The Dementia Trajectory

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DEMENTIA TRAJECTORY OUTLINE

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Teen	Having hobbies, driving a car, getting a job Planning and organizing tasks: preparing a meal, grocery shopping, laundry	Early Dementia
School age child	Able to be left unsupervised Simple math and managing money Reading: being able to understand and follow instructions	Middle Dementia
Preschool child	Grooming: hair, teeth, (shaving and makeup) Dressing Toilet training: bowel and bladder continence Talking: able to express needs in words, then full sentences.	
Baby	Walking (sitting up, crawling, standing, walking) Feeding (spoon fed, finger foods, spoon and fork) Rolling over, sitting up and looking at the world Sleeping and eating Swallowing	Late Dementia Actively Dying

When Things Go Wrong in LTC– Common Ingredients of a Train Wreck

Trevor Janz MD

No Disclosures or Conflicts of Interest

Learning Objectives

The learner will be able to

-Recognize features of a challenging LTC admission

-Identify risk factors for team and family conflict

-provide a supporting strategy to improve each risk factor for team members and families

-Feel more confident in managing and improving interpersonal conflict

Features of a Train Wreck

-high emotional intensity
-interpersonal conflict
-a personal sense of
    -dread or apprehension
    -avoidance or reluctance
    -unhealthy boundaries; when I'm personally losing my balance, and I find myself overly attached or involved, or or a family member pushes my buttons, and I become angry, abrupt, or rigid.

Features of a Train Wreck

-increased frustration and anger
-breakdown in communication
-markedly divergent realities between care team and family
-family loss of trust or confidence in the team
    -mistrust or suspicion
    -accusations of lying hiding, or distorting the truth
    -family providing care for dad “In spite of the team”
-Staff unwilling to work on the unit

Features of a Train Wreck

-presence of unprofessional behaviours from staff
    -hiding or mischarting incidents
    -scapegoating other staff or shifts
    -speaking inappropriately to family
-socially unacceptable behaviours from family
    -shouting, accusations, threats
    -refusing some caregivers

Features of a Train Wreck

-family denial or avoidance of medical facts
-family blaming staff for resident's condition or decline
-family demanding copies of chart or incident reports
    -recording phone calls or conversations
    -videotaping staff members doing care
    -soliciting complaints from other residents' families
    -threatening reporting to licensing, the College, lawyers, or the newspaper

Features of a Train Wreck

Triggering Incidents

-resident-to-resident aggression (falls/ fracture/ death/ coroner’s investigation/ inquest)
-Code White with resident or staff injury
-unreported/unexplained resident injury
-skin breakdown not communicated well to family
-missing resident belongings, jewelery, or money

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Risk factors

Risk factors

1. Bad medical diagnosis

-difficult death with ALS/MS/Parkinson's

-rocky course dementia

-severe BPSD

-resident-to-resident aggression

-sexually inappropriate behaviour

-mental health or substance use diagnosis

-cognitively somewhat intact but making poor choices

-personality disorder

Risk factors

2. Uncertain course/prognosis

“Most chronically ill older people have ambiguous medical prognoses…they could be living on thin ice for some years or die in a week” (Lynn & Adamson , 2003)

Risk factors

2. Uncertain course/prognosis

-CHF with SOB or chest pain

-CVA with partial loss of swallowing

Risk factors

3. Family denial or avoidance of medical facts

-severe frailty

-late organ failure (CHF, COPD)

-late dementia

4. Unrealistic family expectations

-MOST C2

-family insistence on ER transfer

Risk factors

5. Challenging family dynamics

-denial or avoidance

-anger

-blaming coping style

-controlling

-unfinished business/underlying family conflict

    -with parent

    -among siblings

Risk factors

6. Lack of robust Advance Care Planning

-completely absent “We never talked about it”

-vague “ No heroic measures” Living Will

-no disease specific conversation about what the end may look like

-unprepared families often panic as their parent approaches death, and demand burdensome and potentially inappropriate medical interventions

Risk factors

7. Poor communication

-of team with family

-between family members

-mixed messages from the team

Risk factors

8. Poor team function

-poor communication within team

-pain and symptom control

    -after hours analgesia

    -palliative/ contingency medications

-critical incidents (falls, ER transfer, aggression,etc)

-procedures around medication orders, INR, diabetes management, abnormal lab values

Vote on your favourite risk factors

1. **Bad medical diagnosis**
2. **Uncertain course/prognosis**
3. **Family denial or avoidance of medical facts**
4. **Unrealistic family expectations**
5. **Challenging family dynamics**
6. **Lack of robust Advance Care Planning**
7. **Poor communication**
8. **Poor team function**

Risk factors

3. Family denial or avoidance of medical facts
4. Unrealistic family expectations
5. Challenging family dynamics
-anger
-blaming coping style
-controlling

Unfinished Business
and
Unmet Emotional Needs

Emotional Needs

We all need to be

Nurtured
Seen
Valued
Respected
Belong

Emotional Needs

The most irrational and difficult family members are the ones who are most driven by unmet emotional needs

We can help

-name the feelings

“It sounds like you’re angry and really scared.”
“You’re just not ready to say goodbye to your dad yet.”

-recognize their efforts

“You really care about your dad.”
“You’re trying really hard to make sure he’s comfortable.”

We can help

-acknowledge their value

“Your dad is lucky to have you.”
“You make a huge difference to his quality of life.”
“You really show up for your dad.”

-align and collaborate

“Let’s work together to make him as comfortable as we can”.

Our Tasks

1. **Bad medical diagnosis**
2. **Uncertain course/prognosis**
3. **Family denial or avoidance of medical facts**
4. **Unrealistic family expectations**
5. **Challenging family dynamics**
6. **Lack of robust Advance Care Planning**
7. **Poor communication**
8. **Poor team function**

Our Tasks

1. Bad Medical Diagnosis

-Start the ‘Dying’ conversation at admission.
-Prepare family gently for the road ahead.
-Discuss milestones of disease progression, and how they will know the end is approaching.
-Reinforce comfort care and quality of life

Our Tasks

2. Uncertain Course or Prognosis

-Discuss that their loved one is “Frail enough that he could live another year or two, or die tomorrow.”

-Give a general prognosis for the condition;

“For people with this degree of CHF, about half die each year.”

-Prepare family for the next relapse or decompensation, and discuss comfort care options in the facility

Our Tasks

3. Family denial or avoidance of medical facts

-Be the compassionate expert. Gently stick to the truth.
-Use the word “dying”
-Focus on the big picture;
“She’s not dying because she has pneumonia; she has pneumonia because she’s dying.”

Our Tasks

4. Unrealistic family expectations

-Be clear about the likelihood of benefits vs harms of each treatment

-We are not obliged to offer futile therapy.

-I tell families that for frail seniors we do a better job in facility of heart attacks, stroke, pneumonia, and bladder infections than in the hospital.

-for patients with late disease, bring the conversation back to quality of life. Ask “Is your mom having any fun?”

Our Tasks

5. Challenging family dynamics

-When necessary, set ground rules for respectful communication with staff
-Align the team and family in our intention to support their loved one, and focus on their quality of life.
-Don’t back away; lean in. Book regular check ins if needed.
-Support, not blame.

Our Tasks

6. Lack of robust Advance Care Planning

- Start the conversation at admission

-Ask family not what they would want, but what their father in his prime would say, if he could see himself now.

-Anticipate changes and prepare family for decisions coming; hospital transfer, falls and fracture, infections (bladder, skin, pneumonia),feeding difficulties, stroke (feeding tube?), or heart attack.

Our Tasks

7. Poor communication

-Alert the family early when a resident is changing

-Have preemptive conversations about skin breakdown

-Decide on a point person in the family who will be responsible for notifying siblings

Mixed messages from the team

-team meetings weekly; “Who’s died?/ been admitted/ is sick/ palliative/ which families are on the roof?

Who’s going to talk to family?

End of Life Pathways

Completed Pathways.	Date	Pathways to be completed
Ed B.	Oct 5	Edith S
Pat M.	Dec 29	Cam M.
Cheryl F.	May 25	Sigrid J
Hazel P.	Oct 4	Merrill M
Doreen B	Oct 10	John VanRoy
Ivy P.		James B – started
		Bobbi F.
		Croft W.

Palliative Residents - Please indicate if receiving scheduled analgesia

Ivy P. - Nozinan 10mg every 4 hrs
Hydromorphone 2 mg every 4 hrs

Hospice
Vigil
Visits
} - Ivy receiving hospice

*if Coroner's case - do not remove butterfly / catheter
Do not fill out death certificate

Recently passed	Date	New Admissions
Bill	Sep 10	E17 - Megan (Respite - Nov 18)
Margaret	Sep 21	D16 - Regena
Art	Sep 21	E30 - Rose
Fred	Oct 1	A23 - Harry S. (respite to Nov 22)
Clancy	Oct 20	E29 - Frances
Ivy	Nov 18	F28 - Gail
		E27 - Duane

Our Tasks

8. Poor team function

-form a team with your administrator and care coordinator to lead quality improvement.

-focus on team communication and impeccable pain and symptom management

-When you do your job well, you'll make a huge difference in quality of life for frail seniors, families, and staff.

Thank You

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