How to Stay in the Over 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.



burden."

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.
- 3. Strategies to engage seniors and adult children in health care decision-making.
- 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.

CS Pimm, MSW, MPA, MM | Hospice of Michigan 989 Spaulding Ave SE Ada MI 49301 616.356.5214 :: pimmster@hom.org :: www.hom.org



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

J Pain Symptom Manage 2014;47:1-11.

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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.

TIGE:

Smart-ICE Lite: This FREE smart phone app puts an In Case of Emergency banner on your lock screen so EMS will know who to call.

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."

Hastings Center Report 2004:34(2):30-42.

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Critical Information for Patient Advocates

release of information advance directive recent complaints medications vitamins/supplements nutrition/hydration medical allergies diagnoses conditions last hospitalization treatments surgeries psych history care preferences blood type normal blood pressure normal heart rate immunizations flu shot shingles shot physician specialists pharmacy date of birth / SSN medical insurance supplemental plan veteran status



"He's complaining of chest pain, shortness of breath, cramps and dizziness. Do you sell earplugs?"

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



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).

Ann Intern Med 2011;154:336-346.

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Stressors Commonly Reported by Surrogate Decision Makers⁹

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

References

- 1. Dionne-Odom JN, Bakitas M. Why surrogates don't make decisions the way we think they ought to. J Hospice Palliat Nursing. 2012;14(2):99-106.
- 2. Escher M, Perneger TV, Rudaz S, Dayer P, Perrier A. Impact of Advance Directives and a Health Care Proxy on Doctor's Decisions. Journal of Pain and Symptom Management. 2014;47(1):1-11.
- 3. Lee SJ, Lindquist MS, Segal MR, Covinsky KE. Development and validation of a prognostic index for 4-year mortality in older adults. JAMA. 2006;295:801-808.
- 4. Maciejewski PK, Prigerson HG. Emotional numbness modifies the effect of end-of-life discussions on end-of-life care. J Pain Symptom Management. 2013;45(5):841-847.
- 5. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. N England J Med. 2010;362:1211-1218.
- 6. Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. Association between advance directives and quality of end-of-life care: a national study. J American Geriatric Society. 2007;55:189-194.
- 7. Torke AM, Moloney R, Siegler M, Abalos A, Alexander GC. Physicians' views on the importance of patient preferences in surrogate decision-making. J American Geriatric Soc. 2010;58:533-538.
- 8. Wendler D, Rid A. The effect on surrogates of making treatment decisions for others. Annals Intern Med. 2011;154:336-346.
- 9. Zier LS, Sottile PD, Hong SY, Weissfield LA, White DB. Surrogate decision makers' interpretation of prognostic information: a mixed-methods study. Annals Intern Med. 2012;156:360-366.



"The doctors never gave up."

theconversationproject.org

Your Conversation Starter Kit

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.

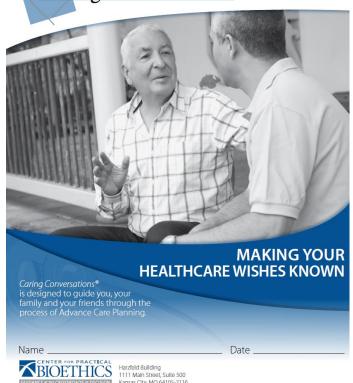




Created by The Conversation Project and the Institute for Healthcare Improvement

www.practicalbioethics.org





www.compassionandchoices.org

Compassion & Choices

MAGAZINE Special Resource Issue



BASICS YOUR WISHES GLOSSARY CONVERSATIONS MYTH & FACT

www.haveyouhadthetalk.com



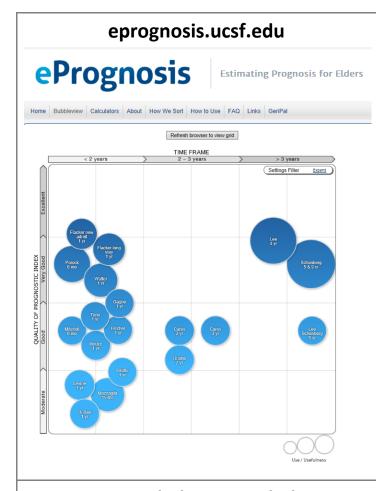




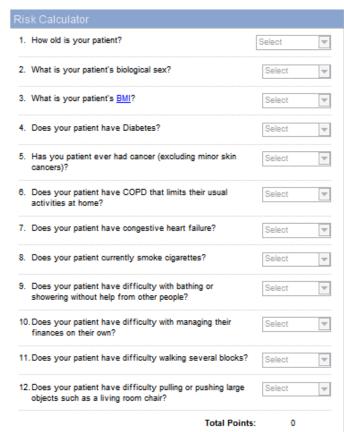
Have You Had the Talk" is provided as a public service by Hospice of Michigan

888-247-5701 / www.haveyouhadthetalk.com

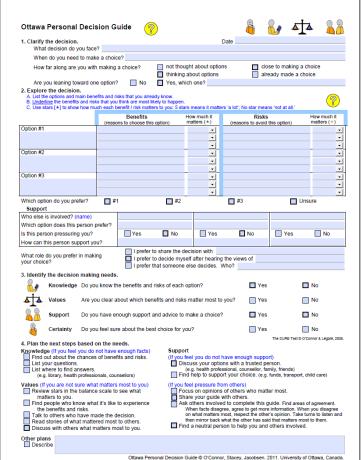
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4yr Index Community Dwelling Adults



Ottawa Tool: decisionaid.ohri.ca



Decision Aids: www.healthwise.net Atrial Fibrillation: Which Anticoagulant Should I Take to Prevent

1 Get the Facts	Compare Options	3 Your Feelings	Your Decision	5 Quiz Yourself	6 Your Summary
Get the fact	ts				
Your options					
 Take warfarir 	to prevent stroke.				
 Take a different 	ent type of anticoag	gulant to prevent s	troke.		
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Key points to	remember				
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	an help you unders our preferences abo		ne might be best fo	or you. This may de	pend on your
			the risk of stroke in ong-term side effect		fibrillation. The
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			u cannot take warfa se, an artificial hear		
dose. And yo	When you take warfarin, you need to have regular blood tests to make sure that you are taking the right dose. And you need to watch how much vitamin K you eat and drink. With other types of anticoagulants, you don't need reqular blood tests to check the dose and you don't have to watch your vitami K intake.				
problems from	 Anticoagulants work by increasing the time it takes for a blood clot to form, so they increase your risk of problems from bleeding. If you take any anticoagulant, you need to be careful to avoid serious bleeding by preventing falls and injuries. 				
FAQs					
▶ How do anti	coagulants lower	your risk of stro	ke?		
▶ How are the	se medicines the	same?			
▶ How are the	ese medicines diff	ferent?			
▶ Why might y	your doctor recon	nmend taking eit	her warfarin or a	different anticoa	gulant?
• Why might y	your doctor recon	nmend taking eit	ner wartarın or a	different anticoa	Next:

www.compassionandchoices.org



CompassionAndChoices.org

Michigan Designation of Patient Advocate for Healthcare

d mind, and I voluntarily make this designation.
l mind, and I voluntarily make this designation.
(name of patient advocate)
(address)
nber) (work phone number)
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My Particular 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 In administration of the respect to specific therapies what could save or instruction of the respect to specific therapies what could save or instruction of the respect to specific therapies what could save or instruction of the respect to specific therapies when the respect to specific therapies when the respect to the respect to specific therapies when the respect to the respe

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 they are acting in my best interests and are consenting or refusing 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. But 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 rationally 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:

	Yes	Trial period*	No
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 tissue swelling threatens vital centers in my brain.			
7. Stimulants, diuretics or any other treatment for heart failure, if the strength and function of my heart is impaired.			
8. Blood, plasma or replacement fluids, if I bleed or lose fluid circulating in my body.			

* This means doctors may see if the therapy quickly reverses my condition. If it does not, I want it discontinued.

Signature	Date

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P. O. Box 101810

tel 800.247.7421 fax 866.312.2690



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 en-titled 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

If I am unable to feed myself while in this condition

I herby incorporate this provision in to my durable power of attorney for health care, living will and any other previously executed advance directive for health care

Signature	Date

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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.

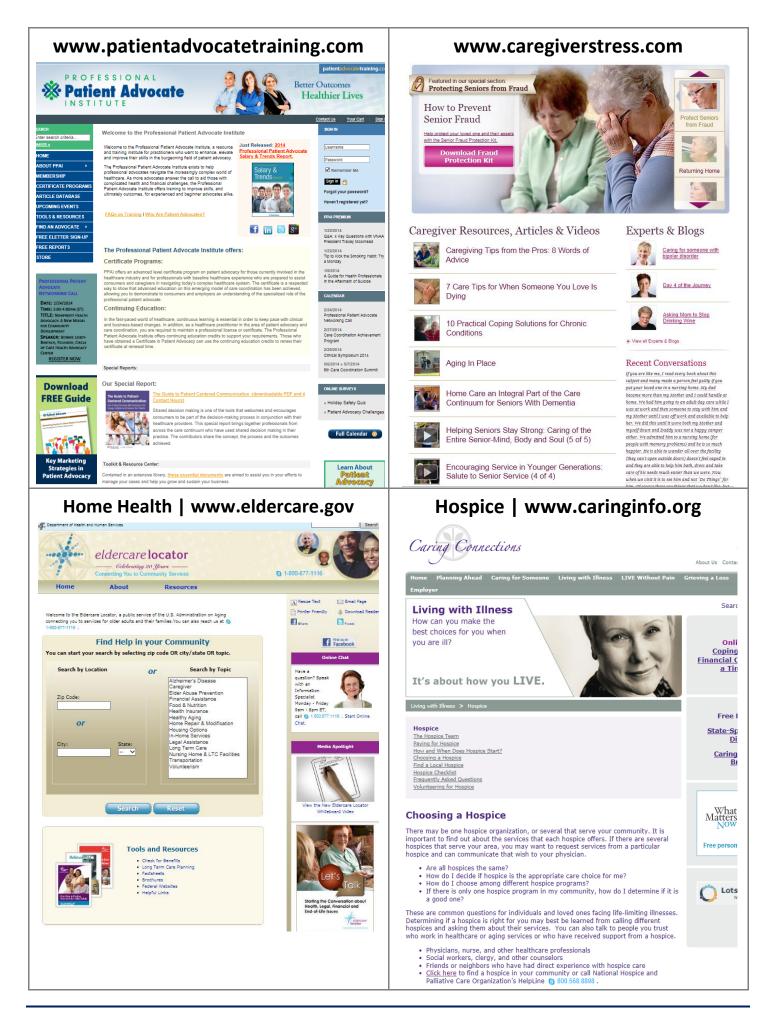
If I am an inpatient in such a religious-affiliated health care institution when this advance directive comes into effect, I direct that my consent to admission shall not constitute implied consent to procedures or courses of treatment mandated by ethical, religious or other policies of the institution,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

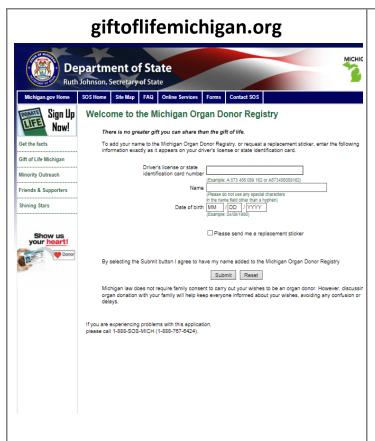
Furthermore, if the health care institution in which I am a patient declines to follow my wishes as set out in this advance directive. I direct that I be transferred in a timely manner to a hospital. nursing home or other institution, which will agree to honor the instructions set forth in this

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	
Print Name		

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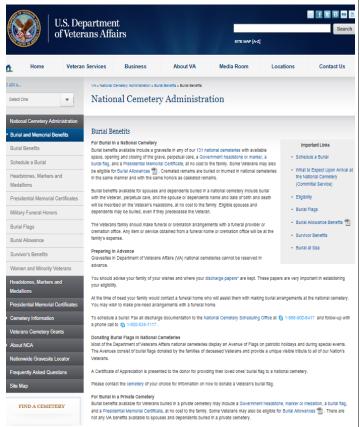




www.med.umich.edu/anatomy/donors

1	M.	University of Mich	igan Medical School, Department of Medical Education
1	Donor Authorization for Anatomical Gift to the Univ	versity of Michigan	n Anatomical Donations Program
1.	Being eighteen years of age or over and of sound mind, I hereby offer my body a anatomical gift to the University of Michigan Anatomical Donations Program.	fter death as an	Please mail completed forms to: Anatomical Donations Program
2.	Applicable Law and Policies This donation is subject to applicable law and University of Michigan Anatomic policies in effect at the time of my death.	al Donations Program	3767 Medical Science Building II 1137 Catherine St. Ann Arbor, MI 48109-5608
3.	Duration of Donation My preference regarding the duration of my donation is as follows:		
	Choose only one option:		
	Temporary Donation: My donation will be used in any manner that appropriate, within or external to the University of Michigan, and will		
	OR Permanent Donation: The University of Michigan may retain my dor Anatomical Donations Program deems necessary and appropriate, wi of my body. Following use of my body, the University of Michigan will the body or ashes will not be returned.	thin or external to the Unive	rsity of Michigan, without time constraints on the use
	I understand the Program reserves the right to retain individual tissues and orga	ans for the purposes of medic	cal education and research.
4.	Release of Medical Information I authorite the network of my medical information to the Program. Release of my medical information to the Program. Release of my medical records from any hospitals, nunning homes and other health acrep my medical records from any hospitals, nunning homes and other health acrep (so plant presses Alcohol and drug/abuse treatment, psychosocial and social work connessing III transmitted diseases, werented disease, thereforesis and hospitals and genetic in others an needed to process my donation (such as to fineral facility personnel on the control of the process my donation (such as to fineral facility personnel on the control of the process my donation (such as to fineral facility personnel on control of the parameter).	oviders from whom I have re statives. This authorization a IV, AIDS or ARC; communi- formation. I further authoris others). The Program will is liable for the actions of other	occived health care/services. I authorize the release of lso includes the release of information regarding: cable disease or infections, including sexually as the Program to disclose my health information to follow all applicable law as well as University of my who may further disclose the information. This
5.	Further information Donor confirms having read the "Gift of Knowledge" informational guide attack questions to the University of Michigan Anatomical Donations Program, by pho	ned to this Donor Authorizati one at (734) 764-4359 or by e	ion form. Donor is also encouraged to direct any mail at donorinfo@umich.edu.
Sig	natures		
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WI	TNESSES		
The Don	Donor signed this Authorization for Anatomical Donation, and we, in the Donor nor's signature. We state that the Donor appears to be at least eighteen years of age	s presence and at the Donor and appears to be of sound a	's request, have provided our names as witnesses to the mind and not under or subject to undue influence.
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Nan	me (Please Print)	Name (Please Print)	
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	Please retain a copy of th	is form for your recor	ds.
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www.cem.va.gov/cem/burial_benefits



www.funerals.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. to release any or all information concerning my medical care to the following individuals: Name Relationship to Patient Relationship to Patient Name Relationship to Patient

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

Date

Name

Name

UPDATED: 01/23/14

Patient Signature



Relationship to Patient

Relationship to Patient

MEDICAL RECORD NAME: BIRTHDATE: **NORMAL VITAL SIGNS:** INSURANCE: **DIAGNOSES / CONDITIONS** SURGERIES / HOSPITALIZATIONS / TREATMENTS **CURRENT MEDICATIONS** medication instructions 3 4 6 7 8 9 10 11 12 MEDICAL ALLERGIES: SPECIAL INSTRUCTIONS:

888-247-5701 | www.hom.org

have you had the tall?

UPDATED: 01/23/14

PHONE LIST	CELL	HOME	OTHER
My Name My Street Address City, ST Zip Code	(999) 999-9999	(999) 999-9999	(999) 999-999
FAMILY			•
FRIENDS			
I MEMBO			
BUSINESS			
Dr. Smith			
Pharmacy			
Non-Emer	gency	000.00	0.000
First Responde	r Dispatch	800-99	9-9999

888-247-5701 | www.hom.org

In Case of Emergency (ICE) Wallet Card

	computer, Type in any card, others will	auto-fill; Print; Cut out; and Lam	inate. Put in wallet, b	ags, pockets, suitcase, glove box of c
In Case	e of Emergency (ICE)		In Case o	of Emergency (ICE)
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CS Pimm: Hospice of Michigan: 616.356.5214: pimmster@hom.org

MEDICATION RECORD



	MEDICATION FORM	DOSE	TIME	DATES		REASON / DIRECTIONS	
	MEDICATION	(pill, patch)	DUSE	of DAY	START	STOP	REASON / DIRECTIONS
1	Nexium (Lansoprazole)	capsule	20mg	AM	10/23/09	Ongoing	Heartburn / Take before breakfast
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