How to Stay in the Driver’s Seat of Life

No one plans to have a medical emergency, lose control over their medical decisions, become a burden and linger in an institution. While an estimated 76% of seniors have completed an advance directive, this document alone will not ensure that they receive the care that is right for them. The key to staying in the driver’s seat of life is to be sure you have the right person next to you in the passenger seat. While these Patient Advocates are always given the burden of responsibility, they are rarely given the training and tools they need to do their best on the behalf of their loved ones.

Research on the effectiveness and long-term impact of surrogate decision-making reveals what a difficult task it is, even with the benefit of good information. Social workers in health care settings collaborate with surrogate decision makers to create appropriate care plans, treatment goals and discharge plans for patients. A greater understanding of the role, responsibility and emotional impact of serving as a patient advocate is essential to practice excellence.

This session will provide tips, tricks and tools to improve the effectiveness of the patient advocate. Seniors, come laugh and learn, before your kids take the car keys away. The rest of you, come and see what they’re laughing about.

Participants will walk away from this session with...

1. Tips, tricks and tools to transform concerned loved ones into effective patient advocates.
2. An understanding of the impact that surrogate decision-making can have on loved ones.
4. The knowledge to put your technotoys to work when you aren’t playing Angry Birds.

PRESENTER: Cynthia Pimm is not distinguished, published, or award-winning… in fact, my parents often call me by the dog’s name (the dog has been dead for 10 years). I am, however – able to make you laugh while you learn practical tips, tricks and tools that enable families to manage health care issues today, and prepare for end-of-life decisions tomorrow. You can request materials referenced in this workshop by contacting me at Hospice of Michigan, where I’ve been getting a paycheck since 1991.

Advance directives and proxy opinions are equally effective in influencing doctor’s decisions, but having both has the strongest effect.

Advance Directive: Document vs. Tool

DOCUMENT: A competent, state-specific legal paper that empowers an individual to make health care decisions if you are unable to speak for yourself. It may be called a Durable Power of Attorney for Health Care, Patient Advocate, Health Care Proxy, or Health Care Agent.

TOOL: A device that aids you in accomplishing a task.

How to Make an Advance Directive an Effective Tool

1. Fill out a wallet card with your Patient Advocate’s contact information and put it behind your driver’s license, right in front of your insurance card. Put additional wallet cards in the glove box of your car with your registration and insurance, and in the freezer of your refrigerator with a copy of your advance directive and medical information.

2. Enter your Patient Advocate’s phone numbers in the contacts of a standard cell phone as ICE, ICE1, ICE2, ICE3, (In Case of Emergency). If you have a smartphone download the free app: Smart-ICE Lite to add an ICE banner across your lock screen.

3. Inform the intent of your Advance Directive by adding supplemental documentation including treatment preferences, a dementia provision, functional loss instruction plan, etc...

4. Keep your original Advance Directive safe and make copies for...
   - Patient Advocate
   - Family and friends
   - Physicians
   - Freezer of refrigerator
   - Glove compartment of car
   - Nursing home or hospital admission

5. Scan your Advance Directive on copy machine to convert it into an electronic document (pdf) which can be sent by email and saved on your laptop, tablet, smartphone, etc...

6. Remember to review your Advance Directive each year and if there have been changes in your life, health, relationship status, advances in medical research, or state law, determine if you need to draft a new document.

… studies suggest that what most people really want is for those who care for them to make the best decisions possible in impossible situations. "They just want someone to make good decisions for them, and for that someone to feel good about the decisions they've made."

### Critical Information for Patient Advocates

<table>
<thead>
<tr>
<th>Release of Information</th>
<th>Last Hospitalization</th>
<th>Flu Shot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance Directive</td>
<td>Treatments</td>
<td>Shingles Shot</td>
</tr>
<tr>
<td>Recent Complaints</td>
<td>Surgeries</td>
<td>Physician</td>
</tr>
<tr>
<td>Medications</td>
<td>Psych History</td>
<td>Specialists</td>
</tr>
<tr>
<td>Vitamins/Supplements</td>
<td>Care Preferences</td>
<td>Pharmacy</td>
</tr>
<tr>
<td>Nutrition/Hydration</td>
<td>Blood Type</td>
<td>Date of Birth / SSN</td>
</tr>
<tr>
<td>Medical Allergies</td>
<td>Normal Blood Pressure</td>
<td>Medical Insurance</td>
</tr>
<tr>
<td>Diagnoses</td>
<td>Normal Heart Rate</td>
<td>Supplemental Plan</td>
</tr>
<tr>
<td>Conditions</td>
<td>Immunizations</td>
<td>Veteran Status</td>
</tr>
</tbody>
</table>

### Tips for being an Effective Patient Advocate

- Get your own life
- Protect and respect boundaries
- Be the second-best authority on the patient
- Stand between the patient and threats to their control
- Ask questions, don’t accept bad answers
- Don’t go it alone
- Try hard, fail soft, try again and with practice – gain confidence

### Six Steps of Shared Decision Making

1. Invite patient to participate
2. Present options
3. Provide information on benefits and risk
4. Assist patient in evaluating options based on their goals and concerns
5. Facilitate deliberation and decision making
6. Assist with implementation

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Making treatment decisions has a **negative emotional effect** on at least one third of surrogates, which is often substantial and typically lasts for months (or sometimes years).

Stressors Commonly Reported by Surrogate Decision Makers

<table>
<thead>
<tr>
<th>Stressors</th>
<th>Possible Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsure of patient’s preferences</td>
<td>Encourage discussion and advance directives</td>
</tr>
<tr>
<td>Uncertain prognosis</td>
<td>Difficult to address</td>
</tr>
<tr>
<td>Logistics of making decisions</td>
<td>Evaluate and address challenges</td>
</tr>
<tr>
<td>Poor communication by clinicians</td>
<td>Establish contact person, hold consistent meetings, use clear language</td>
</tr>
<tr>
<td>Insufficient time</td>
<td>Prepare surrogates and give time to decide</td>
</tr>
<tr>
<td>Sense of sole responsibility</td>
<td>Share responsibility for decisions</td>
</tr>
<tr>
<td>Guilt over decisions</td>
<td>Support decisions, offer counseling</td>
</tr>
</tbody>
</table>

References

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We know that no guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.

www.compassionandchoices.org

www.haveyouhadthetalk.com
Michigan Designation of Patient Advocate for Healthcare

I (Name)

(address)
as of (date), and I voluntarily make this designation.

I designate

(name of patient advocate)

(academic or professional credentials)

(address)

(phone number)

as my patient advocate to make care, custody, or medical treatment decisions for me only when I become unable to participate in medical treatment decisions. The designee is authorized
to make such decisions only when I am unable to participate in medical treatment decisions shall be made by any

If the first individual is unable, unwilling, or unavailable to serve as my patient advocate, then I designate

(name of second individual)

(address)

(phone number)

as my patient advocate.

(Confidential)

www.compassionandchoices.org

The Dementia Provision

Most Advance Directives become operative only when a person is unable to make health care decisions and is either "permanently unconscious" or "terminally ill." There is usually no provision that applies to the situation in which a person suffers from severe dementia but is neither unconscious nor dying.

The following language can be added to any Advance Directive or Living Will. There it will serve to advise physicians and family of the wishes of a patient with Alzheimer's Disease or other forms of dementia. You may simply sign and date this form and include it with the form My Particular Wishes in your Advance Directive.

If I am unconscious and it is unlikely that I will ever become conscious again, I would like my wishes regarding specific life-sustaining treatments, as indicated on the attached document entitled My Particular Wishes to be followed.

If I remain conscious but have a progressive illness that will be fatal and the illness is in an advanced stage, and I am consistently and permanently unable to communicate, swallow food and water safely, care for myself and recognize my family and other people, and it is very unlikely that my condition will substantially improve, I would like my wishes regarding specific life-sustaining treatments, as indicated on the attached document entitled My Particular Wishes to be followed.

If I am unable to feed myself while in this condition

I hereby incorporate this provision into my durable power of attorney for health care, living will and any other previously executed advance directive for health care decisions.

Signature  
Date

www.compassionandchoices.org

My Personal Wishes

For Therapies that Could Sustain Life

In addition to the information on other Advance Directive forms, I have completed, I wish to make my instructions known with respect to specific therapies that could save or prolong my life. This form is meant to inform my physician, nurse or other care provider of my consent or refusal of certain specific therapies. It is also means to guide my family or any other person I want to make health care decisions for me if I cannot make these decisions myself.

I understand it is impossible to know what a person would want in a particular circumstance, unless that person has previously stated his or her wishes. I hope this document helps those who must make difficult decisions to proceed with comfort and confidence. By following these instructions they know are acting in my best interests and are consistent with certain therapies just as I would if I could hear, understand and speak.

Decisions While I am Capable

So long as I am able to understand my condition, the nature of any proposed therapy and the consequences of accepting or refusing the therapy, I want to make these decisions myself. I will consult my doctor, family and those close to me, spiritual advisors and others as I choose. If the final decision is mine. If I am unable to make decisions only because I am being kept sedated, I would like the sedation lifted so I can reasonably consider my situation and decide to accept or refuse a particular therapy.

Comfort Care

I want any and all therapies to maintain my comfort and dignity. If following my instructions in this document causes uncomfortable symptoms such as pain or breathlessness, I want those symptoms relieved. I desire vigorous treatment of my discomfort, even if the treatment unintentionally causes or hastens my death.

Decisions for specific therapies

If my mental or physical state has deteriorated, the prognosis is grave and there is little chance that I will ever regain mental or physical function, I would like the following:

1. Antibiotics, if I develop a life-threatening infection of any kind.

2. Dialysis, if my kidneys cease to function, either temporarily or permanently.

3. Artificial ventilation, if I stop breathing.

4. Electroshock, if my heart stops beating.

5. Heart regulating drugs including electrolyte replacement, if my heartbeat becomes irregular.

6. Cortisone or other steroid therapy, if I lose control of my body.

7. Sedatives, tranquilizers or any other medication for the control of my mental state.

8. Blood, plasma or replacement fluids, if I bleed or have low blood volume in my body.

* This measure may not be if the therapy quickly reverses my condition. If it does not, I want it discontinued.

Signature  
Date

www.compassionandchoices.org

My Directive Regarding Health Care Institutions

Refusing to Honor my Health Care Choices

I understand that circumstances beyond my control may cause me to be admitted to a health care institution whose policy is to decline to follow advance directive instructions that conflict with certain religious or moral teaching.

If I am an inpatient in such a religious-affiliated health care institution when this advance directive comes into effect, I direct that my consent to admission shall not constitute implied consent to procedures or courses of treatment mandated by ethical, religious or other policies of the institution. If those procedures or courses of treatment conflict with this advance directive.

Furthermore, if the health care institution in which I am a patient refuses to follow my wishes as set out in this advance directive, I direct that be transferred in a timely manner to a hospital, nursing home or other institution, which will agree to honor the instructions set forth in this advance directive.

I hereby incorporate this provision into my durable power of attorney for health care, living will and any other previously executed advance directive for health care decisions.

Signature  
Date

www.compassionandchoices.org

Print Name  
Date

Compassion & Choices 600 W. Michigan St., Suite 500, 312/226-7000 • compassionandchoices.org
Email pimmster@hom.org to request these tools in MS Word or pdf file format.

AUTHORIZATION TO RELEASE MEDICAL INFORMATION TO INDIVIDUALS AND FAMILY MEMBERS

PATIENT'S NAME ___________________________ DATE OF BIRTH ___________________________

In accordance with Federal Government privacy rules implemented through the Health Insurance Portability and Accountability Act of 1996 (HIPAA), in order for medical staff to discuss your condition with members of your family or other individuals that you designate, your authorization must be provided.

☐ I do NOT authorize ___________________________ to release information concerning my medical care to anyone other than myself.

☐ I authorize ___________________________ to release any or all information concerning my medical care to the following individuals:

Name ___________________________ Relationship to Patient ___________________________
Name ___________________________ Relationship to Patient ___________________________
Name ___________________________ Relationship to Patient ___________________________
Name ___________________________ Relationship to Patient ___________________________

May we leave a message on your answering machine? YES or NO ___________________________ ________________

Patient Signature ___________________________ Date ___________________________

MEDICAL RECORD

NAME: ____________________________________________________________________________

BIRTHDATE: ___________ NORMAL VITAL SIGNS: ___________________________

DIAGNOSES / CONDITIONS

1. ____________________________________________________________________________
2. ____________________________________________________________________________
3. ____________________________________________________________________________
4. ____________________________________________________________________________
5. ____________________________________________________________________________
6. ____________________________________________________________________________
7. ____________________________________________________________________________
8. ____________________________________________________________________________

SURGERIES / HOSPITALIZATIONS / TREATMENTS

1. ____________________________________________________________________________
2. ____________________________________________________________________________
3. ____________________________________________________________________________
4. ____________________________________________________________________________
5. ____________________________________________________________________________
6. ____________________________________________________________________________
7. ____________________________________________________________________________
8. ____________________________________________________________________________

CURRENT MEDICATIONS

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<thead>
<tr>
<th>#</th>
<th>medication</th>
<th>mg</th>
<th>frequency</th>
<th>instructions</th>
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</table>
1  |            |    |           |              |            |
2  |            |    |           |              |            |
3  |            |    |           |              |            |
4  |            |    |           |              |            |
5  |            |    |           |              |            |
6  |            |    |           |              |            |
7  |            |    |           |              |            |
8  |            |    |           |              |            |
9  |            |    |           |              |            |
10 |            |    |           |              |            |
11 |            |    |           |              |            |
12 |            |    |           |              |            |

MEDICAL ALLERGIES:

SPECIAL INSTRUCTIONS:

UPDATED: 01/23/14 888-247-5701 | www.hom.org

In Case of Emergency (ICE) Wallet Card

Save copies on your computer. Type in any card, others will auto fill. Print, cut out, and laminate. Put in wallet, bag, pockets, suitcase, glove box of car.

FAMILY

My Name ___________________________ My Street Address ___________________________
City, ST Zip Code ___________________________

(999) 999-9999 (999) 999-9999 (999) 999-9999

My Name ___________________________ My Street Address ___________________________
City, ST Zip Code ___________________________

(999) 999-9999 (999) 999-9999 (999) 999-9999

FRIENDS

My Name ___________________________ My Street Address ___________________________
City, ST Zip Code ___________________________

(999) 999-9999 (999) 999-9999 (999) 999-9999

My Name ___________________________ My Street Address ___________________________
City, ST Zip Code ___________________________

(999) 999-9999 (999) 999-9999 (999) 999-9999

BUSINESS

My Name ___________________________ My Street Address ___________________________
City, ST Zip Code ___________________________

(999) 999-9999 (999) 999-9999 (999) 999-9999

My Name ___________________________ My Street Address ___________________________
City, ST Zip Code ___________________________

(999) 999-9999 (999) 999-9999 (999) 999-9999

Non-Emergency First Responder Dispatch ___________________________ 800-999-9999

UPDATED: 01/23/14 888-247-5701 | www.hom.org
**MEDICATION RECORD**

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>FORM (pill, patch, etc.)</th>
<th>DOSE</th>
<th>TIME OF DAY</th>
<th>DATES</th>
<th>REASON / DIRECTIONS</th>
</tr>
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<tbody>
<tr>
<td>1 Nexium (Lansoprazole)</td>
<td>capsule</td>
<td>20mg</td>
<td>AM</td>
<td>10/23/09</td>
<td>Ongoing Heartburn / Take before breakfast</td>
</tr>
</tbody>
</table>

Include ALL medications: prescription, over-the-counter, vitamins and supplements.

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**PILLBOX FILL SHEET**

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>IMAGE</th>
<th>DESCRIPTION</th>
<th>DOSE</th>
<th>START DATE</th>
<th>REASON</th>
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<tr>
<td>1 Nexium (Lansoprazole)</td>
<td><img src="image.png" alt="Image" /></td>
<td>Purple Capsule Imprint: 20mg</td>
<td>20mg</td>
<td>05/17/13</td>
<td>Heartburn</td>
</tr>
</tbody>
</table>

**MORNING**

1  
2  
3  
4  
5  
6

**NOON**

1  
2  
3  
4

**EVENING**

1  
2  
3  
4  
5

**BEDTIME**

1  
2  
3

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CS Pimm : Hospice of Michigan : 616.356.5214 : pimmster@hom.org