Now What? The continuum of Dementia Care
Adapting to a New Normal

One of the hardest lessons in life is letting go. Whether it’s guilt, anger, love, loss or betrayal. Change is never easy. We fight to hold on and we fight to let go.

lessonslearnedinlife.com

I understand why Alzheimer’s caregivers can be so thoroughly disconcerted day after day.

We don’t know how long.

We don’t know what is coming next.

We feel like we are walking “up the down staircase” each and every day.

Bob DeMarco
AlzheimersReadingRoom.com
“If you can’t fix it, why bother with a diagnosis”?

- Clarifies the path ahead
- Helps rally the troops
- Connects you with others on the path
- Opportunities for education
- Time to make changes proactively
- Early intervention allows for Patient Centered Care
Answers from a Good Diagnosis

- Type of dementia
- Neuropsychological testing results
  - What are the strengths and weaknesses
- Imaging: MRI, PET scan
  - What parts of the brain are affected
- Prognosis
  - Rate of decline
  - Repeating the MOCA
- Understand the Stage of Disease
  - (Mild, Moderate, Severe)
Case Examples: Two paths of Dementia care

**Bob**

- Bob lives alone. His kids start noticing that his memory has worsened since mom died 3 years ago. He is repeating himself, he is losing weight, food is rotting in the fridge.
- Bob says he is fine, the kids don’t want to step on his toes.
- Bob goes to his doctor appointments alone and seems to get a new pill every time he goes.

**Bill**

- Bill lives alone. His kids start noticing that his memory has worsened since mom died 3 years ago. He is repeating himself, he is losing weight, food is rotting in the fridge.
- Bill says he is fine. The kids convince him to humor them by getting and evaluation. They go with Bill to his Dr. appointment.
- Bill gets a comprehensive medical workup and a diagnosis of Alzheimer’s Disease. They meet with the doctor and Social Worker to make a plan to increase support. Bill decides to allow an aide to visit 3 times a week and let his kids help with the finances.
Bob

+ Bob continues to live alone for one year. He is loosing weight and the kids notice bruising but he denies falling. They notice pill bottles from multiple different doctors but Bob is not sure what they are for.

+ Bob calls the kids frustrated about the mail piling up. Kids notice Final Notice on envelopes but Bob says he will take care of it.

Bill

+ Bill continues to live alone for several years with the support of his aide. Bill has a fall and the aide lets the family know. Bill gets Physical Therapy. The aide makes sure Bill is getting his medications everyday and on time.

+ Bill’s Son is paying his bills. He notices that Bill has been writing checks to people he shouldn’t and the Son intervenes to stop payment. The Family is aware of financial resources and even with the $1500 a month for aide services Bill is not exceeding his monthly income.
Bob has a bad fall. His son finds him the next day and he goes to the hospital. He is in the hospital for a week and the Doctor says Bob is unsafe to go back home.

The kids scramble to find a rehab. He is in the rehab for 2 weeks while the kids scramble for an assisted living.

The assisted living near them has a waitlist so they have to settle on one farther away.

Bill’s family is getting worried because he has wandered from his house and gotten lost a couple times. They have a family meeting to decide between 3 options:

- Live at home with a live-in caregiver
- Move in with Family (aide support or adult day care would continue)
- Move to an Assisted Living
Bob spends the next 3 years in an assisted living.

He develops difficult behaviors and gets a diagnosis of dementia when the Assisted living transfers him to the Geripsych unit.

The Geripsych unit discharges him to a skilled nursing facility where he dies 6 months later.

Bill and his Family choose Assisted Living.

They tour several locations and choose a facility nearby with Memory care and extra training for staff.

They continue to visit Bob regularly and take him on vacations and to family events.

As his memory declines the staff is trained to support maximum quality of life. They are able to manage his behaviors with minimal medication.

Bob passes away with support from Hospice around 1 year after leaving home.
### Services Offered

- **Home Care Non Medical**
  - Companionship, help with activities of daily living and household chores
  - **Annual Cost (private pay)**
    - $40,000 - $44,000
    - (M-F, 8 hours per day)
  - **Audience**
    - Those that can safely continue to live on their own but require some help
  - **Forms of Payment**
    - Typically paid out-of-pocket, however may also be covered by private insurance or Medicaid

- **Adult Daycare**
  - Social Activities, health monitoring and therapeutic care
  - **Annual Cost (private pay)**
    - $18,000
    - (M-F, full day)
  - **Audience**
    - Those that require monitoring during the day, but have a family member that can look after them in the evening
  - **Forms of Payment**
    - Typically paid for out-of-pocket, however may also be covered by private insurance or Medicaid

- **Assisted Living**
  - Social living, health monitoring, help with activities of daily living and household chores
  - **Annual Cost (private pay)**
    - $42,000 (base rate)
  - **Audience**
    - Those that can safely continue to live on their own but require some help and prefer community living
  - **Forms of Payment**
    - Typically paid for out-of-pocket, however may also be covered by private insurance or Medicaid

- **Skilled Nursing Facility (Nursing Home)**
  - Skilled nursing, medical care and help with activities of daily living
  - **Annual Cost (private pay)**
    - $78,000 - $87,000
  - **Audience**
    - Those that require skilled nursing care and rehabilitation on a daily basis
  - **Forms of Payment**
    - Typically paid for out-of-pocket, however up to the first 100 days may be partially covered by Medicare; may also be covered by private insurance and Medicaid
Building a care team: What kind of medical help?

- Primary Care Physician
  - Medical home, prescriber
- Neurologist
  - Diagnosis
- Geriatrician
  - Complicated medical problems for older adults
- Physical and Occupational Therapists
- Geriatric Psychiatrist
- Social Work and Education
Tips for Working with your Medical team

- Get a Medical Power of Attorney
  - Put it in the medical chart
  - Keep it on hand

- Get access to the electronic medical record.
  - My Chart, Patient Portal Etc.

- Get listed as a Lead Care partner in the medical record

- Be a squeaky wheel
Why should I meet with a Social Worker?
Proactive Dementia Care

- Hospitalization & doctor visit planning
- Disease specific education
- Lifestyle suggestions
- Safety
- Legal/Financial

- Expanding the care support network
- Proactive use of respite
- Planning for unexpected
- Planned living transitions
Hospitalization & Medical Visit Planning

- **Hospitalization - Delirium prevention**
  - Accurate list of current medications & OTC meds
  - Know what medications can cause problems: Pain meds, anticholinergic meds
    - Especially with Parkinson's disease and Lewy Body Dementia
  - Discuss memory diagnosis with treatment team at admission
  - Write on the welcome board in the room
  - Stay with your loved one

- **Doctor visits**
  - Accurate list of current medications & OTC meds
  - Document concerning behaviors (time of day, frequency)
  - Prepare list of questions

- **The Patient Designated Caregiver rule** requires hospitals to:
  + Provide your loved one the opportunity to designate a family caregiver.
  + Inform you when your loved one is to be discharged to another facility or back home and provide you with a written discharge plan.
  + Give you an opportunity for instruction and a demonstration of the medical tasks required when your loved one returns home.
Driving considerations

+ Dementias are a category of diagnosis that requires notification of the DMV
+ Often able to drive safely in the Mild stage but should be evaluated
  + Major independence issues
+ Liability considerations
+ Complicated by Lack of Insight
+ Visual-Spatial issues can be identified through the MOCA and Neuropsych tests like Trails.
+ Plans should be made for loss of driving ability
+ Not “if” but “when”
Legal & Financial Planning

- Completion of appropriate legal documents
  - Advanced health care directive
  - Durable power of attorney for finances
  - If not completed early Guardianship may be necessary
  - Special Needs trust

- Developing a financial plan for care
  - Medicare & Medicaid
  - Aid & Attendance
  - LTC insurance
  - Hospice
Building a family and friend care network

- Parents don’t want to bother their busy children
- Children and spouses need to be invited to Doctor appointments from the beginning
- Long distance family and close friends should be invited to participate
- Regular meetings every few months
Lifestyle Interventions: Fighting back against the Disease

- **Physically Active**
  - 30 mins a day of exercise

- **Intellectually Active**
  - Varied & novel & daily
  - Combine with social,
    - board games, book clubs, taking classes

- **Socially Active**
  - One on one interactions
  - Expanding the social network
  - Building a full calendar

- **Meaningful activities and pursuing passions.**
Caregiver support and preventing burnout

- Caregivers are at risk for medical issues, increased stress and depression.
- Don’t give up your interests
- Be clear with your boundaries
- Make Caregiving a choice
- Avoid isolation
- Take brakes from Caregiving:
  - Get Respite and delegate
Planning for Unexpected & Proactive Respite

- Planning for the unexpected-
  - What if the caregiver gets sick?
    - Short-term plan
    - Permanent plan

- Proactive use of respite
  - Family rotations
  - Adult day services
  - Weekend respite trips

- The disease will change we have to change with it.
Red Flags that more care is needed

- Loosing Weight
- Financial mismanagement
- Mismanaging medications
- Frequent Falls
- Wandering
- Caregiver not sleeping
- Patient unsafe to be left alone
- Aggression

*Remember*

The dementia patient is not giving you a hard time.
The dementia patient is having a hard time.
Resources
Navigating Your Rights
Second Edition

The Utah Legal Guide for Those 55 and Over
Jilene Gunther
Foreword by Former Governor Olene S. Walker

New York Times bestselling author of The Checklist Manifesto

Atul Gawande
Being Mortal

Medicine and What Matters in the End

The Validation Breakthrough
Third Edition

Simple Techniques for Communicating with People with Alzheimer's and Other Dementias
Naomi Fell and Vicki de Klerk-Rubin
Questions ??

- Contact Me:
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- For ongoing updates and additional resources leave your email at:

UtahDementiaCare.com