

UNDERSTANDING GOALS OF CARE WITH
PROGRESSION OF DEMENTIA

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*One of the many challenges faced by
people living with dementia is being able
to participate in decisions about their
own health care.*

Advance care planning

- Meant to look at a person's *values, goals, and preferences*
- Can improve care by facilitating a plan for the future
- May decrease anxiety by having ACP in place
- Provides a mechanism to communicate with caregivers
- Has been shown to reduce hospitalizations and tube feeding for those with advanced dementia
- Important to share in all settings – PCP, hospital, ER, LTC facility to give opportunity to follow
 - *The person living with dementia may not remember their prior decisions OR their surrogate decision-maker*

Each of us is different

- Different in how the disease affects us physiologically
- Different in goals of care before dementia
- Different in goals once a dementia diagnosis is in place
- Different in how those goals change over time as the disease progresses

- *It's one thing to make a decision for ourselves... but altogether different to make the decision for someone else*

the course of Dementia varies....



And, goals of care may differ depending on where you are in the journey

Commonly stated goals for persons living with dementia

- To stay engaged in meaningful activities as long as possible
- To *not* be a burden to family as the disease progresses
- To stay at home as long as possible

Commonly stated goals for *caregivers* of persons living with dementia

- To keep the person safe
- To have them stay at home as long as possible
- To find a way to balance the person living with dementia's wish for autonomy with challenges related to their safety

dementia is unlike other diseases
in that goals of care may be
person-centered but...

the goals are intertwined with what
caregivers are able to facilitate
whether in a personal
or professional setting

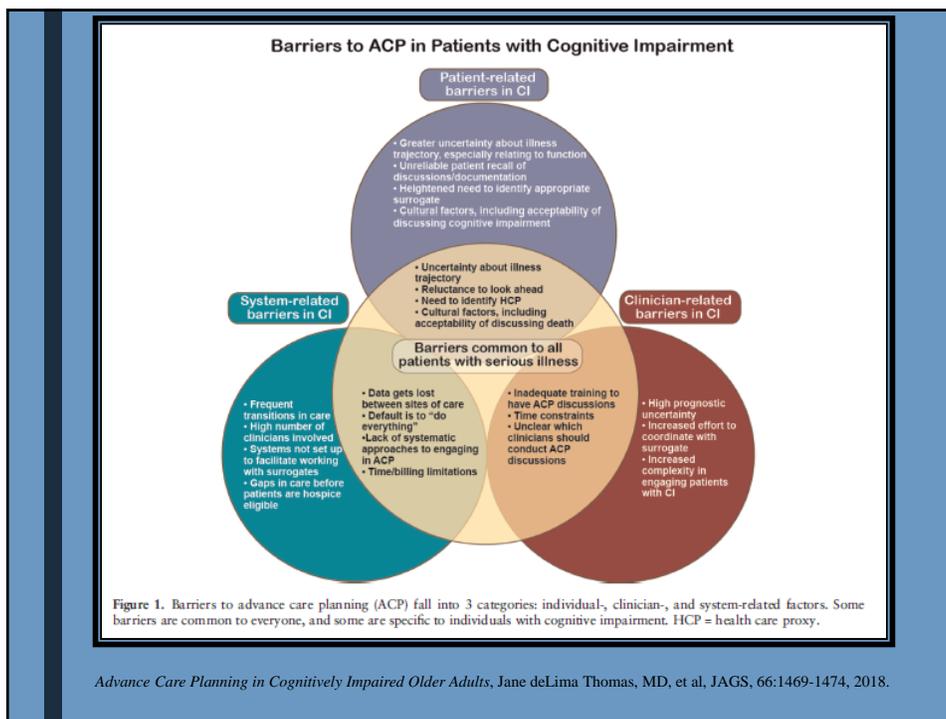
Questions to ask as you begin to consider goals of care

- Does the person with cognitive issues have decision-making capacity?
 - *Include them when possible!*
- Has a surrogate decision-maker who knows the person well been identified?
 - *Need someone who knows the person living with dementia in a day to day manner well and is willing to participate in their care*

Why is this a challenge?

- There is enormous uncertainty about the disease – at early stages... is it there or not? What is the trajectory?
- As clinicians, we are not so good at prognosticating
- A reluctance to look to a future and cultural differences that impact the discussion
- Frequent transitions in care make communication of goals particularly as they change difficult
- Uncertainty about whose role it is to establish goals and conduct these discussions (it's ALL of us)
- Limitations of reimbursement

Some of the issues relate to the person with dementia, some to clinicians, some to systemic problems... but many of the issues are common to everyone.



Types of Goals to consider

- Medical care during the course of dementia and at end of life
- Quality of life- Physical aspects
- Quality of life- Social/emotional aspects
- Accessing services and supports
- Caregiver support

- I'll add:
 - *Quality of life- supported independence*

- Once identified, finding ways to communicate goals is key in having them be honored

compiled from a focus group of persons living with dementia at an early stage and their caregivers and published in *Qual. Life Res.*, Author Manuscript; available PMC 2018 March 01, Lee A, Jennings, MD, MSHS, et.al.

With diminishing ability to communicate goals over time... starting the discussions early matters

What do people tend to care about early on?

- Disclosure/privacy
- Freedom/autonomy
- Independence

- Choices are often ethical dilemmas during this time
 - *Goals of safety and function that bump against changing capacity to manage day to day tasks such as finances or medications*

Things to DO in early stages

- If not already in place establish:
 - *Healthcare power of attorney- appoint a proxy decision-maker*
 - *Living Will- document wishes about healthcare*
 - *Durable power of attorney- appoint someone to assist with business affairs*

Questions that may help guide discussions for advance care planning

- What does quality of life mean to the person?
- How does he or she prioritize longevity, function, comfort?
- During moderate stages of dementia, there is changing function but a retained ability to do things... like participate in conversations

The Conversation Project

At the end stage of dementia

- This is often where attention is given to establishing goals of care but.... it's at a time when the person can no longer participate fully or reliably
- It is the time when those advance care plans can be further implemented with medical orders that include
 - *DNR if the person has said they want to have a natural death*
 - *NC-MOST forms in place*

Sample DNR and MOST Documents

**STOP
DO NOT
Resuscitate**

Effective Date: _____
Expiration Date, if any: _____
 Check box if no expiration

DO NOT RESUSCITATE ORDER

Patient's full name: _____

In the event of cardiac and/or pulmonary arrest of the patient, efforts at cardiopulmonary resuscitation of the patient SHOULD NOT be initiated. This order does not affect other medically indicated and comfort care.

I have documented the basis for this order and the consent required by the NC General Statute 90-21-17(b) in the patient's records.

Signature of Attending Physician/Physician Assistant/Nurse Practitioner: _____
Printed Name of Attending Physician: _____
Address: _____
City, State, Zip: _____
Telephone Number (office): _____
Telephone Number (emergency): _____

Do Not Copy Do Not Alter

NFAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Medical Orders for Scope of Treatment (MOST)

This is a Physician Order Sheet based on the patient's medical condition and wishes. Any section not completed indicates full consent for that section. When the word **yes**, **fill** follow these orders, **fill** means **obtain**.

Patient's Last Name: _____ Patient's Date of Birth: _____
Patient's First Name, Middle Initial: _____ Patient's Date of Birth: _____

Section A: CARDIOPULMONARY RESUSCITATION (CPR) Patient has no pulse and is not breathing.
 Allow CPR (Resuscitation) (CPR) Do Not Allow CPR (Resuscitation) (DNR, No CPR)
When not in cardiopulmonary arrest, follow orders in B, C, and D.

Section B: MEDICAL INTERVENTIONS Patient has pulse and/or is breathing.
Full Scope of Treatment: Use medications, advanced airway interventions, mechanical ventilation, cardiopulmonary resuscitation, medical treatment, IV fluids, etc. also include comfort measures. **Typically to benefit if indicated.**
Limited Additional Interventions: Use medical treatments, IV fluids and cardiac monitoring as indicated. Do not use intubation or mechanical ventilation. **Typically to benefit if indicated.**
Comfort Measures: Keep patient warm and dry, use mouth care by mouth care, positioning, repositioning and other measures to relieve pain and suffering. Use prayer, touch and verbal treatment of any information as needed for comfort. **Do not attempt to benefit unless comfort measure cannot be used in current location.**

Section C: ANTIBIOTICS
 Antibiotics if indicated
 Discontinue use of antibiotics when infection clears
 No antibiotics per other physician's orders/condition

Section D: MEDICALLY ADMINISTERED FLUIDS AND NUTRITION Upper and/or lower tract insertion of percutaneous feeding tube.
 IV fluids if indicated
 Do fluids for a defined trial period
 No IV fluids (specify other reasons to receive fluids)
 Feeding tube if indicated
 Feeding tube for a defined trial period
 No feeding tube

Section E: DICTATED WITH AND AGREED TO BY:
 Patient
 Family or person of patient's choice
 Health care provider
 Legal guardian
 Health care proxy
 Surrogate
 Other (specify): _____
 None of above is a legally recognized relationship with the patient. Use, using the great health care available to the patient.

Phys. DO, PA, or NP Name (Print): _____ MED. DO, PA, or NP Signature and Date (Signature): _____ Phone #: _____

Signature of Patient, Patient's Proxy, Guardian, Health Care Agent, Spouse, or Other Personal Representative: _____
Signature is required to be valid for use in an EMS.
I agree that accurate information has been provided, and significant changes have been given to life prolonging measures. Treatment preferences have been expressed to the physician (MD/DO), physician assistant, or nurse practitioner. This document reflects those treatment preferences and indicates informed consent.
If signed by a patient representative, preference or agreement must reflect patient's wishes as best understood by that representative. Current information for personal representative should be provided on the back of this form.
You are not required to sign this form to receive treatment.

Physician or Representative Name (Print): _____ Patient or Representative Signature: _____ Electronic only: "X" if printed

SEND FORM WITH PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

How to communicate the wishes?

- Talk early and keep talking
- Document via legal documents.. HCPOA, DPOA, living will
- Document via medical orders: DNR and NC-MOST
- Use tools like the Conversation project
- Consider completing or sharing a sample *healthcare directive for people with dementia*
- and talk.. Throughout the disease process

Why talk about this here today?

- It is something we all need to keep on our radar in the course of our care of those living with dementia
- What kind of care does the person want?
- If I have a role in helping to communicate those goals, how do I do so?
- What is my part in honoring their wishes?
- People are different and, as possible, we need to talk and not assume... take the time to know them and honor wishes as we can.

We talk about this because
there are no easy answers
but... it matters and

all of us have a role

RESOURCES

- <https://www.theconversationproject.org/>
- <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>
- <http://www.caringinfo.org/files/public/ad/NorthCarolina.pdf>
- <https://www.nhpco.org/wp-content/uploads/NorthCarolina.pdf>

A WONDERFUL RESOURCE IN THE COMMUNITY:

Advance care planning workshops at OLLI

<https://olliasheville.com/special-programs#advance-care-planning>

get your living will and power of attorney for health care legally documented....for free
(workshops scheduled every 4 months)

**“It’s always too early
until it’s too late”**

The Conversation Project

I recommend starting now

THANK YOU!

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