## UNC School of Social Work/Wake AHEC Clinical Lecture Series

### Ethics of Self-Determination: Empowering Older Adults to Make Their Own Life Decisions

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## It can start with a phone call like this...

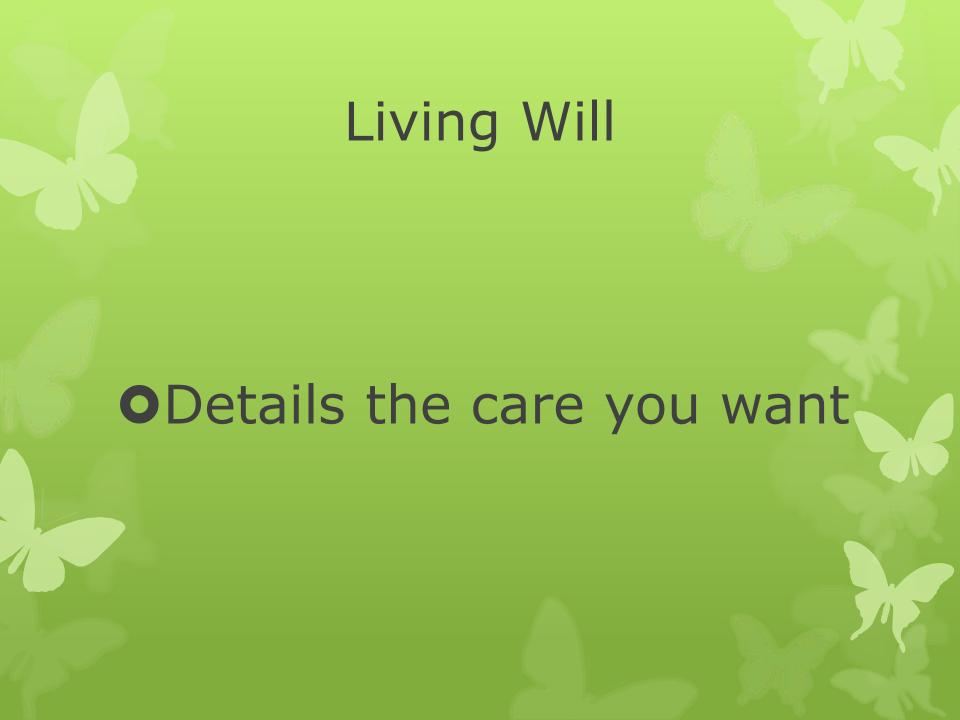


## Advanced Care Planning



## Health Care Power of Attorney

OAppoint someone to be your decision maker



### When do your directives start?

- When you lack capacity, and
- Oyou can't communicate your wishes

#### When do the directives end?

- When you revoke them
- When a court invalidates them
- OWhen a court revokes your agent's authority
- OWhen you get a divorce
- OAfter your death

## Having that critical conversation

The notions of autonomy and self-direction do not only apply when people are healthy

## Having that critical conversation

Too often, people are excluded from medical decision-making because they are presumed to be incompetent and/or not capable by the sheer virtue of their label as an older adult...particularly if they have had any cognitive issues or events.

## Having that critical conversation

Trying to gather information and plan at the eleventh hour when a critical decision is staring us in the face makes no sense, is immensely difficult, is fraught with emotion that often leads to poor judgment, and is a poor response on our part as a system.

## Medical Goals and Family Decisions

## **3 Goals of Medical Treatment**

- **O** Cure
- Stabilization of functioning
- OPreparation for a comfortable and dignified death

#### **Family Decisions**

- **O**CPR
- Artificial hydration/ nutrition
- O Hospitalization
- Palliative or comfort care only

## Pearl's Surgery



#### Issue 1

Too often people are presumed to be incompetent and/or not capable because they have the label of some kind of cognitive or intellectual disability

#### Issue 2

Self-direction and autonomy do not stop as one gets older and/or develops a critical, chronic, or terminal illness



## What Could Have Happened?

- We could have gone through the "emergency Healthcare Power of Attorney" process again.
- We could have gone to court and request to have a Guardian appointed immediately.
- We could have looked to "the system" for a decision

## The dreaded phone call...



#### Issue 3

Eleventh-hour planning is not planning; it is an ineffectual response to our lack of process for thinking ahead.

## Need for Advanced Directive Planning Training

Statistically, it is estimated that only 18% to 36% of Americans have an Advance Directive

Which brings us to tools that can assist in communicating...

Person Centered Profiles Relationship Maps

### ~ Ruth's One Page Description ~

#### What People Like and Admire about Ruth

- Such a "grandmother"
- A true lady
- •Has the gift of gab ~ can hold a conversation with anyone!
- Always dressed so nice ~
   everything always matches, right down to socks and earrings
- Very liberal thinker for her age



#### What is Important to Ruth

- Living with granddaughter and grandson-in-law
- Being warm and feeling safe with caregivers
- Having "a little pour" before bed (rum and tea)
- Being a part of whatever is going on at home ~ being in the middle of it!
- Sweets during the day!

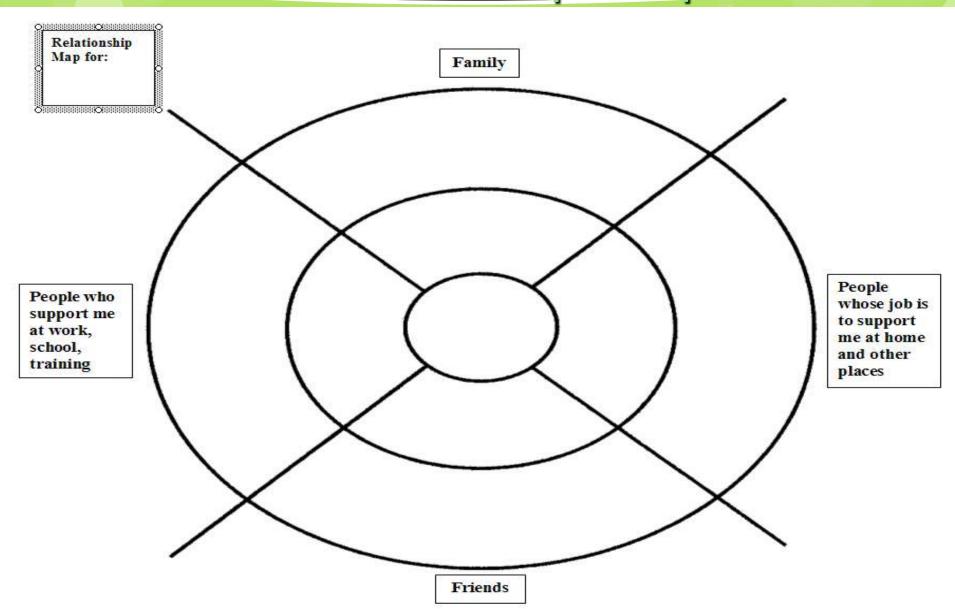
#### Supports Ruth Needs to be Happy, Healthy and Safe

- •Needs people to ask <u>frequently</u> if she is warm enough and help her put on sweater/sweatshirt if she is not (she'll be cold when you're not)
- Must have assistance with her medications ~ knows them by color but you need to dole them out and keep track of times
- Needs assistance with bathing and dressing ~ will tell you what clothes she wants to wear for the day/event
- •When bathing, no water on face ~ she will wash with cloth
- •Must talk with daughter 2-3 times a week on the phone ~ will need you to dial for her
- •Must see her doctor right away if she has cough, fever or is "off balance" ~ indications of systemic infection that will grow quickly!

#### Supports, continued

- Must feel safe with her caregivers
- Must always have her wheelchair with her in case she gets tired
  - •Someone to sit with her during thunder storms

## "Relationship Map"



## Three ways to have a

conversation

Linear:

**Branching:** 





**Meandering:** 

# A few tips for getting the best information and understanding motivations:

- Make it personal
- Make it empowering
- Make sure it comes from a trusted source
- Make it self-directed
- Make it solution-oriented

## What about people with cognitive decline?

- ODo you think someone with cognitive decline should be able to make healthcare decisions?
- ODiscuss why or why not with a partner.

## Guidelines for Decision-Making Capacity:

- OUnderstanding of right to choice
- OUnderstanding of being asked to make a choice
- Can apply personal values
- OCan offer a justification for the decision
- Makes the same decision over a period of time

## Communication Challenges

- Remember the potential difficulties with cognition and interaction
  - •Paying attention, remembering
  - OLogical thinking and planning
  - OFollowing the flow of a conversation and responding accordingly
  - OUnderstanding social cues and norms

## Adapting Professional Communication

- ODo not use jargon.
- OExpress one thought or idea at a time.
- Expect missed cues; repeat information as needed, ask questions in different ways.
  - OUse reminders creatively.
- Work to maintain trust and a positive alliance.

### For more information, contact:

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