GOALS OF CARE PLANNING & CONVERSATIONS

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DEDICATION
Patients with serious illness have priorities besides living longer.

- Symptom management and quality of life
- Sense of control and completion
- Strengthening relationships

Singer JAMA 1999; Steinhauser JAMA 2000; Heyland Palliative Medicine 2015
WHAT PATIENTS GET OFTEN HARMS THEM AND THEIR FAMILIES

Aggressive care for patients with advanced illness is often harmful:

- For patients:
  - Lower quality of life
  - Greater physical and psychological distress

  Wright, AA JAMA 2008; Mack JCO 2010

- For caregivers:
  - More major depression
  - Lower satisfaction

  Wright, AA JAMA 2008; Teno JM JAMA 2004
Most people want to be at home and prefer comfort-focused care at the end of life, but that is often not the reality.

- 86% Medicare beneficiaries want to spend final days at home. Barnato 2007
- 25-39% die in an acute care hospital. Teno JAMA 2013; Silveira NEJM 2010
- 70% are hospitalized in the last 90 days. Teno JM JAMA 2013
- 29% receive intensive care in the last 30 days. Teno JM JAMA 2013
- Many experience care transitions and very short hospice stays. Teno JM JAMA 2013
CONVERSATIONS ARE A KEY COMPONENT OF THE EFFECTIVENESS OF PALLIATIVE CARE INTERVENTIONS

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
CONVERSATIONS ARE TOO LITTLE, TOO LATE, AND NOT GREAT

- Multiple studies show patients with serious medical illnesses do not discuss EOL preferences, or first discuss them only in the last days to month of life Wright 2008, Dow 2010, Halpern 2011

- Many conversations fail to address key elements of quality discussions, especially prognosis
DEFINITIONS

• Advanced healthcare directive
• Durable power of attorney
• POLST form
• Goals of care conversations
AUDIENCE POLL

- How many of you have a signed Advanced Health Care directive?
- How many have had a conversation with family about goals of care?
- How many feel that you feel prepared to act as a spokes person for a loved one in a medical crisis?
UNIQUE DISEASE COMPLEXITIES

**Acute**
- Stroke
- Heart Attack

**Chronic**
- Alzheimer’s disease
- CAD
## UNIQUE END OF LIFE COMPLEXITIES

<table>
<thead>
<tr>
<th>Acute</th>
<th>Chronic</th>
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<tbody>
<tr>
<td>Sudden death</td>
<td>Prolonged death</td>
</tr>
<tr>
<td>- Abrupt decisions</td>
<td>- Slow, stepwise decisions</td>
</tr>
<tr>
<td>- Removal of life support</td>
<td>- Adding life support</td>
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STEPS TO COMPLETE ADVANCED DIRECTIVE

• Obtain form https://aging.utah.edu/_documents/utah-coa/directives/ad-6-9-09.pdf
• Determine roles
• Determine healthcare wishes
• Complete form
• Have a conversation with family
• Share form with PCP/medical providers
TOOL KIT FOR ADVANCE HEALTHCARE PLANNING
Utah Advance Health Care Directive
(Pursuant to Utah Code Section 75-2-117, effective 2009)

Part I: Allows you to name another person to make health care decisions for you when you cannot make decisions or speak for yourself.
Part II: Allows you to record your wishes about health care in writing.
Part III: Tells you how to revoke or change this directive.
Part IV: Makes your directive legal.

My Personal Information

Name: __________________________________________________________
Street Address: _________________________________________________
City, State, Zip Code: ___________________________________________
Telephone: (_____) ___________________ Cell Phone: (_____) __________
Birth Date: ____________________________________________________

Part I: My Agent (Health Care Power of Attorney)

A. No Agent
If you do not want to name an agent, initial the box below, then go to Part II; do not name an agent in B or C below. No one can force you to name an agent.

I do not want to choose an agent.

B. My Agent
Agent’s Name: _____________________________________________
Street Address: _____________________________________________
City, State, Zip Code: _______________________________________
Home Phone: (_____ ) ___________________ Cell Phone: (_____) __________
Work Phone: (_____ ) ___________________
Compare up to 3 people with this tool. The person best suited to be your Health Care Agent or Surrogate will meet most or all of these qualifications...

<table>
<thead>
<tr>
<th>Name #1:</th>
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<tbody>
<tr>
<td>Name #2:</td>
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</tr>
<tr>
<td>Name #3:</td>
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</table>

1. Meets the legal criteria in your state for acting as agent? (This is a must! See next page.)
2. Would be willing to speak on your behalf.
3. Would be able to act on your wishes and separate his/her own feelings from yours.
4. Lives close by or could travel to be at your side if needed.
5. Knows you well and understands what’s important to you.
6. Could handle the responsibility.
7. Will talk with you now about sensitive issues and will listen to your wishes.
8. Will likely be available long into the future.
9. Would be able to handle conflicting opinions between family members, friends, and medical personnel.
10. Can be a strong advocate in the face of an unresponsive doctor or institution.

This worksheet adapted by the American Bar Association’s Commission on Law and Aging from R. Pearlman, et. al., Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will, Veterans Administration Medical Center, Seattle, Washington.
Part II: My Health Care Wishes (Living Will)

I want my health care providers to follow the instructions I give them when I am being treated, even if my instructions conflict with those of other advance directives. My health care providers should always provide health care to keep me as comfortable and functional as possible.

Choose only one of the following options, numbered Option 1 through Option 4, by placing your initials before the numbered statement. Do not initial more than one option. If you do not wish to document end-of-life wishes, initial Option 4. You may choose to draw a line through the options that you are not choosing.

Option 1

I choose to let my agent decide. I have chosen my agent carefully. I have talked with my agent about my health care wishes. I trust my agent to make the health care decisions for me that I would make under the circumstances.

Initial

Additional comments:

Option 2

I choose to prolong life. Regardless of my condition or prognosis, I want my health care team to try to prolong my life as long as possible within the limits of generally accepted health care standards.

Initial

Additional comments:

Option 3

I choose not to receive care for the purpose of prolonging life, including food and fluids by tube, antibiotics, CPR, or dialysis being used to prolong my life. I always want comfort care and routine medical care that will keep me as comfortable and functional as possible, even if that care may shorten my life.

Initial

If you choose this option, you must also choose either (a) or (b), below.

(a) I put no limit on the ability of my health care provider or agent to withhold or withdraw life-sustaining care.

Initial

(b) My health care provider should withhold or withdraw life-sustaining care if at least one of the initiated conditions is met:

Initial

If you selected (a), above, do not choose any options under (b).

I have a progressive illness that will cause death

I am close to death and am unlikely to recover

I cannot communicate and it is unlikely that my condition will improve

I do not recognize my friends or family and it is unlikely that my condition will improve

I am in a persistent vegetative state

Additional comments:

Option 4

I do not wish to express preferences about health care wishes in this directive.

Initial

Additional comments
HEALTHCARE DECISION MAKING TIMEFRAME

- Advanced Healthcare Directive
  - Everyone over the age of 18 should have an advanced health care directive
- Goals of Care Conversations
  - When diagnosed with life limiting illness
- POLST form
  - When nearing end of life
GOALS OF CARE STATISTICS

90% of people say that talking with their loved ones about end-of-life care is important.

27% have actually done so.

Source: The Conversation Project National Survey (2013)

60% of people say that making sure their family is not burdened by tough decisions is extremely important.

56% have not communicated their end-of-life wishes.

Source: Survey of Californians by the California HealthCare Foundation (2012)

80% of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life.

7% report having had this conversation with their doctor.

Source: Survey of Californians by the California HealthCare Foundation (2012)

82% of people say it’s important to put their wishes in writing.

23% have actually done it.

Source: Survey of Californians by the California HealthCare Foundation (2012)
GOALS OF CARE CONVERSATIONS

- Early, in-depth conversations with patient, spouse & family
- Assess patient’s health care & end of life goals
- Understand disease specific red flags
- Reassess & update!
  - Perspectives on quality of life changes as disease changes
- Each decision should support patient’s primary goals of care
  - Each decision should answer “to what end?”
ATUL GAWANDE’S GOALS OF CARE QUESTIONS

1. What is your understanding of where you are and of your illness?
2. Your fears or worries for the future
3. Your goals and priorities
4. What outcomes are unacceptable to you?
5. What are you willing to sacrifice and not?
6. What would a good day look like?
Where I Stand Scales

Select the number that best represents your wishes. (You can write on the dotted line below each scale if you’d like to explain or add notes about your answer.)

As a patient, I’d like to know...

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5
Only the basics about my condition and my treatment

If I had a terminal illness, I would prefer to...

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5
Know my doctor’s best estimation for how long I have to live

As doctors treat me, I would like...

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5
My doctors to do what they think is best

How long do you want to receive medical care?

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5
Indefinitely, no matter how uncomfortable treatments are

What are your concerns about treatment?

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5
I’m worried that I won’t get enough care

How involved do you want your loved ones to be?

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5
I want my loved ones to do exactly what I’ve said, even if it makes them a little uncomfortable

What are your preferences about where you want to be?

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5
I wouldn’t mind spending my last days in a health care facility

When it comes to sharing information...

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5
I am comfortable with those close to me knowing everything about my health
FIVE WISHES®

MY WISH FOR:

The Person I Want to Make Care Decisions for Me When I Can’t

The Kind of Medical Treatment I Want or Don’t Want

How Comfortable I Want to Be

How I Want People to Treat Me

What I Want My Loved Ones to Know
POLST FORM

• Physician’s Order for Life Sustaining Treatments
  – Differs from advanced directive
  – Physician’s order
  – Upload into EMS system
# Provider Order for Life-Sustaining Treatment (POLST)

## Utah Life with Dignity Order

<table>
<thead>
<tr>
<th>Patient's Last Name</th>
<th>First Name/Middle Initial</th>
<th>Effective Date of this Order</th>
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<tr>
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</table>

<table>
<thead>
<tr>
<th>Date of Birth</th>
<th>Last 4 of SSN</th>
<th>Address (street/city/state/zip)</th>
<th>Medical Provider's Name (NPI/IDX/OID/PAPN)</th>
<th>Medical Provider's Phone</th>
</tr>
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**Brief description of patient's medical condition**

<table>
<thead>
<tr>
<th>Patient's stated goals for medical care</th>
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### A. CARDIOPULMONARY RESUSCITATION (CPR) Treatment options when the patient does not have a pulse and is not breathing (CHECK ONE)

- [x] Attempt to resuscitate (selecting attempt to resuscitate requires selecting full treatment in Section B)
- [ ] Do not attempt or continue any resuscitation (Do Not Resuscitate (DNR) or Allow Natural Death (LND) may need to attempt to resuscitate)

### B. MEDICAL INTERVENTIONS Treatment options when the patient has a pulse and is breathing (CHECK ONE)

- [ ] FULL TREATMENT: Preserving life by all medically effective means. Medical care may include endotracheal intubation, mechanical ventilation, defibrillation, cardioversion, vasopressor, and any other life-sustaining care that is required. Also includes medical care described below.
- [ ] LIMITED ADDITIONAL INTERVENTIONS: Treating medical conditions while avoiding burdensome measures. Medical care may include treatment of airway obstruction, bag-valve-mask ventilation, monitoring of cardiac rhythm, IV fluids, IV antibiotics and other medications as indicated. Also includes medical care described above.

- [x] NO PREFERENCE: I do not wish to express a preference (selecting this may lead to full treatment).

**Other instructions or clarification: Describe goals and/or time period if a trial intervention is desired:**

<table>
<thead>
<tr>
<th>Other instructions or clarification: Describe goals and/or time period if a trial intervention is desired</th>
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<tbody>
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</table>

### C. ARTIFICIAL NUTRITION

- [ ] Long-term artificial nutrition with feeding tube
- [ ] Trial period of artificial nutrition with feeding tube

**Describe goals and/or time period if a trial intervention is desired:**

<table>
<thead>
<tr>
<th>Describe goals and/or time period if a trial intervention is desired</th>
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</tbody>
</table>

### D. ADVANCE DIRECTIVE AND PATIENT PREFERENCES

- [ ] Advance Directive available, reviewed and confirmed free from conflicts
- [ ] No Advance Directive available

**Health care agent named in Advance Directive:***

<table>
<thead>
<tr>
<th>Health care agent named in Advance Directive</th>
<th>Phone Number</th>
</tr>
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<tbody>
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<td></td>
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</table>

- [ ] I, the patient, want this order to serve as a general guide. I understand in some situations, the person making decisions for me may decide something different if they think it is consistent with my preferences.
- [ ] I, the patient, want this order to be followed strictly.
A **guardian** is a person appointed by the court to make healthcare and other mostly non-monetary decisions for someone who cannot make these types of decisions because of an injury, illness, or disability.

A **conservator** is a person appointed by the court to take care of someone's finances when he or she cannot make these types of decisions because of an illness, injury, or disability.
Five Times to Re-Examine Your Health Care Wishes

1. Before each annual physical exam.
2. At the start of each decade of your life.
3. After any major life change – such as a birth in the family, marriage, divorce, re-marriage, and especially after the death of a loved one.
4. After any major medical change – such as being diagnosed with a serious disease or terminal illness. Or if such conditions worsen.
5. After losing your ability to live independently.
<table>
<thead>
<tr>
<th>Event</th>
<th>Definitely Want Treatment</th>
<th>Definitely Do Not Want Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>i. Need someone to take care of you 24 hours a day.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>j. Can no longer control your bladder.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>k. Can no longer control your bowels.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>l. Live in a nursing home.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>m. Can no longer think or talk clearly.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>n. Can no longer recognize family or friends.</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>o. Other:</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

Comment

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This worksheet adapted by the American Bar Association & Commission on Law and Aging from A. Pachman, et al., Your Life Your Choice: Planning for Future Medical Decisions: How to Prepare a Personalized Living Will, Veterans Administration Medical Center, Seattle, Washington.
CAPACITY & COMPETENCE

- Informally & formally assess capacity & competence
- How does Capacity & Competence relate to caregiving?
  - Early key decision making allows patient to be more involved
  - *What is the capacity of the spouse/caregivers?*
  - Is the couple guardians of adult children with developmental disorders?
HELPFUL RESOURCES

- https://www.utcourts.gov/howto/family/gc/
- http://theconversationproject.org/
- http://coalitionccc.org/
Questions?

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