

Care and Choice at the End of Life

The Good-to-Go Toolkit

Introduction

Regardless of age or health status, none of us knows when a future event might leave us unable to speak for ourselves. Talking with your loved ones now, appointing a representative and preparing a written record of your wishes will be invaluable should you become unable to make or communicate health care decisions.

The Good-to-Go Toolkit is designed to help you identify your priorities and help ensure your wishes are honored. This collection of material is designed to guide the process of making and communicating your decision. Just as the choices are yours, there is no one way to go about it but we suggest you start with the **Values Worksheet**. The conversations you have with your loved ones and your physician are essential in communicating your wishes. And, documenting your decisions, and the people you want to support you, records those wishes.

Use the checklist below as you work through the toolkit to keep track of your progress.

Checklist

- Read the Good-to-Go Resource Guide, a 16-page introduction to end-of-life planning with ideas, inspiration, information and answers. (Also, available at https://www.compassionandchoices.org/userfiles/Good-To-Go-Resource-Guide.pdf)
- □ Complete the Values Worksheet.
- Complete your State-Specific Advance Directive/Living Will (Available at https://www.compassionandchoices.org/what-we-do/advance-directive/)
- □ Review **Dementia Provision** as possible addition to your advance directive.
- Review My Directive Regarding Healthcare Institutions Refusing to Honor My Healthcare Choices as possible addition to your advance directive.
- Complete My Particular Wishes as a helpful tool to promote conversations with your loved ones and medical providers. Consider adding this document to your advance directive.
- Review Rider to Residential Agreement with Assisted-Living Facility as possible addition to your advance directive.
- Complete the Hospital Visitation Form. This is especially important for people who are not traditionally recognized family members.
- □ Talk to your healthcare provider. You can use Letter to My Healthcare Provider as an outline for conversation with your provider.



Values Worksheet

The following are questions you may want to consider as you make decisions and prepare documents concerning your healthcare preferences. You may want to write down your answers and provide copies to your family members and healthcare providers, or simply use the questions as "food for thought" and discussion.

How important to you are the following items?

	Very Important		Not I	Not Important	
Letting nature take its course	4	3	2	1	0
Preserving quality of life	4	3	2	1	0
Staying true to my spiritual beliefs/traditions	4	3	2	1	0
Living as long as possible, regardless of quality of life	4	3	2	1	0
Being independent	4	3	2	1	0
Being comfortable, and as pain free as possible	4	3	2	1	0
Leaving good memories for my family and friends	4	3	2	1	0
Making a contribution to medical research or teaching	4	3	2	1	0
Being able to relate to family and friends	4	3	2	1	0
Being free of physical limitations	4	3	2	1	0
Being mentally alert and competent	4	3	2	1	0
Being able to leave money to family, Friends, or charity	4	3	2	1	0
Dying in a short while rather than lingering	4	3	2	1	0
Avoiding expensive care	4	3	2	1	0

- 1) What will be important to you when you are dying (e.g. physical comfort, no pain, family members present, etc.)?
- 2) How do you feel about the use of life-sustaining measures in the face of terminal illness? Permanent coma? Irreversible chronic illness, such as Alzheimer's disease?
- 3) Do you have strong feelings about particular medical procedures? Some procedures to think about include: mechanical breathing (respirator), cardiopulmonary resuscitation (CPR), artificial nutrition and hydration, hospital intensive care, pain relief medication, chemo or radiation therapy, and surgery.
- 4) What limitations to your physical and mental health would affect the health care decisions you would make?
- 5) Would you want to have financial matters taken into account when treatment decisions are made?
- 6) Would you want to be placed in a nursing home if your condition warranted?
- 7) Would you prefer Hospice care, with the goal of keeping you comfortable in your home during the final period of your life, as an alternative to hospitalization?
- 8) In general, do you wish to participate or share in making decisions about your health care and treatment?
- 9) Would you always want to know the truth about your condition, treatment options, and the chance of success of treatments?



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 form 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 do / do not (circle one) want to be fed.

I do / do not (circle one) want to be given fluids.

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



My Directive Regarding Healthcare Institutions Refusing to Honor My Healthcare Choices

I understand that circumstances beyond my control may cause me to be admitted to a healthcare 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 healthcare 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, I direct that if the healthcare institution in which I am a patient declines to follow my wishes as set out in this Advance Directive, I am to 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



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 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 meant to guide my family or any other person I name 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 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.			
9. Artificial nutrition.			
10. Artificial hydration.			

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

Signature

Date



Rider to Residential Agreement with Assisted-Living Facility

Resident and Facility agree that Facility will be the Resident's "home," with the dignity and privacy that concept implies. Resident hopes to remain in this home for the duration of his/her life.

Facility will respect Resident's end-of-life choices and will not delay, interfere with, or impede any lawful option of treatment or non-treatment freely chosen by Resident or Resident's authorized health care proxy or similar representative, including any of the following end-of-life options:

- Hospice or palliative care services in the home;
- Foregoing or directing the withdrawal of life-prolonging treatments;
- Aggressive pain and/or symptom management, including palliative sedation;
- Voluntary refusal of food and fluids, with palliative care, if needed;
- Any other option not specifically prohibited by the law of the state in which Facility is located.

Resident:	Date:
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Facility Representative:	Date:
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Hospital Visitation Authorization

l,	, residing at		
	inCounty, State of		
, do hereby give notice and authorization that if I should become ill or			
incapacitated throug	h any cause that neces	ssitates my hospitalization, trea	atment, or long-term
care in a medical fac	cility, it is my wish that t	he following person(s)	
			be
given first preference	e in visiting me in such	medical or treatment facility, w	hether or not there are
parties related to me	e by blood or law or oth	er parties desiring to visit me,	unless or until I freely
give contrary instruc	tions to medical persor	nnel on the premises involved.	
Executed this	Day of	(Month),	(Year)
at (location of signin	g)		
Ву:			
Signature		Da	ite
Witness Signatures	S:		
Witness 1		Witness 2	
Signature		Signature	
Address		Address	
Date		Date	

This form is provided by Compassion & Choices. For information about choices at the end of life and case management services for the terminally ill, please contact us or visit our website: CompassionAndChoices.org

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A Letter to My Primary Health Care Provider Concerning Decisions to be Made at the End of My Life

Dear Dr. _____

It is important to me to have excellent and compassionate care- to stay as healthy and active as possible over the course of my life. At the end of life, my personal values and beliefs lead me to want treatment to alleviate suffering. Most importantly, I want to ensure that if death becomes inevitable and imminent, the experience can be peaceful for me and my family.

If there are measures available that may extend my life, I would like to know their chance of success, and their impact on the quality of my life. If I choose not to take those measures, I ask for your continued support.

If my medical condition becomes incurable, and death the only predictable outcome, I would prefer not to suffer, but rather to die in a humane and dignified manner. I would like your reassurance that:

- If I am able to speak for myself, my wishes will be honored. If not, the requests from my health care representative and advance directives will be honored.
- You will make a referral to hospice as soon as I am eligible, should I request it.
- You will support me with all options for a gentle death, including providing medications that I can self-administer to help my death be as peaceful as possible.

I am not requesting that you do anything unethical while I am in your care, but I hope for your reassurance that you would support my personal end-of-life care choices as listed above.

I hope you will accept this statement as a fully considered decision, and an expression of my deeply-held views. If you feel you would not be able to honor such requests, please let me know now, while I am able to make choices about my care based on that knowledge.

Signed:	
Date:	
Print name:	