

Supported Well and Living Well: The Dementia Experience and a Proactive Approach to Care



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<http://www.todaysmeet.com/Dementia>

Questions/Comments at any time

The dementia journey



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- Unique
- No single pathway
- Start in a different place, involve various routes with a variety of potential destinations

(SCIE 2011)

Objectives

- Better understanding of the stages of dementia
 - Focus of this workshop on Early Stages
- Approach to the workup of cognitive impairment
- Proactive approach to management of dementia as a chronic disease
- Explore 3 perspectives: health care provider, person living with dementia, and care partner
- Highlight the importance of future planning

Mrs. Franks Case Study



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- 78 years old
- widowed 5 years ago, lives alone
- daughter Julie visits daily on the way home from work
- lived in the same community all her life
- very social, active in church choir, loves to go to church events

Julie's concerns

- Mom is losing track of dates, time, possessions
 - missing meals
 - no longer keeping house clean to her high standards
-
- Mrs. Franks response:
 - blames memory problems on age
 - says she gets muddled because of poor hearing
 - “I’m just daydreaming about the past”
 - blames poor eyesight for forgotten bill payments

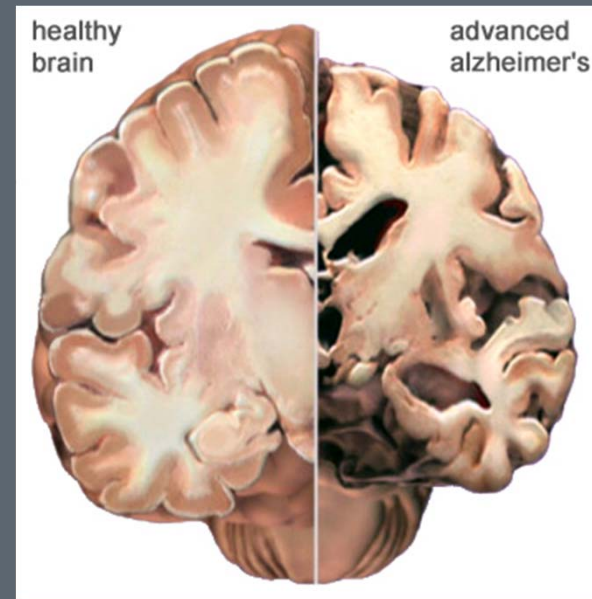


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Julie : “Mom, I think you should see your Dr.”

The stages of dementia

- Alzheimer's Model





Early/ Mild dementia

- Loss of memory of recent events (long term memory intact)
- Misplacing items
- Word finding problems, losing train of thought
- Hard to learn new things, refuses to try new things
- Harder to plan activities/make decisions
- Loses track of the day/dates
- Problems with managing IADLs

Middle/ Moderate Dementia

- ADLs impaired, need support to manage day to day life
- Frequent reminders to eat, wash, dress, toilet
- Disorientation to time/place-get lost, day-night reversal
- May put themselves at risk by their forgetfulness (leaving stove on)
- May become very easily upset or angry/aggressive OR May lose confidence and require a lot of reassurance
- Lose ability to manage pain, constipation-difficult identifying problems
- Delusions- strong beliefs without proof

Late/ Severe Dementia

- Completely dependent on others for ADLs
- Inability to recognize familiar objects, surroundings, close family/friends
- Loss of speech
- Loss of mobility, may be bed or wheelchair bound
- Difficulty eating, swallowing ->pneumonia risk
- Weight loss
- Incontinence
- Return of primitive reflexes
- Distress/aggression- misinterpret, lack of understanding

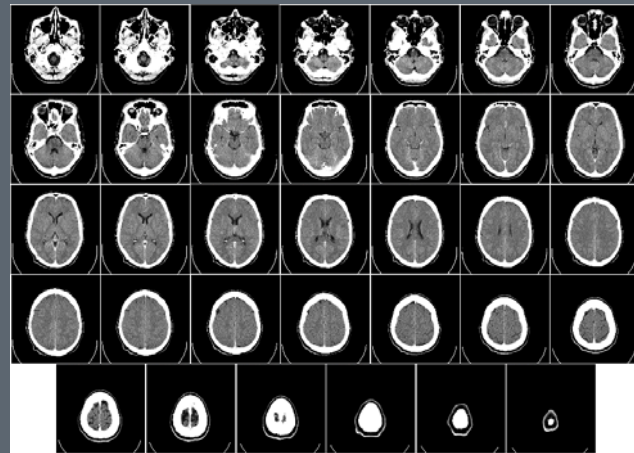
Screening/ Diagnostic Tests

- MMSE, MOCA, mini-cog
 - is not diagnostic – it's like taking a blood pressure
- Rule out reversible causes
 - Bloodwork
 - Medication Review
- Best diagnostic test?
 - Your exam + Collateral history!
 - <https://www.bostonmemory.com/memory-screen-questionnaire> Sensitivity >90%, Spec >85%

Reversible causes of dementia - Bloodwork

- TSH
- Calcium + Albumin for correction
- B12 – ?
- Electrolytes
- CBC, Creatinine
- Ammonia, LFT
- Serum drug levels

How about a CT scan?



Indications for a CT scan

- Age <60
- Rapid deterioration
- Unexplained decline in function of cognition
- Recent significant head trauma
- History of cancer, esp. types with metastases to brain
- Urinary incontinence and gait disorder
- Unusual/ atypical cognitive symptoms
- Unexplained neurological/localizing signs
- Gait disturbance
- “Short” duration of Dementia <2 years

What you tell Mrs. Franks ?



- Investigations → Book a Follow up visit
- Your admin assistant notes to you that Mrs. Frank missed 2 appointments
- Investigations come back normal
- You tell Mrs. Franks your most likely diagnosis- Alzheimer's Dementia
- Offer to connect her to the Alzheimer's society
- Offer a medication trial
- Book a follow up

Mrs. Franks' Perspective

Dementia Experience: Diagnosis



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- Dismay, deep sadness, anger and despair
- Relief and closure
- Opportunity to adjust, accommodate and focus on meaningful activities

Acceptance and Adjustment



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Shaped by:

- Personality
- Previous life experiences
- Connections with significant people/activities

Acceptance and Adjustment



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Influenced by:

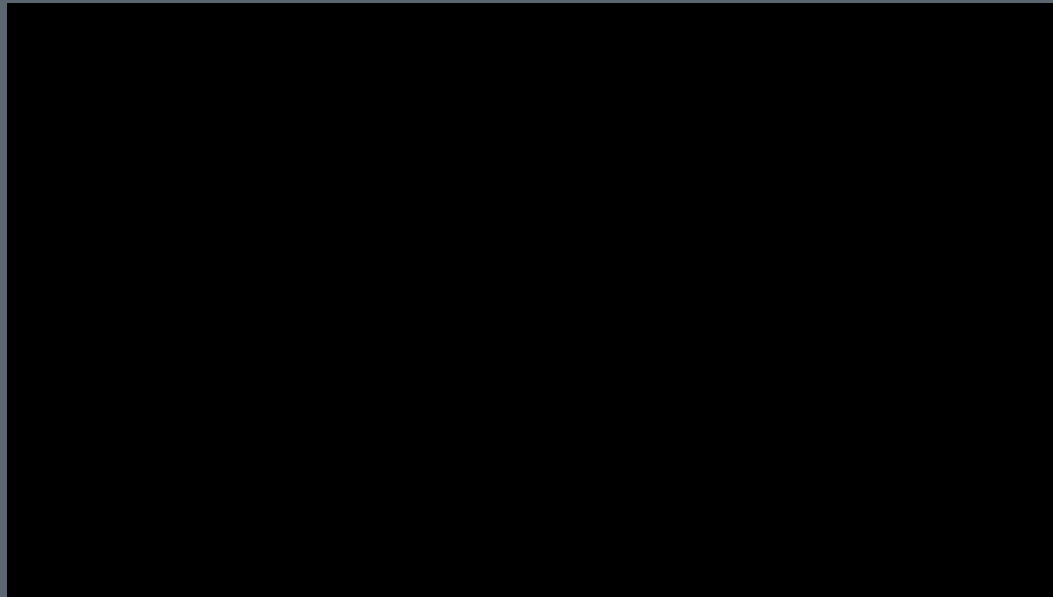
- Perception and understanding of dementia
- How others, family and wider society view and respond to the diagnosis

The influence of the media



- Create a “good story”
- Catch our attention
- Raise awareness and create a sense of urgency

“Power of Words”



<https://vimeo.com/122528299?start=12>

Supportive care-supportive language



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- Accurate
- Respectful
- Inclusive
- Empowering
- Non-stigmatizing
- Culturally sensitive

Cultural sensitivity



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Culturally and linguistically diverse (CALD) communities

Common Goals Identified by those with Dementia



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- Maintain a sense of normalcy
- Hold onto a former sense of identity
- Maintain relationships
- Engage in meaningful activities

Keeping active and occupied



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- Meaningful activity
- Health promotion measures

Keeping active and occupied



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- Creative arts
- Reminiscence therapy/life-story work

Julie's Perspective

- Julie comes back to the family doctor's office on her own
- Concerned that mom seems more sad
- She arranged for grocery delivery so that her mom doesn't have to carry the heavy groceries
- Worried about what the future holds for her mom
- What could you do for Julie?
- → Referral to Alzheimer's society- First Link



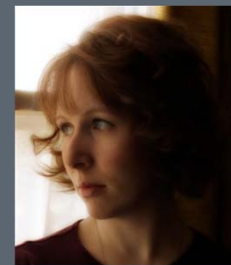


How can the Alzheimer's Society help??



What is First Link?

First Link®, is a direct referral program funded by Alberta Health and it provides an opportunity for healthcare professionals to refer individuals to the Alzheimer Society for information, support, and education.



Pillars of First Link

Direct referral - of clients to the Alzheimer Society by the health care providers

Intentional follow-up - of clients





First Link engages clients by using a Direct Referral Intake model



Who is a Care Partner?



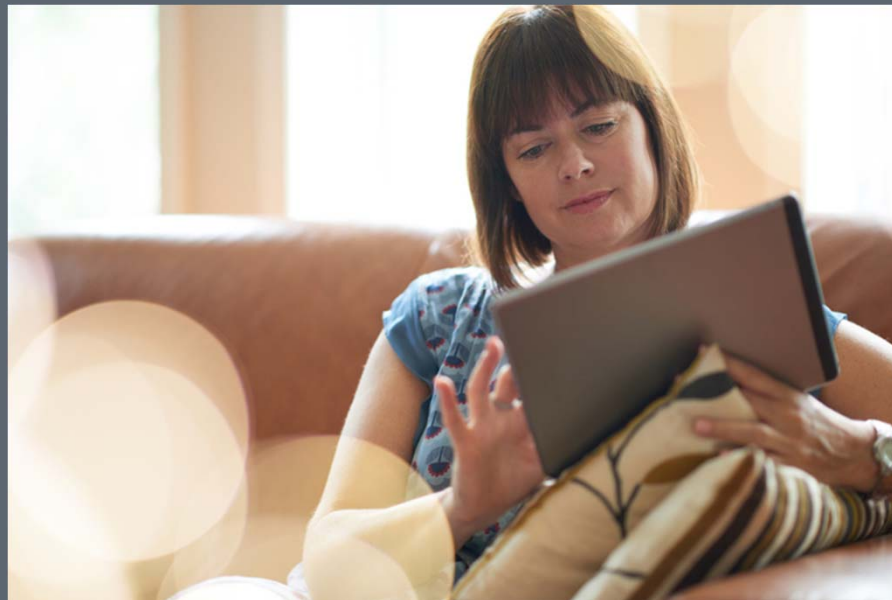
What does Support look like for Care Partners?



What does Education look like?



Education





“What is happening to my Mom?”



The Follow Up
with Mrs. Franks

Mrs. Franks' thoughts



- “I’m losing my mind” – describes how she misidentified a door to door salesman as someone she knew and let him in the house.
- “Dr. I think I want to try that memory medication”

Julie's thoughts



- Mom seems more sad
- Mom felt really foolish about letting that salesman in
- She's been hesitant to answer the door now ... and that limits her visitors

How can your team help
Mrs. Franks?

Transitions



By U.S. Air Force photo/Airman 1st Class Katrina Heikkinen [Public domain], via Wikimedia Commons

Support

Dementia can be an isolating disease. Cultivating a community of support is essential in assisting care partners.



Informal Support



- Community connections
- Peer support
- Family caregiving

Formal Supports



- Timely intervention
- Community support services
- Intermediate care

Alzheimer Society Support Groups



- Care Partners – Spouses and Adult Children
- Early Stage
- Activity Engagement
- ASANT Cafe - online community www.asantcafe.ca
- Telephone

Information

- Connecting Care Partners and People Living with Dementia to community resources
- Connecting with agencies
- Increasing community awareness

The Invisible Patient



Cognitive Flexibility and Coping Style



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Degree of awareness

- Of memory functioning will vary significantly
- Will guide the approach to support

Risk Enablement

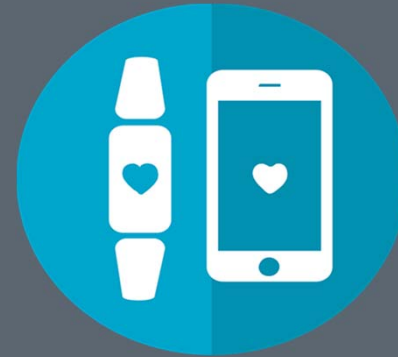


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Measuring risk involves identifying and balancing

- The positive benefits from taking risks
- The negative effects of attempting to avoid risk altogether

Assistive technology



By: mcmurryjulie, Pixabay

- Medic Alert Safely Home bracelet
- Medication dispensers
- Door alarms
- Lifeline
- Movement sensors (monitoring of doors/taps)
- Wireless audio-visual technology



Some suggestions for Mrs. Franks

- Ask Visitors to call before they come or scheduled visits
- Alarm button system – quick call for help
- Companion to grocery shop together
- Having church members pick her up for events



Planned Follow Ups with Mrs. Franks

- Dementia is a chronic illness and requires scheduled follow ups

Assessing acetylcholinesterase inhibitor trial



What do these “memory pills” do for me?

- Cholinesterase inhibitors
- Modest benefits – able to complete 1 ADL 6-12 months longer than untreated patients
- Realistically, you don't expect any improvement in cognition.
- Benefit = no change, slower change
- If no contraindications, no intolerable side effects. Continue.

Proactively anticipating needs Developing a support plan

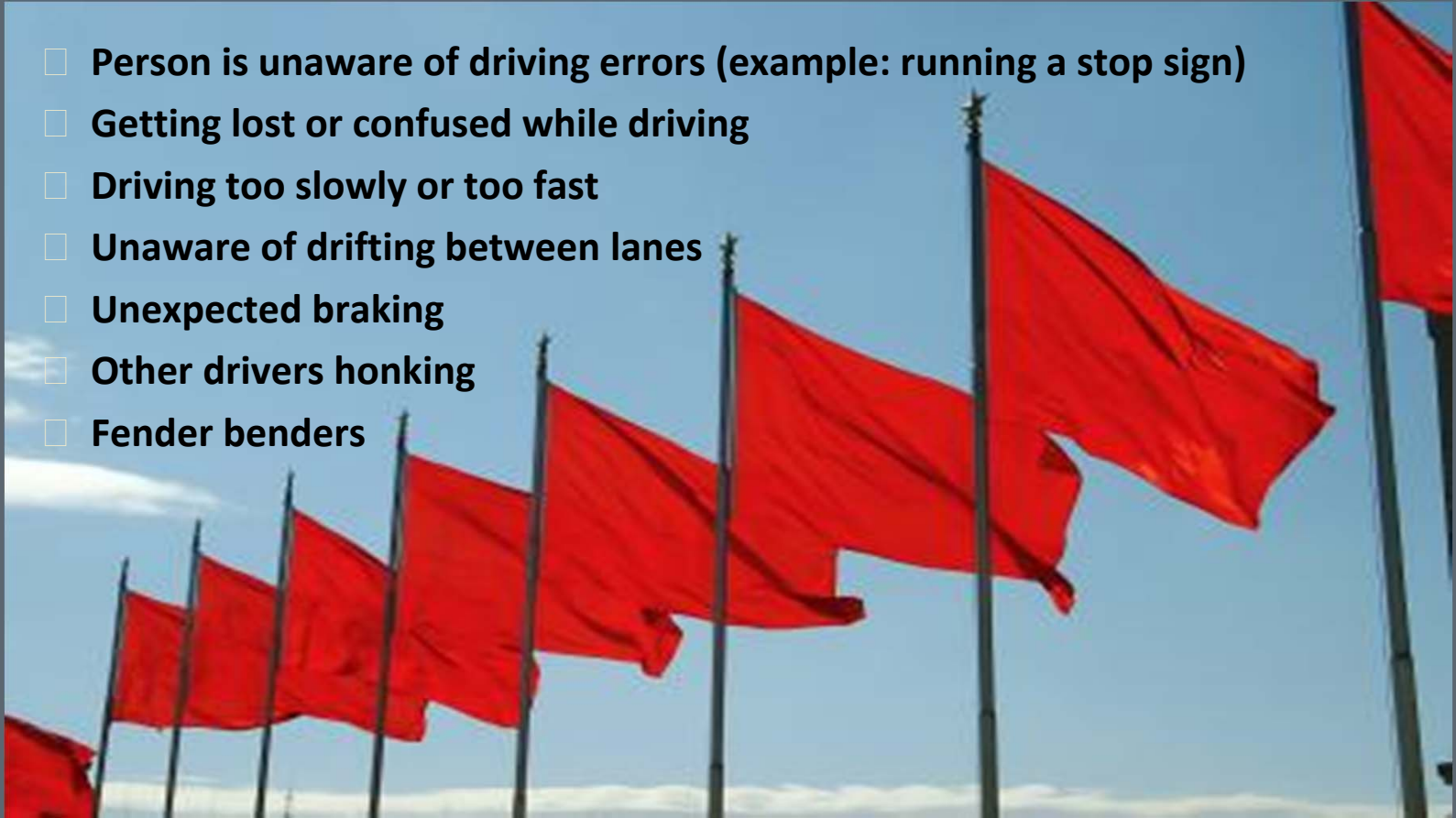


Driving- proactive planning

- Eventually, every person with progressive dementia will stop driving
- Plan for driving retirement
- Ask your patient to consider making an Advanced Driving Directive (www.mard.ualberta.ca)
- Plan ahead for alternative transportation

Red Flags to consider driving cessation

- ☐ Person is unaware of driving errors (example: running a stop sign)
- ☐ Getting lost or confused while driving
- ☐ Driving too slowly or too fast
- ☐ Unaware of drifting between lanes
- ☐ Unexpected braking
- ☐ Other drivers honking
- ☐ Fender benders



Decision Making Planning- PD/EPOA

- Gives people diagnosed with dementia opportunity to have important conversations with their family.
- Choose the person to help them makes decisions (family, friend, OPG)

Pro-active anticipation of needs and supportive planning



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Support the person with dementia to prioritize and plan for the future as dementia progresses

- avoid crisis situations
- person with dementia's pace and at his/her choosing

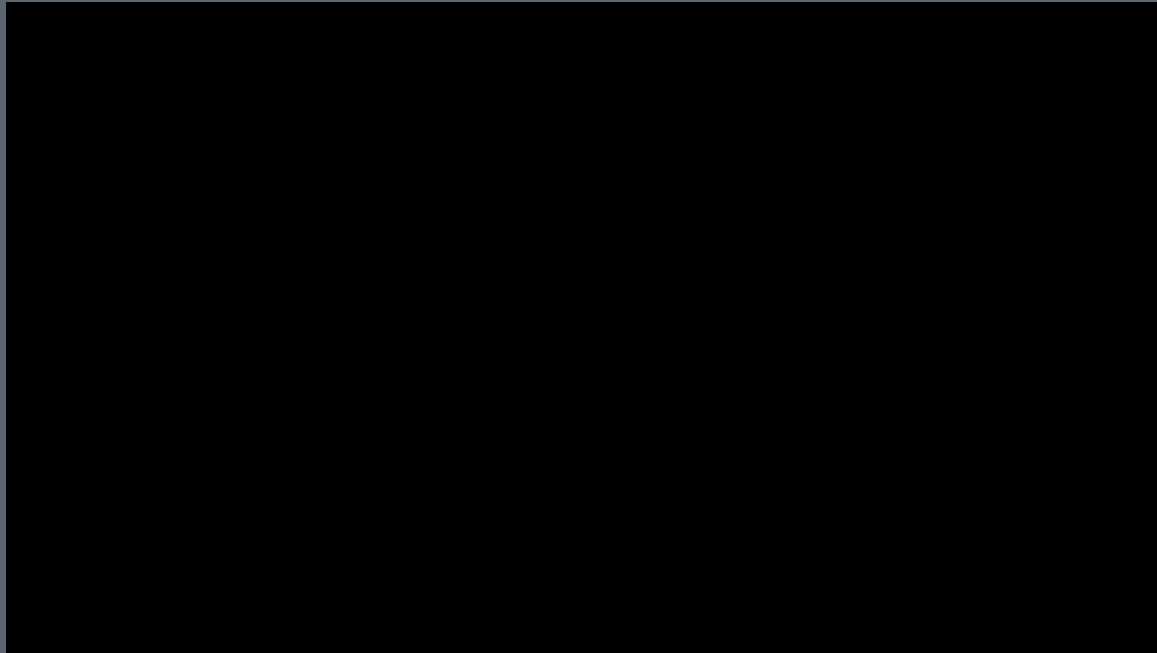
Take Home Messages



“It takes a village”

- Make use of the resources outside of the healthcare model
- Early, organized, and proactive future planning is essential
- Involve the person living with dementia in planning

“How dementia could be”



<https://www.youtube.com/watch?v=5h4IV1IVjM8>