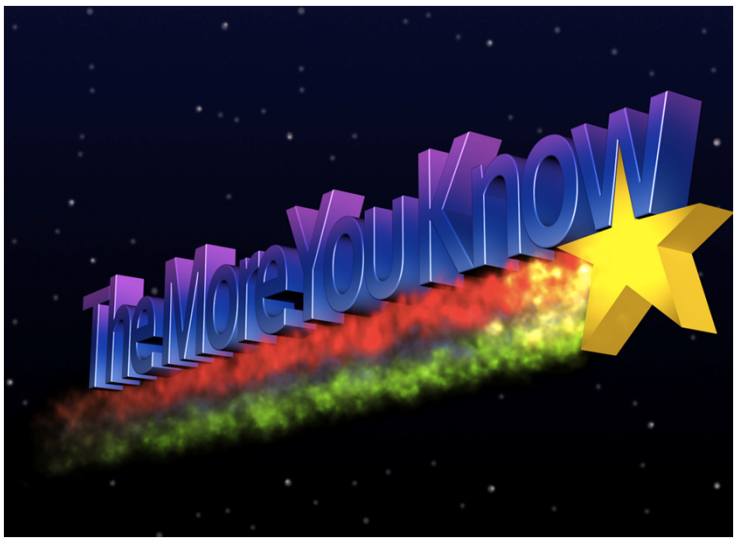
IPHONE ANDROID



Prognostic Physical Exam

2 weeks – drinks OK but eats no more than teaspoonfuls

8.7 days – stops dialysis (1 hour to 1.5 years)

1 week – neither eats nor drinks nor IVF (0-23 days)

2-3 days – unconscious and cool, purple feet or knees
(clock resets if resolves – won't happen in sepsis)

Hours to a day – pulselessness of the radial artery
– mandibular breathing (NOT called agonal breathing because no agony!)

Oncologist. 2014 Jun; 19(6): 681–687.

Delirium (not Delerium)

- Reversible or part of dying? Can't always tell.
- 75% hypoactive, 25% hyperactive
- Confusion Assessment Method (1 and 2 and (3 or 4))
  1. Acute onset and fluctuating course
  2. Inattention
  3. Disorganized thinking
  4. Altered level of consciousness
- ***Ativan = Badivan --- Use Hal-lelujah-dol and Quiet***
- Benzos work on GABA – like whiskey. Paradoxical reaction = mean drunk?

https://www.mypcnow.org/blank-tjksj

	Extrapyramidal	Sedation	Weight gain	Hyperglycaemia	Anticholinergic	Orthostatic hypotension
Atypical antipsychotics						
Risperidone	●●	●● initially	●●	●●	●	●● initially
Quetiapine	○*	●●●	●●	●●●	●●	●●
Olanzapine	○	●●●	●●●	●●●	●●●	○
Clozapine	○	●●●	●●●	●●●	●●●	●●
Amisulpride	●●*	○	○	○	●	○
Aripiprazole	○	○	○	●	●	○
Ziprasidone	○	●●	○	○	○	●●
Typical antipsychotics						
Haloperidol	●●●	○	●●	●●	○	○
Chlorpromazine	●●	●●●	●●●	●●●	●●●	●●●

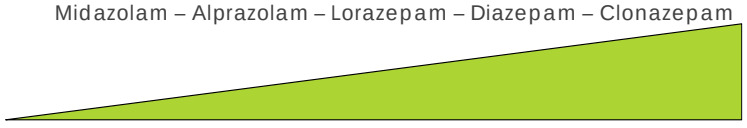
Approximate frequency of adverse effects: ● (<2%) = negligible or absent; ○ (>2%) = infrequent; ●● (>10%) = moderately frequent; ●●● (>30%) = frequent. * rarely a problem at usual therapeutic doses

Psychotropic Expert Group. Therapeutic guidelines: psychotropic. Version 6. Melbourne: Therapeutic Guidelines Limited; 2008.

Anxiety

- Subjective feeling of worry. NOT screaming out.
- Benzos are perfect here. Geriatric mantra – start low, go slow. (Ativan 0.25-0.5mg for tiny elderly folks)
- Take one chaplain daily, titrate to effect.
- Common benzos by duration (short to long)

Midazolam – Alprazolam – Lorazepam – Diazepam – Clonazepam



https://www.mypcnow.org/blank-zh5tm

Anorexia

- Most patients at EOL do not eat
- Not eating does NOT mean starving to death
- Aim for "full and comfortable", not "eating enough"

Language around not eating:

- "Think about the sickest you ever were. What was your appetite like?"
- "Dying makes you not eat – not eating does not make you die"

Medication options

- Megesterol increases fat/causes DVTs (Progestin and Derivatives)
- Mirtazapine 7.5-15mg at hs or decadron 2-4mg/day

https://www.mypcnow.org/fast-fact-314
https://www.mypcnow.org/blank-bn2th

Fatigue

- 60-90% of cancer patients report fatigue
- Meta-analysis endorses methylphenidate (start 2.5-5mg at 8a and noon to max 30mg/d – beware in AFib)

PLoS One. 2014 Jan 8;9(1):e84391

- Modafanil doesn't work.

Eur J Cancer Care (Engl). 2016 Nov;25(6):970-979.

- Decadron 2-4mg BID can help for 2-4 weeks.

https://www.mypcnow.org/blank-hgeds
https://www.mypcnow.org/blank-azovr
https://www.mypcnow.org/blank-c0kts

Oral secretions

- "Frog in the throat" analogy – NOT choking
  - Scopolamine patch ($18 for 72h) takes 6-12h to work (and causes delirium, blurry vision, and dry mouth)
  - IV or SQ glycopyrrolate (quaternary amine so no delirium– relatively expensive)
  - Atropine eye drops SL (2 drops q4h standing - $30-60 for first dose and next 19-29 doses are "free")
  - Levsin/hyoscyamine 0.125mg crushed in the cheek (<$1/dose)

https://www.mypcnow.org/blank-wz9l3

Pain

- 1mg IV dilaudid = 7mg IV morphine = 21mg po morphine = 14mg oxycodone = 5 po dilaudid
- M-6-G good, M-3-G builds up in renal failure -> myoclonus/seizure
- Opioids never stand alone. Use an adjuvant too.
- All patients on long acting need breakthrough opioids. 10-15% of total daily dose q3h prn for oral breakthrough dosing.
- Fentanyl patch = $\frac{\text{oral morphine in 24h}}{\text{dose in mcg/h} \qquad 3}$
- The pelvis is a land of mystery and nerves. Treat neuropathic pain (decadron, gabapentin, pregabalin, TCA). Opioids will often not be enough by themselves. Methadone can help neuropathic pain.
- Don't forget about interventional procedures (pudendals and tunneled epidurals)

Dyspnea

- Dyspnea is subjective. Normal O2 sat does not rule out dyspnea.
- Opioids (there is no "best" for dyspnea), cool room, fan to the face (CN V), pleurex cath, nebs, lasix (dry lungs are happy lungs), blood, sit up, d/c IVF.
- Oxygen is only better than "medical air" or a fan if baseline hypoxemia.

Lancet. 2010 Sep 4;376(9743):784-93

https://www.mypcnow.org/blank-mbri1

Fevers

- Infections anywhere, DVTs, the 5 Ws
- Microaspiration at EOL when unconscious is common. Frame fevers as the way the body PREVENTS pneumonia.
- Treat with IV/rectal acetaminophen or IV ketorolac.

Nausea (A VOMIT)

- A – Anticipatory – benzos to calm cortex
- V – Vestibular – scopolamine patch/Phenergan
- O – Obstruction by Constipation – senna/sorbitol
- M – Motility of Upper Gut - Metoclopramide
- I – Infection/Inflammation – Phenergan for labyrinthitis/viral gastro or Compazine
- T – Toxins stimulating CRTZ
  - Ondansetron for chemo-induced
  - Compazine for opioid-induced nausea
  - Haldol (0.5-1mg up to TID)

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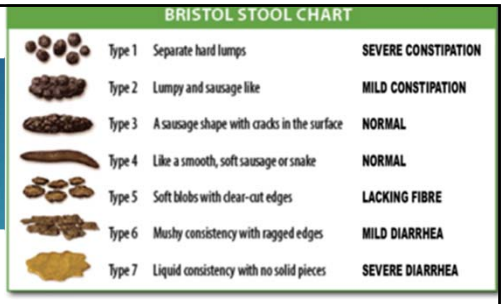
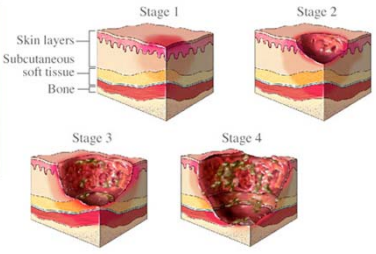
Opioid-Induced Constipation



1. Hope is not a plan.
2. Senna (1 tab QOD to 12 tabs divided up per day!) and Miralax 17g up to 2xd
3. Sorbitol 70% - 30-60ml q12h prn until BM if no BM in 48-72h
4. Bisacodyl suppository or Fleets enema if no BM in 72h to clear possible impaction
5. Methylnaltrexone (weight-based dose) or naloxegol if no BM in 4-5 days and no obstruction (inpt, will check KUB first). Risk of perforation if used in obstruction.

Clin Gastroenterol Hepatol. 2018 Jan 25. pii: S1542-3565(18)30087-9. doi: 10.1016/j.cgh.2018.01.021

Pressure Ulcers



- Kennedy ulcer = pressure ulcer that comes with dying. Stage IV ulcers have no nerves so don't hurt.
- Rule of thumb – put anything on the ulcer except the patient
- For anaerobic infections in wounds, crush flagyl pills and sprinkle on the wound for odor control.
- This is not from bad nursing care; this is from low albumin/BP. Short of a rotisserie, no way to prevent if dying is slow.

Medications for the Dying

Medications for the Dying

HAM Sandwich

H = haldol for agitation (if possible in SNF)

A = ativan for anxiety

M = morphine or another opioid for pain/dyspnea/RR > 22

S = something for secretions (atropine eye drops sublingually, or Levsin buccally. TD scopolamine patch takes 6-12 hours to work)

Take Home Points

- Patients value being pain free, at peace with God, and in the presence of family at end of life.
- Family members and SNF staff can struggle before and after a resident's death.
- 'Culture eats strategy for lunch' when setting up a PC program.
- Provide anticipatory guidance to normalize the normal and ensure the nurses are empowered to care for dying patients by having a HAM Sandwich ordered.