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GUIDANCE AT THE CROSSROADS OF DECISION

Impact of COVID-19 Pandemic on Advance Care Planning and Re-setting Goals of Care in Nursing Homes

National Consumer Voice for Quality Long-Term Care
Thursday, Aprl 2, 2020
Webinar

CENTER FOR PRACTICAL BIOETHICS
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HOST and FACULTY

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Global Impact and National Crisis

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Devastating Effects

Impact of Physical Distancing/Separation

Threat to Intimacy and Integrity

Insidious nature of contagion

Vulnerability of our Population

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What can we do?

What ought we do

How can we help?

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Caring Conversations®
in a Pandemic

Linda Ward

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Caring Conversations®

- **Relevant information** free resources for consumers to help sort out complex situations
- **Educational programs** about advance care planning

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Caring Conversations®

Having an opportunity to reflect *before there is a crisis* can make the difference between:

–A family torn apart by disagreements over "what Mom would have wanted"

OR

–The peaceful, dignified end that we all want for ourselves and those we love.

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ACP Conundrum

- People are reluctant to think or talk about serious illness, goals of care and death
- Especially when things are going well and people feel pretty good
- But this is exactly the time to have these conversations and make plans
- DO NOT wait until you are seriously ill
- Variety of tools to guide you through this process

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COVID-19…

- The world's turned upside down…
- Americans are death averse under normal circumstances— especially when it comes to our own
- We all agree making an advance care plan is good, but only 1/3 of us actually do it.
- Easy to say death is a long way off. We can do this later.

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Mistaken Beliefs

"I'll always be able to make my own decisions."

Not only will we not necessarily be able to make our own decisions, but with crisis standards, decisions may be made for us.

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Reasons for *Caring Conversations*®

- 85% of us will die without capacity to make decisions/on life support—BEFORE COVID
- It can get complicated-even under normal circumstances and these are NOT normal…

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Reasons for *Caring Conversations*®

- How we die is changing

  In a pre Covid19 world, we could say that most of us will die…

  – of complications from chronic illnesses

  – with slow and uncertain disease paths

  – affected by dementia

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Reasons for *Caring Conversations*®

- We had the luxury to fret about the difficulties in the process:
  - Legalistic forms are limited in what they can anticipate and how well they guide agents.
  - Anticipating all the “what ifs” can seem like an infinite puzzle—so we used a frame to help us narrow down the possible ways we will die.

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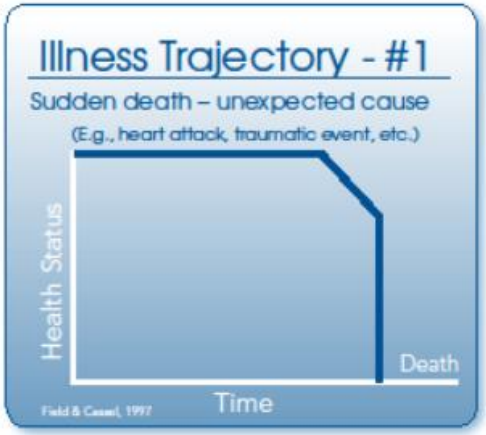
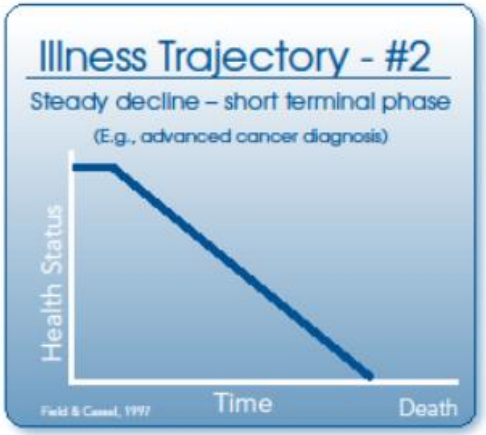
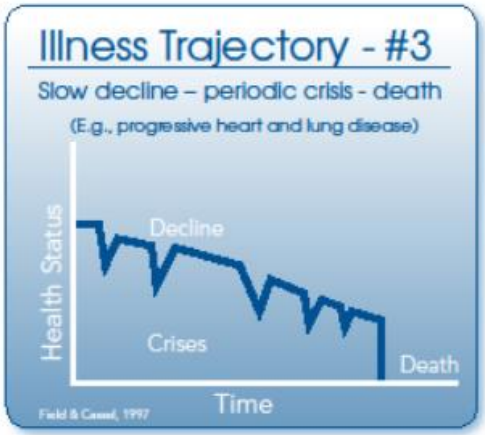
Pictures of Illness

- The four basic ways a person might experience an illness or serious health condition







Non-Pandemic ACP

More relaxed process—

Reflect on your own values, what does a good life followed by a good death look like to me?

What would I want and not want as I die?

Who is the best person to speak for me when I cannot speak for myself?

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Act on your reflections

- “Talk” with that person
- Get their commitment
- Discuss likely scenarios
- Document
- Share your wishes with anyone who might have a point of view about your care
- Revisit annually or when your health changes

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Values and Goals

- Even before the pandemic, lots of people (including some close to you) are getting closer to changes in physical and sometimes mental capacity…

- And we know, taking the hard step of clarifying values, naming someone to speak for us, talking about it, can help.

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Conversations first and here's why

Earlier conversations about patient goals and priorities for living with serious illness are associated with:

- Enhanced goal-concordant care Mack JCO 2010
- Improved quality of life
- Reduced suffering
- Better patient and family coping
- Higher patient satisfaction Detering BMJ 2010
- Less non-beneficial care and costs Wright 2008, Zhang 2009

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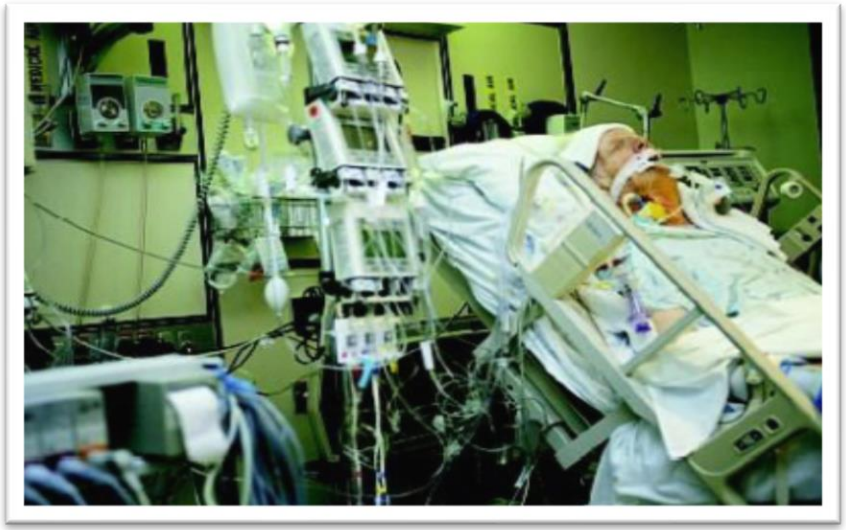
Lesson from ACP…

What we want v. What we get

Dying at home… Surrounded by loved ones



ICU - Isolated from family (waiting room)

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Brave New World…

- Timeline will be significantly compressed for hundreds of thousands of us through this pandemic – Accelerated discussions
- Usual health events including injuries will continue—without regard to COVID19
- ACPs used to be all about maintaining some control of our final days
- Options are narrowed now through scarce resources

How can we retain some control of this?

- Don’t delay — the time is now
- Do your own work first
- Use Facetime to talk with YOUR family
- Go slowly – technology will not promote the kind of intimate conversation required but it is better than nothing

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Don’t assume

My family already knows my wishes.

- last conversation was…

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Mistaken Beliefs

My doctor knows best…

I've written it down, so I don't need to talk.

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Some suggestions for the talk

- Glad you are doing OK so far
- Acknowledge it's a scary (terrifying?) time
- We know many people will get this virus
- No one is exempt
- "I want to share with you how I've been thinking about this for myself and hope you will share your thoughts, too…."

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Who needs an ACP?

Anyone 18 and older needs to identify a health care proxy

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Reasons for *Caring Conversations*®

- Family and friends are often unwilling and/or uncertain agents
- Don't assume…

call from the waiting room…

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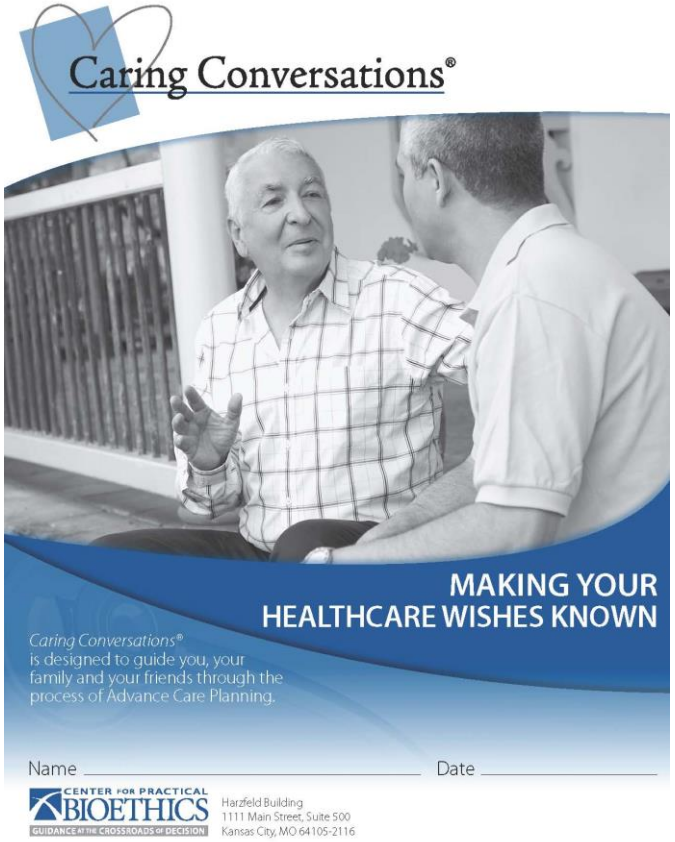
Caring Conversations® Workbook (overview)

Free to Consumers

Downloadable

Or order large quantities online



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What's next…

- Talk to those close to you
- Share your thoughts/workbook with family, staff/doctors, clergy
- Store paper copies where they can be found and upload e-version to cloud through *MyDirectives – more tomorrow!*

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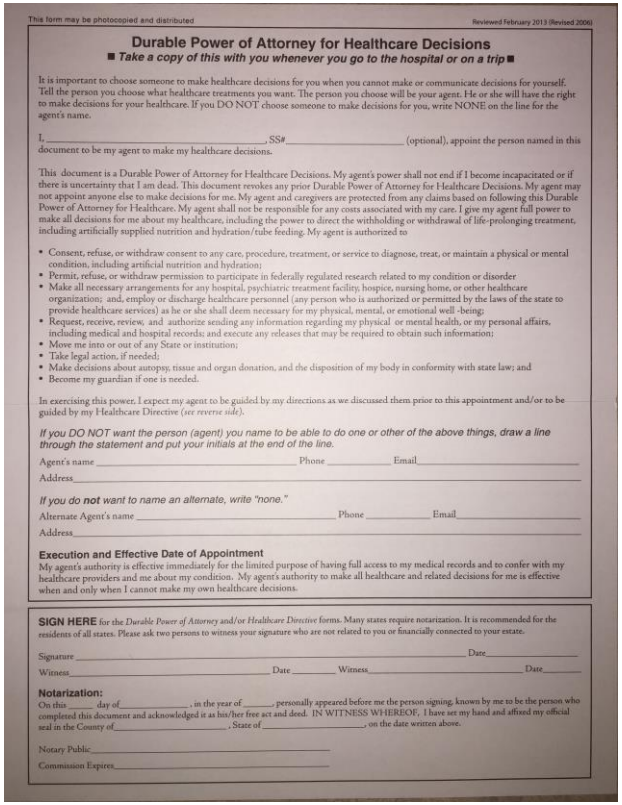
- What about the formal written documents?



This form may be photocopied and distributed — Reviewed February 2013 (Revised 2006)

Durable Power of Attorney for Healthcare Decisions

■ Take a copy of this with you whenever you go to the hospital or on a trip■

It is important to choose someone to make healthcare decisions for you when you cannot make or communicate decisions for yourself. Tell the person you choose what healthcare treatments you want. The person you choose will be your agent. He or she will have the right to make decisions for your healthcare. If you DO NOT choose someone to make decisions for you, write NONE on the line for the agent's name.

I, _____, SS#_____ (optional), appoint the person named in this document to be my agent to make my healthcare decisions.

This document is a Durable Power of Attorney for Healthcare Decisions. My agent's power shall not end if I become incapacitated or if there is uncertainty that I am dead. This document revokes any prior Durable Power of Attorney for Healthcare Decisions. My agent may not appoint anyone else to make decisions for me. My agent and caregivers are protected from any claims based on following this Durable Power of Attorney for Healthcare. My agent shall not be responsible for any costs associated with my care. I give my agent full power to make all decisions for me about my healthcare, including the power to direct the withholding or withdrawal of life-prolonging treatment, including artificially supplied nutrition and hydration/tube feeding. My agent is authorized to

- Consent, refuse, or withdraw consent to any care, procedure, treatment, or service to diagnose, treat, or maintain a physical or mental condition, including artificial nutrition and hydration;
- Permit, refuse, or withdraw permission to participate in federally regulated research related to my condition or disorder
- Make all necessary arrangements for any hospital, psychiatric treatment facility, hospice, nursing home, or other healthcare organization; and, employ or discharge healthcare personnel (any person who is authorized or permitted by the laws of the state to provide healthcare services) as he or she shall deem necessary for my physical, mental, or emotional well -being;
- Request, receive, review, and authorize sending any information regarding my physical or mental health, or my personal affairs, including medical and hospital records; and execute any releases that may be required to obtain such information;
- Move me into or out of any State or institution;
- Take legal action, if needed;
- Make decisions about autopsy, tissue and organ donation, and the disposition of my body in conformity with state law; and
- Become my guardian if one is needed.

In exercising this power, I expect my agent to be guided by my directions as we discussed them prior to this appointment and/or to be guided by my Healthcare Directive *(see reverse side)*.

If you DO NOT want the person (agent) you name to be able to do one or other of the above things, draw a line through the statement and put your initials at the end of the line.

Agent's name _____ Phone _____ Email_____

Address_____

If you do not want to name an alternate, write "none."

Alternate Agent's name _____ Phone _____ Email_____

Address_____

Execution and Effective Date of Appointment

My agent's authority is effective immediately for the limited purpose of having full access to my medical records and to confer with my healthcare providers and me about my condition. My agent's authority to make all healthcare and related decisions for me is effective when and only when I cannot make my own healthcare decisions.

SIGN HERE for the *Durable Power of Attorney* and/or *Healthcare Directive* forms. Many states require notarization. It is recommended for the residents of all states. Please ask two persons to witness your signature who are not related to you or financially connected to your estate.

Signature _____ Date_____

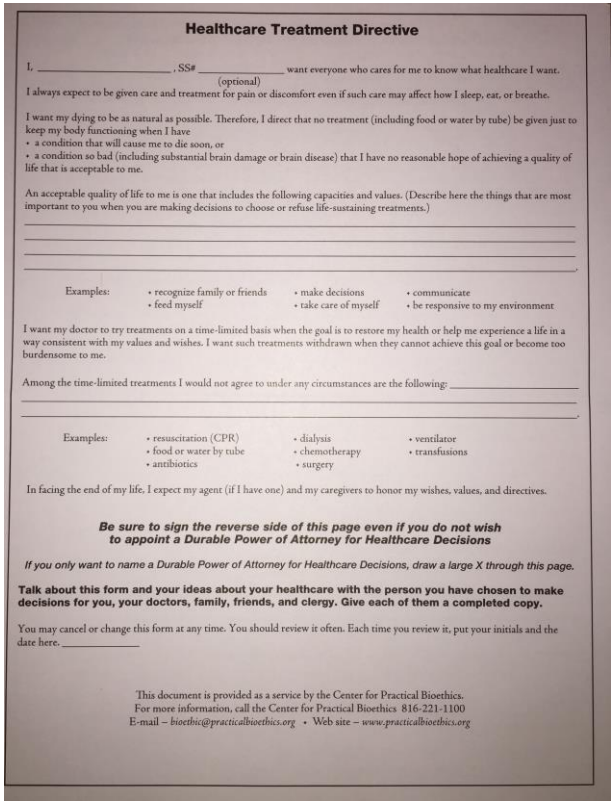
Witness_____ Date _____ Witness_____ Date_____

Notarization:

On this _____ day of_____, in the year of _____, personally appeared before me the person signing, known by me to be the person who completed this document and acknowledged it as his/her free act and deed. IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of_____, State of _____, on the date written above.

Notary Public_____

Commission Expires_____



Healthcare Treatment Directive

I, _____, SS# _____ want everyone who cares for me to know what healthcare I want.
(optional)

I always expect to be given care and treatment for pain or discomfort even if such care may affect how I sleep, eat, or breathe.

I want my dying to be as natural as possible. Therefore, I direct that no treatment (including food or water by tube) be given just to keep my body functioning when I have

- a condition that will cause me to die soon, or
- a condition so bad (including substantial brain damage or brain disease) that I have no reasonable hope of achieving a quality of life that is acceptable to me.

An acceptable quality of life to me is one that includes the following capacities and values. (Describe here the things that are most important to you when you are making decisions to choose or refuse life-sustaining treatments.)

_____

_____

_____

_____.

Examples:
- recognize family or friends
- feed myself
- make decisions
- take care of myself
- communicate
- be responsive to my environment

I want my doctor to try treatments on a time-limited basis when the goal is to restore my health or help me experience a life in a way consistent with my values and wishes. I want such treatments withdrawn when they cannot achieve this goal or become too burdensome to me.

Among the time-limited treatments I would not agree to under any circumstances are the following: _____

_____

_____.

Examples:
- resuscitation (CPR)
- food or water by tube
- antibiotics
- dialysis
- chemotherapy
- surgery
- ventilator
- transfusions

In facing the end of my life, I expect my agent (if I have one) and my caregivers to honor my wishes, values, and directives.

Be sure to sign the reverse side of this page even if you do not wish to appoint a Durable Power of Attorney for Healthcare Decisions

If you only want to name a Durable Power of Attorney for Healthcare Decisions, draw a large X through this page.

Talk about this form and your ideas about your healthcare with the person you have chosen to make decisions for you, your doctors, family, friends, and clergy. Give each of them a completed copy.

You may cancel or change this form at any time. You should review it often. Each time you review it, put your initials and the date here. _____

This document is provided as a service by the Center for Practical Bioethics.
For more information, call the Center for Practical Bioethics 816-221-1100
E-mail – *bioethic@practicalbioethics.org* • Web site – *www.practicalbioethics.org*

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Tools to Help Start the Conversation

Workbook

Conversation Starter

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For information contact the Center:

- **816-221-1100**
- **lward@practicalbioethics.org**
- **http://www.practicalbioethics.org**

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ACP during the COVID-19 Pandemic

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Clinical Director

UPMC Innovative Home Care Solutions

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Facts about COVID-19

- Serious health threat to frail and elderly.
- 3x more contagious than influenza
- 10x more deadly than influenza
- No treatment, care is supportive
- Individuals can be carriers, and not become infected
- Virus not a bacteria
- Testing tells us the epidemiology and helps with tracking
- Death is due to respiratory failure, secondary to interstitial pneumonia.

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Goals for Advance Care Planning

- Map out plans for future care
- Best before a crisis
- Encourage conversations with family and loved ones.
- Clarify diagnosis, prognosis and life expectancy
- Educate
- Identify individual's values

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POLST and Medical Orders

- Use as a guide or outline for conversation
- Code Status: yes or no
- Degree of Medical Interventions
  - Full, Selected and Comfort
- Additional Orders
- Nutrition

Evidence

- **CPR**
  - Survival rate about 17% when occurring in-hospital.
  - Survival rate 7.5% outside hospital (community setting)
  - Of those who survive CPR in long term care <1%, most die within 120 days.
- **Mechanical Ventilation**-short term effective, long term high morbidity and mortality.

Evidence

- Tube feedings do not prolong life and may cause more complications.
- Withholding artificial nutrition is neither painful nor uncomfortable. People adapt physiologically to decreases intake of food and fluid
- Dehydration has a sedating effect.
- IV Hydration-at EOL can increase suffering,(fluid accumulation in the tissues, and increased secretions).
- Antibiotics can cause complications and may not be palliative.
  - Pneumonia can be managed through comfort measures

Assessing life expectancy

- Functional predictors: impairment in ADL
- Cognitive predictors: moderate to severe dementia
- Nutritional predictors: weight loss, fluid accumulation, sarcopenia
- Patients self-report
- Critical Illness in patients with moderate to severe debility=high mortality.

Debility and Critical Illness

- More than half died within 1 month or experienced significant functional decline over the following year with poor outcomes in those who had high levels of pre-morbid disability.

- Does decisions for ICU make sense when we know the outcome is the same?

Ferrante et al: studied functional trajectories in older adults both prospectively and following admission to an ICU

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Components of the Goals of Care Discussion

- Introductions
- Take the emotional pulse/empathize
  - Emotional will not be able to listen to the cognitive
- Clarify the purpose of the meeting
  - Define why everyone is meeting
  - Discuss why this meeting is important
  - Include that this is about the planning for future medical care.

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Clarify and Conclude

- Don't force a decision
- Start with the basics: DNR, feeding tubes
- Restate " as I understand you, it sounds like you want___ and do not want ___. Is that correct?
- Based on my understanding of your values and goals and what I think is best, my plan will be to _____. Is that OK?

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Ethics during a crisis

- Hospitals and physicians will need to balance individual needs of each patient and larger needs of community.
- Decision to not institute aggressive rescue treatment is ethically allowable as is withdrawal of treatment when it does not achieve goal
- Emotionally difficult for families to withdrawal treatment
- The fact that we are facing a crisis is an ethical lesson.
- Allowing for a natural death.

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Tools and Resources

CAPC COVID-19 Response Resources

COVID Ready Communication from VitalTalk

POLST and COVID-19

Working with Families Facing Undesired Outcomes (SWHPN)

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Tools and Resources

A decision aid for patients considering life support at a time of COVID-19 Univ of CO

Caring Conversations

And tomorrow…

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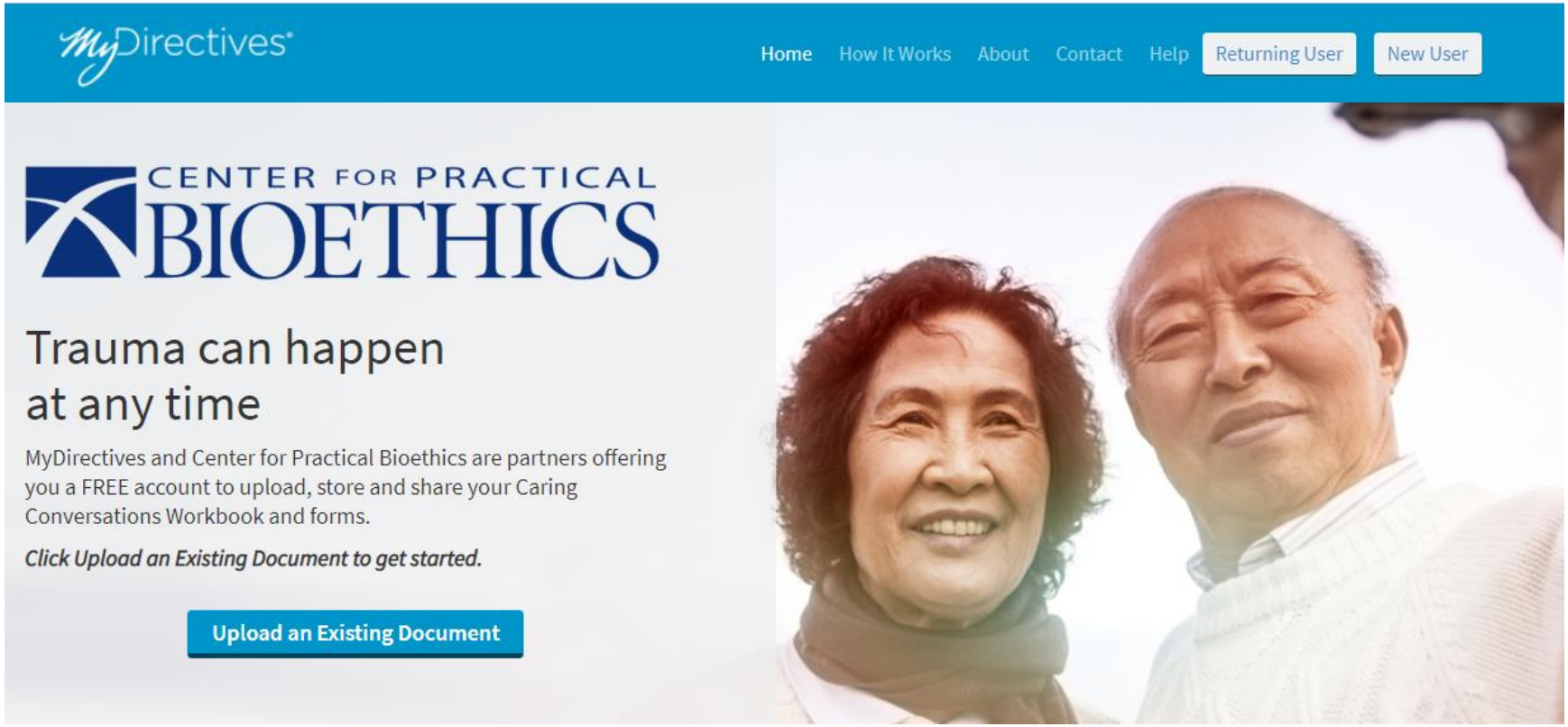
Tomorrow-Electronic Options



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Questions?

THANKS for all you are doing!

STAY WELL

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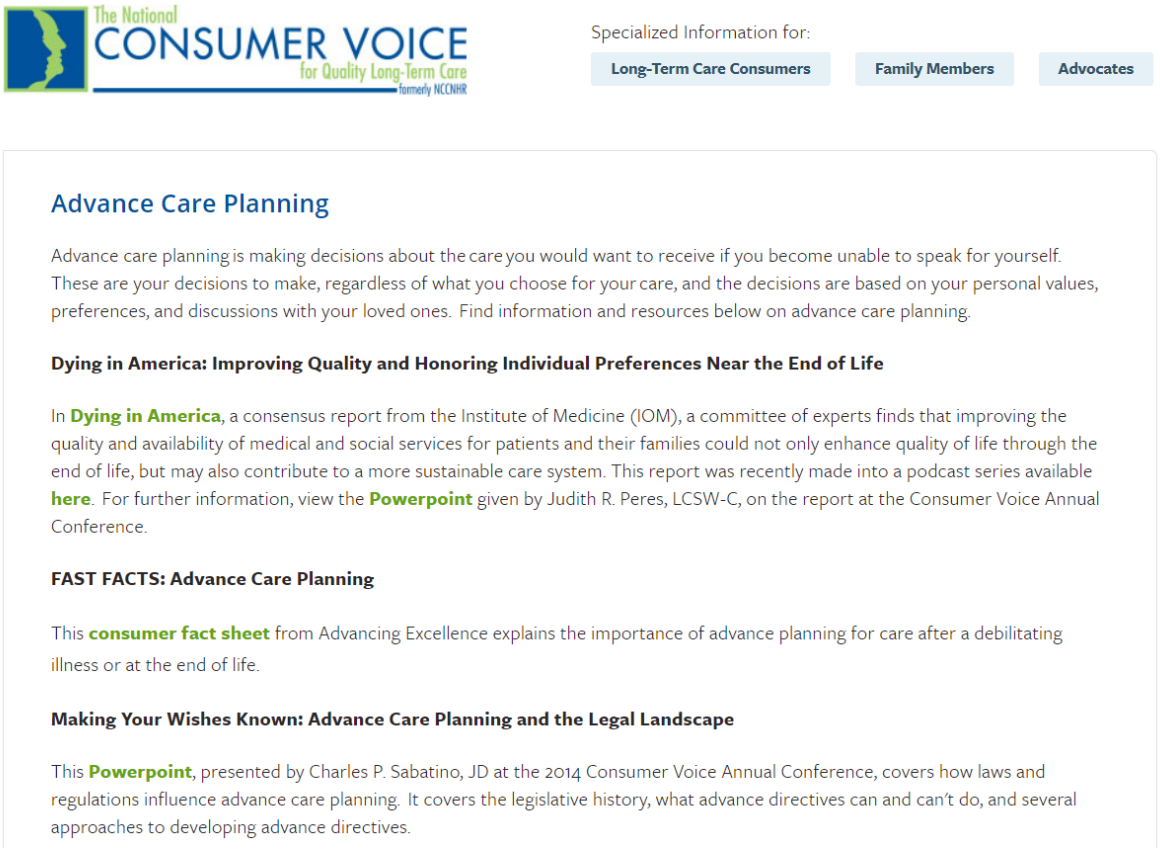
Consumer Voice: Getting Quality Care

https://theconsumervoice.org/issues/recipients/nursing-home-residents/getting-quality-care/advance-care-planning



NORC Issues Page

https://ltcombudsman.org/issues/advance-care-planning-and-end-of-life-care