University of Wyoming | Wyoming Center on Aging

A Fork in the Road: Facing a Life-Altering Diagnosis

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Our objective

- To think together about comprehensive care planning in the face of an uncertain future

Our patient

- 80 yo widow living 8 miles from the nearest small town with her middle-aged son with Down syndrome, next door to her other son and his family. She recently gave up driving. Not well known to clinic – occasional doctor visits, stable hypertension, no other known medical concerns.
- 8 months ago: during routine PCP visit asked about advance care planning. Family wondered about her son's capacity to assign his own DPOA-HC. Soon after, her PCP left the practice.
- 2 months ago: Returned to see a new PCP with completed DPOA-HC and a bleeding, foul-smelling fungating mass over her biceps, and a mass under her arm both wrapped in soiled Depends.

- Dermatology debrided and biopsied 3 lesions and found 3 different types of cancer, including adenocarcinoma of unknown primary, basal cell, and squamous cell carcinomas. Home health was sent to help with wound care.
- She made funeral plans and bought burial plots for herself and her son.
- A month ago: she presented weak, faint, hypotensive, and hypokalemic and was admitted to the hospital anemic and dehydrated. She was transfused, hydrated, and treated for her wounds.
- She met several times with a chaplain, speaking of the comfort she takes in her strong evangelical and fundamentalist faith. No fear of dying.
- Now: she has completed her cancer workup and is in the care of an oncologist. Whole body PET disclosed no primary source for her adenocarcinoma.

What Matters Most?

Assuring the wellbeing of her son with Down syndrome.

Mentation

- Highly self-reliant.
  - Why did she give up driving?
- Resourceful – followed through quickly on social work recommendations.
- No apparent dementia, anxiety, or depression.
- Confident in faith and part of a faith community.

Mobility

- Independent in ADLs, gets around well, grows sunflowers, and cooks for her son.
- Trouble maneuvering to manage wounds alone (R upper arm).
- Hates having to depend on family for transportation.

Medical treatment/medications

- Cancer treatment and surveillance
  - Waiting for final recommendations
  - What will she choose?
- Longstanding hypertension
  - Does she need 3 drugs?
    - Chlorthalidone can cause hypokalemia (but unclear in her case)
- Overall health care
  - “Not much for doctors.”
  - Serious delay in seeking medical care for obvious wounds

Arriving at a comprehensive care plan

- Who should be involved?
  - Who's in her caring network?
  - Who will she accept?
- Family conference(s)
  - Current and future needs
  - Preparing others to take her place
- How much active outreach?
  - Who should take charge of this?
- Health care oversight and care management
  - Roles of multiple physicians, social worker, home care nurse, care manager
- What does she want for the future of her son with a disability? What does he want? And what of the family who will be left after her death?