

Necessary Conversations for Dementia Caregivers

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Objectives

- Review the 3 Stages of Alzheimer's Disease and use of the FAST scale.
- Identify conversations that should occur for good decision-making during disease progression.
- Clarify treatment options and patient/caregiver goals of care at all stages of dementia.

What is a Conversation?

- interactive communication between two or more people.
- a talk, especially an informal one, between two or more people, in which news and ideas are exchanged.
- Not one-sided.
- Requires active listening.
- Prepare!



Early Signs of Dementia

1. Memory Loss that disrupts daily life.
2. Challenges in planning or solving problems.
3. Difficulty completing familiar tasks at home, at work or at leisure.
4. Confusion with time or place.
5. Trouble understanding visual images and spatial relationships.
6. New problems with words in speaking or writing.
7. Misplacing things and losing the ability to retrace steps.
8. Decreased or poor judgement.
9. Withdrawal from work or social activities.
10. Changes in mood or personality.

Reluctance to Converse

- **Recent Alzheimer's Association Survey results:**
- ¾ of Americans would be concerned about offending a family member/friend if they were to approach that person about observed sign of AD
- 80% – conversation would cause unnecessary worry
- 69% – concerned it would ruin their relationship
- 1/3 wouldn't say anything; more than 1/3 would wait until symptoms worsened
- 8/10 would shift responsibility of discussing observed signs of AD to another family member.
- *We all would rather avoid difficult conversations!*

Set the Stage for Success

- Recognize signs/symptoms
- Don't put off the conversation
- Pick a comfortable time and setting
- Keep trying no matter how much pushback you get
- Get family and healthcare providers involved
- Create a concrete plan
- Reach out for professional help
- www.Alz.org



First Conversations...

- Is this really Dementia?
 - **Delirium**
 - Most common symptom in elderly
 - Infection, dehydration, pain, oxygen, etc.
 - **Depression**
 - Memory issues, confusion
 - Chronic pain, loss
 - **Dementia**



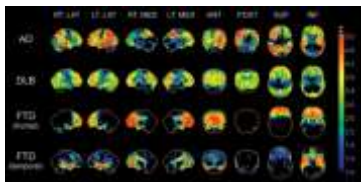
Who to Talk to...?

- **To Evaluate Memory and Thinking Problems:**
 - PCP
 - Specialists
 - Geriatricians
 - Geriatric Psychiatrists
 - Neuropsychologists
 - Dementia Diagnostic Centers



Conversation:

- What type of dementia?
 - Alzheimers (early or late onset)
 - Vascular dementia
 - Lewy body Dementia
 - Frontotemporal dementia



Alzheimer Disease Stage 1 – Mild Dementia

This stage aligns with FAST 1-4.

Mild Dementia

FAST 1:

No difficulty either subjectively or objectively.



Mild Dementia

FAST 2:

Complains of forgetting location of objects. Subjective work difficulties.



Mild Dementia

FAST 3:

Decreased job functioning evident to co-workers.
Difficulty in traveling to new locations.
Decreased organizational capacity.*

**Scored primarily on the basis of information obtained from knowledgeable informant.*

Mild Dementia

FAST 4:

Decreased ability to perform complex tasks, e.g., planning dinner for guests, handling personal finances (such as forgetting to pay bills), difficulty marketing, etc.



Mild Dementia

It is important at this time to:

1. Recognize the changes
2. Evaluate the goals of care
3. Discuss care preferences



Alzheimer Disease Stage 2– Moderate Dementia

This stage aligns with
FAST 5 and 6.

Moderate Dementia

FAST 5:

Requires assistance in choosing proper clothing to wear fit for the day, season or occasion, (e.g. patient may wear the same clothing repeatedly, unless supervised.



Moderate Dementia

FAST 6:

Occasionally or more frequently over the past weeks:

- A) Improperly putting on clothes without assistance or cueing
- B) Unable to bathe properly (not able to chose proper water temperature)

Moderate Dementia

- C) Inability to handle mechanics of toileting (e.g., forgot to flush the toilet, does not wipe properly or properly dispose of toilet tissue)
- D) Urinary Incontinence
- E) Fecal incontinence



Moderate Dementia

It is important at this time to:

1. Recognize the changes
2. Re-evaluate the goals of care
3. Discuss the care preferences



Moderate Dementia

It is time for a “family” meeting.

Request a Palliative Care Consult if available.



Moderate Dementia

Get an update on stage and progression of illness.



Moderate Dementia

Conversation

Who is going to provide the increasing care needs of the person?



Moderate Dementia

Conversation

Where will the person receive this care?



Moderate Dementia

Re-evaluate goals of healthcare based on the person's values and preferences.



Moderate Dementia

Remember people find comfort in their routine.

Remember people find comfort when in their familiar surroundings.



Moderate Dementia

Conversations

Caregiver needs:

1. Ask for help
2. Family dynamics
3. Family meetings
4. Visiting places/websites designed for caregivers



Alzheimer Disease Stage 3– Severe Dementia

FAST 7



Severe Dementia

FAST 7:

- A. Ability to speak limited to approximately 6 intelligible different words in the course of an average day or in the course of an intensive interview.
- B. Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview

Severe Dementia


- C. Ambulatory ability is lost (cannot walk without personal assistance.)
- D. Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.)
- E. Loss of ability to smile.
- F. Loss of ability to hold up head independently

Severe Dementia

It is important at this time to:

1. Recognize the changes
2. Re-evaluate the goals of care
3. Discuss the care preferences

Sound Familiar?




Severe Dementia

Conversations

It is no longer possible for the person to have input into the goals of care ***unless*** they completed an Advance Directive prior to this stage of Dementia.

Severe Dementia

Conversations



- Discuss with person's primary care provider what the treatment options are for a person with severe dementia.
- Remember to use the person's preferences if they were discussed prior to this stage in the disease.


Severe Dementia

Conversations

- DMOST (Delaware Medical Orders for Scope of Treatment)
- Hospice referral
- Care plan per patient's wishes

Severe Dementia

Are there guidelines to determine if someone with Alzheimer's disease is terminally ill?




National Hospice and Palliative Care Organization

The National Hospice and Palliative Care Organization has published guidelines to help identify which patients with dementia are likely to have a prognosis of six months or less if the disease runs its normal course.

Severe Dementia

Remember, these are only guidelines to assist doctors in determining whether a patient may be appropriate for hospice care. Some Medicare contractors responsible for paying hospice claims have specific rules around hospice coverage for dementia patients.



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Hospice Criteria

Patients will be considered to be in the terminal stage of Alzheimer's disease if they meet the following criteria:

#1 *plus* either #2 or #3 MUST be present:

Hospice Criteria #1

- **Stage 7 on the Functional Assessment Staging (FAST) Scale – A, B & C criteria are very important indicators of end stage Alzheimer's disease.**
- Additional criteria lend additional support to terminal status:
 - Incontinence
 - Inability to communicate meaningfully (1 to 5 words a day)
 - Non-ambulatory (unable to ambulate and bear weight)
 - All intelligible vocabulary lost
 - Unable to sit up independently
 - Unable to smile
 - Unable to hold head up

Hospice Criteria #2

- **Presence of co-morbid disease distinct from the terminal illness will impact functional impairment. The combined effects of Alzheimer's and any co-morbid condition should support a prognosis of 6 months or less.**
- COPD
- CHF
- Cancer
- Liver Disease
- Renal Failure
- Neurological Disease

Hospice Criteria #3

- **Patients should have had one of the following secondary conditions within the past 12 months:**
- Delirium
- Recurrent or intractable infections, such as pneumonia or other URI
- Pyelonephritis or other urinary tract infection
- Septicemia
- Decubitus ulcers, multiple, stage 3-4
- Fever, recurrent after antibiotics
- Inability to maintain sufficient fluid and calorie intake demonstrated by either of the following: 10% weight loss during the previous six months OR Serum albumin < 2.5 gm/dl
- Aspiration pneumonia

Summary

The best care we can provide to a person with Alzheimer's Disease is to listen to them and their "family" and to help them establish goals of care and levels of medical interventions that most align with medical research and the person's preferences, values, and wishes.



Questions?

