Patient & Family Experiences of Dementia

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WHY IS THIS SO IMPORTANT?

01 Perceptions of Hypertension Care in Bateyes in the Dominican Republic



02 Patient Case: Distress with Disclosure of Dementia Diagnosis



OBJECTIVES

- Understand the perspectives of patients and their families as they navigate living with Dementia
- Explore feelings and concerns that arise at key transition points in the Dementia journey, including:
  - Diagnosis
  - Health crises and Hospitalization
  - Transition to LTC
  - End Stage Dementia + Death
- Review recommendations on how family physicians and other care providers can support patients and families, with particular emphasis on what to do immediately after your patient receives a diagnosis



Disclosures

None

BACKGROUND [1-4]



Definitions

Dementia: Cognitive decline that is associated with and leads to functional impairment, and exists outside of other pathologies

Caregiver: Someone who provides ongoing informal assistance to a person with dementia (PWD) living in the community who cannot care for themselves. The person is not paid to provide care.

BACKGROUND [1-4]



- Dementia is one of the biggest global public health challenges facing our generation
- By 2030, Canada will have 1 million people living with dementia
- In approximately 1 in 5 cases, the primary care physician is the first provider to share the diagnosis
- Recommendations around the process of disclosure have historically not been informed by “lived experiences”
- 60-80% of dementia care is provided by informal caregivers in the community, a number which is expected to rise

METHODS

- **PubMed and Google Scholar**

- **Search Terms:** “Patient and Family” AND “Experiences” AND “Diagnosis” AND “Dementia”, “Patient and Family” AND “Experiences” AND “Dementia”, “Patient Experiences” AND “Dementia,” “Family Experiences” AND “Dementia,” “Patient and Family” AND “Dementia,” “Experiences” AND “Dementia,” “patient and family experiences of dementia,” “ family experiences caring for dementia”

METHODS

INCLUSION CRITERIA

- Published in or after **2004**
- **English** abstracts

EXCLUSION CRITERIA

- Study set outside of **North America or Europe**
- Focus on **young-onset dementia**
- Reviews of literature **published primarily before 2004**

RESULTS: DEMENTIA DIAGNOSIS DISCLOSURE[3,5-12]

Do Patients Want to Know They Have Dementia?

- 92% of PWDs favoured open disclosure, compared to 98% for a hypothetical cancer diagnosis
- PWD believe they should have a choice in whether they are told their diagnosis
- 90% of caregivers wish to be told of a diagnosis of dementia for themselves if they had it, but only 43-76% wanted to disclose to the PWD



RESULTS: DEMENTIA DIAGNOSIS DISCLOSURE[3,5-12]

Reasons For Disclosure

- Patients have the right to know
- Confirmation of suspicions
- Planning treatment and earlier access to treatment
- Treatment compliance
- Positive adaptations within family and spouse relationships

Reasons Against Disclosure

- Potential for emotional upset
- Thinking PWD won't understand
- Prior distressing experience
- Rejection by family and friends
- No effective medical care available
- Worry for suicide ideation or harm

RESULTS: DEMENTIA DIAGNOSIS DISCLOSURE[3,5-12]



Feelings at Time of Disclosure:

- Relief for patients that felt there was something wrong with their body and now had an answer
- Carers felt a loss but also a sense of increased responsibility for physical care and to maintain the emotional “status quo”
- The nature of dementia being a long journey rather than a fast decline felt daunting
- Other feelings: anxiousness, doubt, uncertainty, grief

RESULTS: OUTCOMES OF DISCLOSURE[3,5-12]

Psychological Impact of Disclosure



In general, symptoms of anxiety and depression remained stable and the majority of participants did not have adverse psychological reactions (not affected by age, sex, education level, dementia severity)



6% were diagnosed with depression 1 year after disclosure but no recorded catastrophic reactions or suicides amongst 50 patients observed

RESULTS: INFORMATION DESIRED AT DIAGNOSIS[3,5-12]

- Patients/family want **up-to-date lists of supports and services available**, with their costs
- Carers want to be connected with their respective **Alzheimer's Associations**
- Carers **want to know about what is in store** - this may protect against adverse outcomes and help cope (natural hx of dementia, treatments, BPSD)
- Patients and families found hope in the physician giving them **"things to do"**
- There is **some hesitancy around asking questions** to professionals

50%



Of patients and families were dissatisfied with the lack of follow up after diagnosis

RESULTS: DEMENTIA DIAGNOSIS DISCLOSURE[3,5-12]

The term **“Alzheimer’s disease” held more negative connotation than the word “Dementia”** (but 69% prefer specific terms such as Alzheimer's over "memory impairment")

Patients want **simple, clear language** used

People would **appreciate the discussion of the possibility of dementia** before the diagnosis is “officially” confirmed so that the revelation is not a complete shock

80% of carers thought that **having written information** would have been helpful to refer to afterwards

50% of carers/patients preferred a direct **“all at once” diagnosis**, 50% preferred **progressive diagnosis**

The FP’s attitude (kind, understanding, and honest) can change a person’s outlook on dementia

RESULTS: OUTCOMES OF DISCLOSURE[3,5-12]

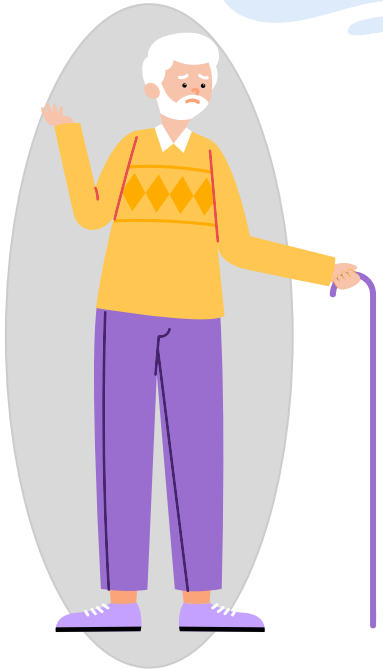
Recall of Information

- Most patients with MCI were not aware of a specific name of their diagnosis
- 24% of patients and 67% of carers remembered being told the diagnosis

  <50% remembered the name of the dementia
- Spouses were more likely to forget information around the diagnosis and advice than children
- 3 patients in the study were advised to stop driving but only 1 patient/carer dyad remembered this 6 months in

RESULTS: LIVING WITH DEMENTIA[13-15]

1. **A sense of change within one's own body**
    a. **Participants described feeling much more aware of their deteriorating body functions:** Unusual behaviour, clumsy gestures, inappropriate language and uncontrolled mind.
    b. **Losing a sense of what you can do and who you are, fear of deterioration**
        i. Some tried to "feign normalcy" in order to cope with uncertainty and distrust in their own body



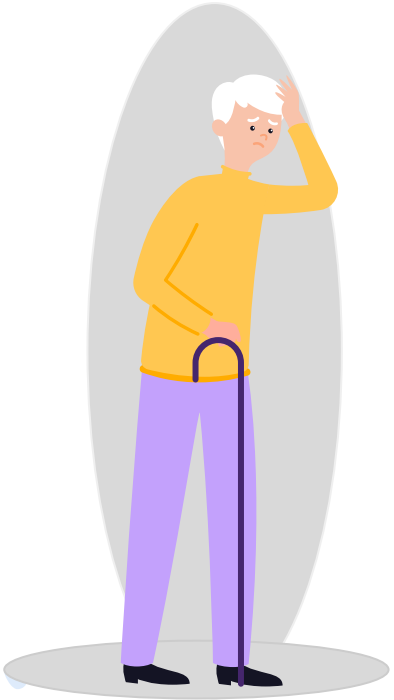
RESULTS: LIVING WITH DEMENTIA[13-15]

"I pondered, within my head, **the dementia has definitely changed everything! It's like a kind of grey veil has fallen over your brain and I really want to clean it up"**

"**I** used to engage in conversations with other people but now I **sometimes notice that I don't give the right answers, you know, stray from the theme. That makes me terribly insecure. I can't trust myself. (. . .)** Most people are very decent, they'll never joke about it (. . .) **but I have this annoying feeling that I'm not equal anymore. I'm different."**



RESULTS: LIVING WITH DEMENTIA[13-15]



2. Disrupted Relationships

a. Feeling as though **everyone is watching and scrutinizing them**

b. Some report **stronger support networks** after diagnosis

c. **Trying to mask the symptoms and feelings** around dementia makes patients feel more isolated

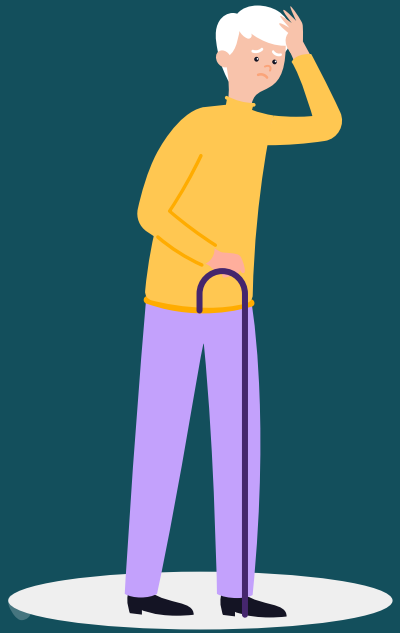
d. **Redrawing their own boundaries and abilities** improved self-worth

e. Haunted by the idea of **being a burden to their loved ones**

   i. **Feelings of inequality** with family members/partners

   ii. Feeling that their **loved one's roles as partner, spouse, child changed to "caregiver"** first and foremost

RESULTS: LIVING WITH DEMENTIA[13-15]



“You are assumed to be incapable of anything. But actually, that’s ridiculous (..) You know, I have lots of experience, **and that’s not all gone at once.”**

“Well, you’re going one step down in society. You’re no longer considered a full member of society.. Someone who is now avoided by everyone”

RESULTS: LIVING WITH DEMENTIA[13-15]

3. Disrupted Sense of Space and Time

a. Most described **starting to feel like a stranger in their own world,** and the world becoming more alien

b. **Feeling like their world has gotten smaller**, because where they can go is limited

c. Meaningful connections between self and space are disrupted, leading to a **feeling of "not being at home" and insecurity**

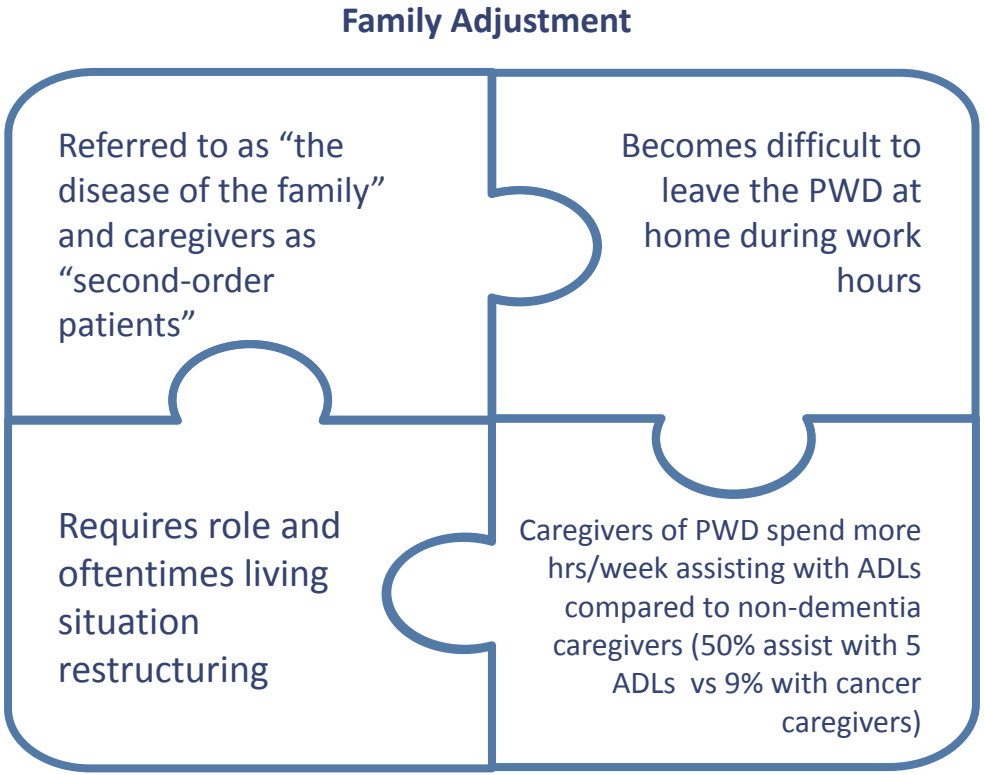
d. **Natural rhythms of day, night, and time** are disrupted

e. Thinking about the future and **wondering if you can even trust your own assessment of now and the future**

Pearl: Adding items such as **clocks, calendars, schedules, or a wall full of memos** for re-orientation can be helpful



RESULTS: LIVING AT HOME WITH DEMENTIA[7-14,16-20]



RESULTS: LIVING AT HOME WITH DEMENTIA[7-14,16-20]

Patient Suffering

Studies describe five dimensions of suffering for PWD from the perspective of caregivers:

1) untreated BPSD

2) emotional distress

3) loss of agency

4) loss of engagement

5) loss of sense of self

If left unaddressed, **made caregivers feel that PWDs' life had lost meaning** and **worsened caregiver distress**

Suffering determined caregivers' **decisions around life-prolonging interventions**

- When caregivers see PWD struggling, they **may wish for their life to end**, leading to **guilt, grief, and hopelessness**

RESULTS: LIVING AT HOME WITH DEMENTIA[7-14,16-20]

Caregivers found both the physical and emotional aggression challenging

(patients may target loved ones in delusions, blame, and other behaviours)

RESULTS: LIVING AT HOME WITH DEMENTIA[7-14,16-20]

Asking for Help

- Reports of families being **initially apprehensive to ask for help**
- **Especially spouses** and individuals of older generations, **who tend to uphold a level of stoicism**
- **Children often have to become involved** to ask for the help on behalf of the parents
- **There are roles unfilled in the home** that the PWD used to do

RESULTS: LIVING AT HOME WITH DEMENTIA[7-14,16-20]

System Navigation

- After diagnosis, several mentioned **difficulty navigating the system** and finding the right person to contact for support with certain aspects of care (fragmented systems)
- Compounds the difficult feelings during this time (frustration, loss) when a **family finally accepts that they need help and are struggling to get it**
- The system is set up to be **reactive rather than proactive**
- **Limitation of overnight resources**

RESULTS: LIVING AT HOME WITH DEMENTIA[7-14,16-20]

Respite

- Some found it difficult to access respite, but found it helpful when they did
- Others found respite unsuccessful because there were **increased negative behaviours of the PWD in respite and when returning home**

RESULTS: LIVING AT HOME WITH DEMENTIA[7-14,16-20]

Caregiver Health:

- 35% of caregivers' health worsens within months to short years after starting to care for their loved ones
- High risk of CVD, poor wound healing, decreased immunity, less health prevention
- Anxiety, depression, and physical strain are more common amongst caregivers of PWD than those with physical impairments only
- Worse when living with PWD



RESULTS: LIVING AT HOME WITH DEMENTIA[7-14,16-20]



Implications:

- Disruptions in employment, leisure activities, relationships
  - 71% had work disruptions
  - 50% used up vacation time
  - 14% had to retire early or quit
- Inability to properly care for PWD
- Grief and loss around previous life

Pearl: Even small functional gains for PWD help relieve caregiver burnout

Another who was crying intermittently throughout the interview was asked by the researcher whether she would prefer to stop the discussion. She responded ***"No, it's a relief to get this all off my chest."***

"No one had asked me how I felt before."

RESULTS: HOSPITALIZATION[5,18,21]

Hospitals for the PWD: “I’m not stupid.. but where am I? I just can’t figure out where I am..”

- Feelings of **comfort when familiar faces** are around
- **Difficult when providers consult the patient** rather than the family
- **The level of engagement required by PWDs is often not met**
- **Importance of making a connection**: “How do you put a person at ease if you don’t know anything about them”
    - Consider during care tasks ie. bathing
    - Having personalized information and items from family



RESULTS: HOSPITALIZATION[5,18,21]

Hospitals for Family: “I sort of feel lost at home - this was the worst thing. I’d go home and have nothing to do”

- **Change in role** for the caregivers
- **Not having a life to go back to**
- Feelings of neglect by the hospital especially when making **care plans around discharge**
- Disempowerment when **made to not feel like the expert of the PWD** (ie. eating preferences → poor intake)

RESULTS: HOSPITALIZATION[5,18,21,22]



Post-Discharge:

- Hospitalizations lead to **disconnect from prior routines** for the PWD, with potentially grave consequences
- May lead to a **worsened baseline with disruptions to abilities** given their lack of practice while hospitalized
- **May exacerbate confusion and agitation**

RESULTS: TRANSITION TO LONG-TERM CARE (LTC)[6,8,15,18]

Similar to hospitalizations, requires transitioning to a new role as caregivers

- Advocate for individual needs of PWD and monitor quality of care

Feeling unprepared or lonely with these changes

- Usually occurred after a crisis event (fall, hospitalization, illness)
- Often initiated by the children, leaving the spouse feeling unprepared for transition
- May feel like no longer the most important person in their loved one's care
- None of the participants in one study expressed feeling prepared
- Feeling like the person had passed away

RESULTS: TRANSITION TO LONG-TERM CARE (LTC)[6,8,15,18]

Very strong expressions of guilt and grief throughout the literature

- Not being able to maintain caregiver role
- Not being able to do more
- Not having the finances to keep the person at home
- Feeling deceitful and betraying to PWD



RESULTS: TRANSITION TO LONG-TERM CARE (LTC)[6,8,15,18]

“I just don’t seem to be able to do enough. Can’t come enough, can’t say enough, can’t do enough. And the most difficult thing to deal with is knowing the conversations that won’t be had because the mind is going.”

RESULTS: TRANSITION TO LONG-TERM CARE (LTC)[6,8,15,18]

Factors for a Difficult Transition

- Being unprepared for trajectory of disease
- Poor communication with LTC staff
    - Family needing to initiate communication
- Staff shortages or high turnover
- Not having a decision in which LTC was chosen (or not being able to tour the LTC)
- PWD voicing that they want to return home or threatening self-harm

RESULTS: TRANSITION TO LONG-TERM CARE (LTC)[6,8,15,18]

Factors for an Easier Transition

- PWD involved in decision-making process
- Recognition that the person required 24-hour care
- Getting to observe the care, engaged staff, consideration of person's individuality
- Having private time with family member, otherwise felt like relationship was on display when in common areas only
- Being phoned to ask information on the person, continuing to feel like the expert on the PWD
- Having professional help for caregiver, rather than logistics-focused support only

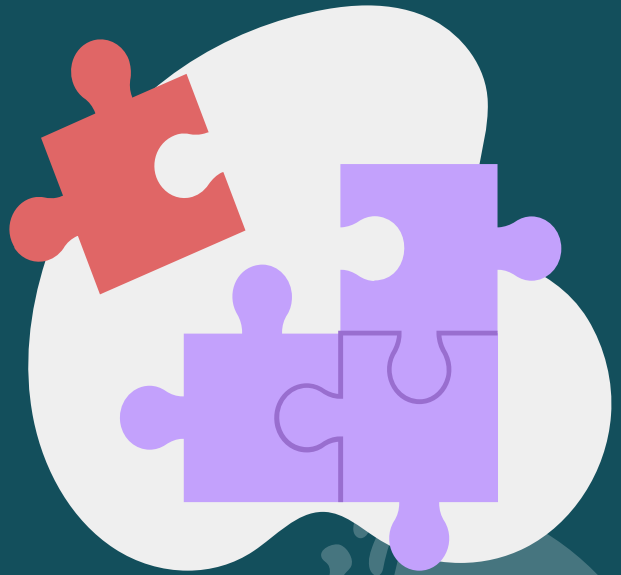
RESULTS: TRANSITION TO LONG-TERM CARE (LTC)[6,8,15,18]

The Patient Voice

- Feeling like family is their connection to their life outside of LTC, and feeling sad when family could not visit
- Poor companionship with co-residents
- Difficulty seeing patients worse off than them
- Distrust of people in the facility
    - “It’s little things that don’t matter to you when you’re younger, but little things matter a lot to me now.”
- Feeling of value when they can contribute to their facility and surroundings and engage in activities

RESULTS: END-STAGE DEMENTIA[4,17,23]

- Dementia is generally seen as a life-limiting illness but not a terminal condition by HCPs
- Failure to recognize and discuss the terminal nature of dementia leads to:
    - invasive and burdensome interventions
    - poor symptom management
    - inadequate care planning
    - unmet needs for the patient and family
- ~90% of individuals in Canada with ESD are expected to receive care in LTC
- Very limited research on the experiences of patients



RESULTS: END-STAGE DEMENTIA[4,17,23]

Goals of Care

- Most PWDs have never discussed their wishes for their care with their caregivers due to:
    - A lack of sense of urgency to have these difficult decisions
    - poor knowledge about disease trajectory
    - inconsistent HCPs
    - personal discomfort
- A significant role of the caregiver is to be a surrogate decision-maker, which many feel unprepared for and unsupported in, especially EOL decisions
- Research suggests patients with MCI/mild-mod Dementia (18-26/30 MMSE) can make informed care decisions, choose SDMs, and state preferences

RESULTS: CULTURAL NUANCES & DEMENTIA CARE[3,5,19]

Especially **in the context of rising levels of immigrants and refugees into Canada**, thought must be given to the care of older people from minority groups

Health System Barriers:

- **Limited understanding of the healthcare system** made it difficult to navigate
- Can **increase the load on families** in caring for their loved one
- May **delay diagnoses** and professional care
- Delays also due to perceiving duty to **protect and respect Elders' autonomy and independence**
- **Worry about discriminatory and stereotyping attitudes** from healthcare system
- Study found that Chinese-Americans **cognitive changes were more likely to be brought up due to being noticed by HCP** not brought to attention by family members
- **Language barriers**

RESULTS: CULTURAL NUANCES & DEMENTIA CARE[3,5,19]

Cultural Perceptions of Health and Dementia:

- Cultural understandings of dementia may worsen **stigma**
  - Perceptions of the condition as “madness, forgetfulness” or **a transient disease**
  - Reports of **consequences for unmarried females** in the family
  - Therefore **trying to hide the person and the disease** from the outside world
  - On the contrary, **strong belief in fate** and may be able to accept diagnosis as part of it
- The word “**Dementia” being insulting**, therefore “cognitive impairment” may be used to explain to PWD
- In other situations, the **PWD does not feel a need to know their diagnosis** as long as family is aware

RESULTS: CULTURAL NUANCES & DEMENTIA CARE[3,5,19]

Caregiving:

- Different **perceptions of the family's role in care for elders** (moral/religious/cultural obligation)
- Caregiver often determined by **factors such as birth order & entrenched gender roles** (mostly female)
- Most family caregivers in the studies **lived in the same house as the PWD**
- **Exacerbated consequences for caregiver** (emotionally, economically, socially)
- Most studies had caregivers refer to positive aspects: "**being satisfying even if it is a heavy burden**"
- **Some report caregiving gradually became a hardship** → feelings of disappointment, failure, distress
    - May lead to **dissociation from community** that was once a source of strength
    - Fear of being perceived as a "**bad child**" if not able to care for parent or seeking help from the system

SUMMARY & RECOMMENDATIONS

- Do not assume the patient does not want to know their diagnosis
- Do not assume patients and families will ask questions
- Do not dismiss the difficulty of returning home from hospital
- Do not forget that dementia is a terminal disease and requires advance care planning

- Do become comfortable talking about the trajectory of dementia
- Do become acquainted with local supports
- Do consider cultural nuances
- Do provide extra support during transitions
- Do normalize and provide support for diverse feelings along the journey

Your Patient Has Been Diagnosed with Dementia - Now What?

First Follow-Up (~2-4 weeks post-diagnosis)

- Review the diagnosis definition
- Review treatments
- Discuss local supports
- Review safety concerns and driving
- Answer questions
- Review follow-up plan

Second Follow-Up (~4 weeks later)

- Review Dementia trajectory
- Review safety concerns
- Explore feelings
- Discuss local supports
- Answer questions
- Prepare for next follow-up

Third Follow-Up (~4 weeks later)

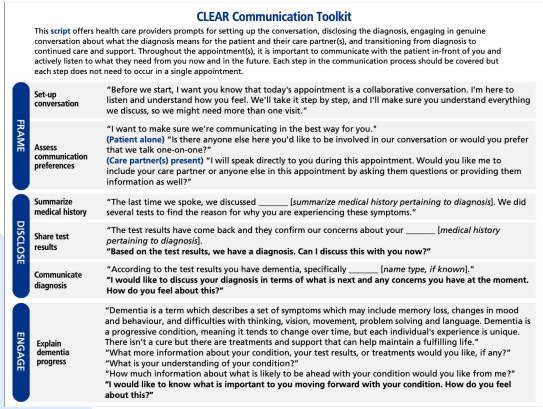
- Discuss Advance Care Planning (POA, Rep agreement, will, MOST)
- Recommend keeping a hospital package ready
- Answer questions
- Prepare for next follow-up

Ongoing Follow-Up (~q3-6m)

R. Suleman, 2024

RECOMMENDED RESOURCES

CLEAR COMMUNICATION TOOLKIT: DISCLOSING DEMENTIA DIAGNOSIS



CLEAR Communication Toolkit

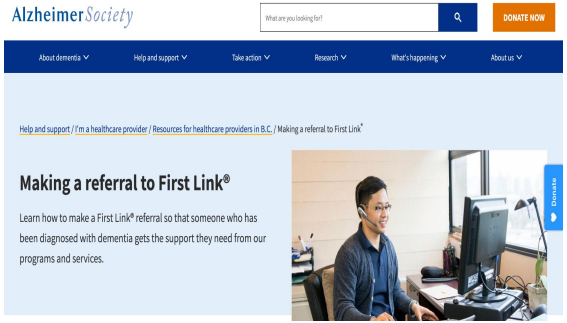
This **script** offers health care providers prompts for setting up the conversation, disclosing the diagnosis, engaging in genuine conversation about what the diagnosis means for the patient and their care partner(s), and transitioning from diagnosis to continued care and support. Throughout the appointment(s), it is important to communicate with the patient in-front of you and actively listen to what they need from you now and in the future. Each step in the communication process should be covered but each step does not need to occur in a single appointment.

FRAME	Set-up conversation	"Before we start, I want you know that today's appointment is a collaborative conversation. I'm here to listen and understand how you feel. We'll take it step by step, and I'll make sure you understand everything we discuss, so we might need more than one visit."
	Assess communication preferences	"I want to make sure we're communicating in the best way for you." **(Patient alone)** "Is there anyone else here you'd like to be involved in our conversation or would you prefer that we talk one-on-one?" **(Care partner(s) present)** "I will speak directly to you during this appointment. Would you like me to include your care partner or anyone else in this appointment by asking them questions or providing them information as well?"
DISCLOSE	Summarize medical history	"The last time we spoke, we discussed _____ [*summarize medical history pertaining to diagnosis*]. We did several tests to find the reason for why you are experiencing these symptoms."
	Share test results	"The test results have come back and they confirm our concerns about your _____ [*medical history pertaining to diagnosis*]. **"Based on the test results, we have a diagnosis. Can I discuss this with you now?"**
	Communicate diagnosis	"According to the test results you have dementia, specifically _____ [*name type, if known*]." **"I would like to discuss your diagnosis in terms of what is next and any concerns you have at the moment. How do you feel about this?"**
ENGAGE	Explain dementia progress	"Dementia is a term which describes a set of symptoms which may include memory loss, changes in mood and behaviour, and difficulties with thinking, vision, movement, problem solving and language. Dementia is a progressive condition, meaning it tends to change over time, but each individual's experience is unique. There isn't a cure but there are treatments and support that can help maintain a fulfilling life." "What more information about your condition, your test results, or treatments would you like, if any?" "What is your understanding of your condition?" "How much information about what is likely to be ahead with your condition would you like from me?" **"I would like to know what is important to you moving forward with your condition. How do you feel about this?"**

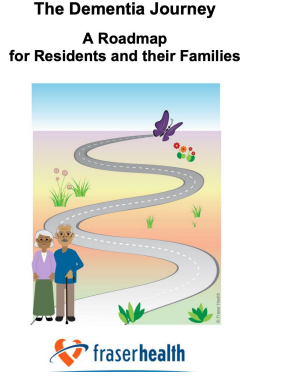
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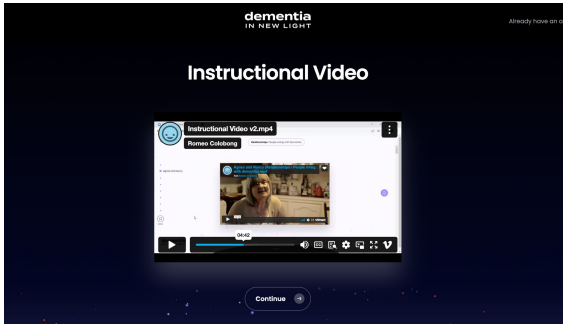
FIRST LINK



DEMENTIA ROADMAP



DEMENTIA IN NEW LIGHT



COMMUNITY RESOURCES

ADULT DAY PROGRAM

SOCIAL PRESCRIBING

HOME HEALTH
(CASE MANAGERS AND SUPPORTS)

SENIORS CENTERS

HANDYDART

GET UP AND GO

BETTER AT HOME

211

LOCAL SUPPORT GROUPS
(PURPLE ANGELS)



Questions?



THANKS!

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END OF PRESENTATION

APPENDIX: A NOTE ON PALLIATIVE CARE & END-STAGE DEMENTIA[4,17,23]

Referrals to palliative care for dementia are rising, perhaps a need to better integrate this approach and these practitioners into dementia care overall