

Voicing My CHOICES

A Planning Guide for Young Adults





When living with a serious illness there are often things in life that are out of your control. Voicing My CHOICES gives you a way to express something very important – your thoughts about how you want to be comforted, supported, treated, and remembered.

This booklet was developed based on feedback from young people living with a serious illness. There are no right or wrong ways to answer the items in Voicing My CHOICES. You can complete as much or as little of this booklet as you would like. There are boxes to check if you agree with certain items, and there is also space to express your thoughts in your own words.

At the end of the booklet, there are some blank pages. On these pages, feel free to share any additional thoughts and wishes not covered in this booklet. You can also use these pages to write a letter(s) to friends or family members.

Please keep in mind that the topics covered in this book can sometimes be difficult or confusing to think about. Your healthcare providers are available to help explain terms and/or procedures that you may not understand or may have questions about.

Voicing My CHOICES is not a legal document. People over the age of 18 may also want to consider completing a legally binding advance directive.

Any term **underlined in blue** throughout this booklet is defined in the glossary on page 18. On this page you will also find a list of terms that may provide additional clarification for you.



Voicing My **CHOICES** Table of Contents

Say What Makes You Feel Supported, Write What Decisions Bring You Peace

- Introduction, page 2
- My Comfort, page 4
- My Support, page 5
- My Family/Friends To Know, page 6
- My Medical Care Decisions, pages 7-8
- My Life Support Preferences, pages 9-10
- My Spiritual Thoughts, page 11
- My Remembrance, page 12
- My Belongings, page 13
- My Personal Information, page 14
- My Voice, page 15
- My Children, page 16
- My Reflections, page 17
- Glossary, page 18
- My Signature, page 19

Choose What Provides You the Most Comfort, Voice Your Thoughts and Needs



How I Want To Be Comforted

Sometimes people can feel very uncomfortable when they are ill. For example, they might have pain, become sleepy or not feel like themselves. It is important for others to know how you want to be cared for and what will make you feel more comfortable, especially if you become very ill and cannot express your wishes on your own.

My Choice

(Please check all that apply)

I would like to be comforted if I:

- Am feeling sad
- Am irritable/frustrated
- Feel nauseated
- Seem confused
- Look like I am having a hard time breathing
- Am cold or hot
- Other: _____

Improve my comfort by:

- Being bathed
- Relaxation exercises
- Massage
- Acupuncture
- Meditation/mindfulness
- Animal/pet therapy
- Other: _____

A Few Comforts that are Important to Me

If I am in pain, I would like:

- My doctor to give me enough medicine to relieve my pain, even if that means I will not be awake enough to interact with my friends or family.

Or To receive medications to reduce my pain, but I do not want to be too sleepy or drowsy. I want to be awake enough to interact with my friends and family.

Other thoughts I have about treating my pain (e.g., timing, pain severity, other methods of pain control) are:

My Voice

Ways I like to be comforted (e.g., food, music, TV/movies, books, games, aromatherapy, other):

I would like my room/space to include (e.g., lighting, sounds, decoration, bedding, photographs):

Other things that are important to me are:

Whether you are in the hospital or at home, when you are feeling badly or are very ill, there may be times when you want people around you, or you may prefer to not have visitors present.

How I Would Like To Be Supported



So I Don't Feel Alone

My Choice

It is important to me that my family/friends respect my wishes, decisions and choices even if they don't agree with them.

The ways I like to be supported are: (Please check all that apply)

- I would like my family and friends to be with me whenever possible
- I would like visitors whenever possible
- Please always ask me before visiting
- Please help make me look my best when I have visitors
- If people are very upset or crying, I would like them to:
 - Share their feelings with me
 - Visit me at another time

My Voice

I would like my family to be with me when:

I would like my friends to be with me when:

I would like to be alone when:

If I am sleeping, I would like visitors to:

If people are unable to visit, I would like them to communicate with me by:

What I Would Like **My Family and Friends** to Know



My Choice

It is important to me that my family/friends:

- Get along
- Take care of themselves
- Take care of one another
- Get counseling or find a support group for themselves and/or my siblings if they are having a hard time
- Pursue the things that bring them comfort and joy



My Voice

I want my family to know that I am especially thankful for:

I want my friends to know that I am especially thankful for:

If I have hurt or upset any of my friends, family, or others, I want them to know:

If I have been hurt or upset by my family, friends, or others, I want them to know:

The things I value most in my life include:

HOW I Want to Make My Medical Care Decisions If I Cannot Make Them On My Own

There might be a time when you cannot make medical decisions for yourself. If this happens, it might be necessary for someone else to speak with the doctors and make decisions about your medical care. This person, called a **healthcare agent**, would make sure that your thoughts and preferences are respected.

My Choice

I give my healthcare agent permission to make these choices for me about my medical care or services: (Please check all that apply)

To allow or refuse:

- Tests
- Medicines
- Surgeries
- Other care that can help keep me alive
- Medication(s) or procedure(s) to help with pain
- Discontinuation of previously started treatment
- Donation of my usable organs
- All of the above

Act on my behalf to:

- Determine which healthcare worker(s) should take care of me
- See and approve release of my medical records
- Apply for Medicaid, Medicare, or insurance benefits for me
- See my personal files, like bank records, to access necessary information
- Perform any necessary legal action(s)
- All of the above

To arrange for:

- Hospital or hospice admission
- Admission to a facility in another state to get the care I need or to carry out my preferences
- Hospital discharge to take me home
- All of the above

- My healthcare agent is also allowed to make decisions based on conversations we have had about my preferences and what they believe my wishes to be**



WHO I Want to Make My Medical Care Decisions If I Cannot Make Them On My Own

Things to Consider When Choosing a Healthcare Agent:

It can be helpful to choose someone who knows you well, cares about you, lives nearby, and can make difficult decisions. If you are under the age of 18, your parents/guardians will have legal rights to make decisions, so the person you recommend can be your parents/guardians or someone you would like your parents/guardians to work with.

Remember, your healthcare agent...

- Must be at least 18 years old
- Cannot be your doctor or any of your other **healthcare providers** nor can it be an employee of any of your healthcare providers
- Should agree to follow your preferences

My Choice The person I want to make healthcare decisions for me is:

First person (Full name)

Relationship to me

Phone

Address

Email address

If the person I chose above is somehow unavailable, others who can make healthcare decisions for me are:

Second person (Full name)

Relationship to me

Phone

Address

Email address

Third person (Full name)

Relationship to me

Phone

Address

Email address

My Voice How I want my healthcare agent(s) to make decisions:

The types of **Life Support Treatment** I Want or Do Not Want



If a time comes when you are very ill and not able to speak for yourself, it will be important for your healthcare agent to know your preferences about **life support treatment**.

Life support treatment includes any medical procedure, device or medication used to try to keep you alive. In place of life support treatment, you may choose to allow a **natural death**, in which life support measures that prolong the dying process are not used, and care is focused on providing comfort and support. You can choose a natural death by completing a Do Not Resuscitate order.



A person's decisions about life support are deeply personal, and making these decisions can be emotional. Gather the facts you need to make informed decisions by talking to your healthcare team. In particular, understand the benefit as well as the burden the treatment may offer you. A treatment may be beneficial if it relieves suffering, restores functioning, or enhances the quality of life. The same treatment can be considered burdensome if it causes pain or prolongs the dying process without offering benefit.

No matter what you decide about life support treatment:

- Everything will be done to support you and help you feel comfortable, including medications to treat pain, anxiety, or any discomforts, as well as care to maintain your hygiene and dignity
- You will always be offered food and fluids by mouth if it is safe to do so

Examples of Life Support Treatments

Interventions to treat life-threatening conditions may include:

- Antibiotics to treat infections
- Placement of catheters to provide treatments or to monitor organ function
- Placement of tubes through the nose or mouth into the stomach to provide nutrition
- Placement of tubes to drain urine from the bladder or stool from the intestine
- Transfusion of blood or blood products
- Surgery if needed to help increase survival
- Chest compressions (CPR) if your heart stops
- Machines or devices to support injured lungs (oxygen therapy, ventilators, breathing tubes)
- Machines to replace kidney function (dialysis)
- Medications or devices to help injured heart functions

My Choice



Reminder: The back of this booklet has extra space for any additional thoughts.



Indicate your preferences for whether you would want or not want life support treatment in each of the following scenarios:

a If treatments are available that may cure or improve my disease or disorder

- I would like life support treatments provided to me to help me survive
- I would not like life support treatments to be provided

b

My disease or disorder is not responding to available therapies or cannot be treated	- OR -	I have developed severe permanent brain injury and no recovery is expected	- OR -	I cannot be awakened from a coma or cannot recognize or respond to any person or place
---	--------	---	--------	---

- I would like to focus and limit my care to only those interventions that provide me comfort from physical and emotional distress. Treatments that otherwise only prolong death are unnecessary
- I would like all treatment to be continued

c If life support is unsuccessful to stabilize or improve a disorder in a reasonable period of time

- I would like to reassess the goals of my care, or if unable, to have my healthcare agent reassess the goals of my care
- I would like to continue life support

My Voice



Describe here if you would want to try certain forms of life-support treatment, but not others, or if you wish to state other conditions in which you want, or do not want, life -support treatment:

The place I want to be when the end of my life is near is: At home At the hospital

Other: _____

Other decisions I would like respected:

I have completed a DNR (Do Not Resuscitate) order:

Yes, it is located _____ No



Not everyone has a religion or spiritual tradition with which they feel connected. Others find great comfort in their faith, a belief system, or spiritual practices. On this page, you can write down your own thoughts on spiritual topics or sources of meaning, discuss your preferences and indicate what brings you the greatest comfort.

My Spiritual Thoughts and Wishes



My Choice

- I would not like to have spiritual/religious activities incorporated into my care.
- I would like to have spiritual/religious activities incorporated into my care. I would like:
(Please check all that apply)
 - People to offer to come pray with me.
 - Members of my religious/spiritual community to be told about my illness.
 - Members of my religious/spiritual community to visit me.
 - An opportunity to explore my own spiritual beliefs and questions I might have about death.
 - A hospital-based spiritual leader such as a chaplain, rabbi, priest, pastor, or imam to visit me while I am sick.
 - Every day
 - Once a week
 - Just when I ask
 - Spiritual/religious support for my family.

My Voice

The spiritual words, music, and/or activities I find meaningful are:

People from my spiritual community that I would like to come visit me are:

Based on my personal beliefs, I would like people to talk about death or the afterlife as:

The spiritual objects (such as prayer beads or holy books) that I would like to have with me are:

Other spiritual thoughts or preferences that I would like to share and have honored are:



How I Wish To Be



If it is more comfortable, you may choose to let others decide about a funeral, a memorial service, and caring for your body after death. Or you can use these pages to voice your preferences.

Honored and Remembered

My Choice

The type of service(s) I would like are:

- | | |
|--|--|
| <input type="checkbox"/> Funeral | <input type="checkbox"/> I prefer to be a part of planning my service. |
| <input type="checkbox"/> Memorial service | <input type="checkbox"/> I prefer to have _____ |
| <input type="checkbox"/> Celebration of my life | (e.g., family/friends) make choices about my service. |
| <input type="checkbox"/> No service | <input type="checkbox"/> I prefer not to be a part of planning my service. |

I would like: (Please check all that apply)

- | | | |
|---|---|--|
| <input type="checkbox"/> To be buried | <input type="checkbox"/> A limited autopsy | <input type="checkbox"/> To donate my body to science |
| <input type="checkbox"/> To be cremated | <input type="checkbox"/> A standard autopsy | <input type="checkbox"/> To be an organ donor , if possible |
| <input type="checkbox"/> An open casket | <input type="checkbox"/> A research protocol autopsy | <input type="checkbox"/> I would like my healthcare agent |
| <input type="checkbox"/> A closed casket | | to make the autopsy decision |

This is where I prefer to be buried: _____

This is where I prefer to have my ashes/remains placed: _____

My Voice

The clothes that I would like to be wearing (for service/cremation/burial) are:

The music I want at my service:

The food I want at my service:

The people I would like to be present are:

I would like these readings at my service:

I would like these other arrangements at my service:

If my family or friends want to make contributions or donations, I would like them to go to:

People in your life will always love you and think about you. There may be special ways that you want to distribute your belongings and be remembered, especially on certain days such as your birthday, holidays or any other day that is important to you. This is a page to detail any preferences that you have for how you would like to be remembered for the years after you are gone.

As with the other pages, take your time filling this out. Your family and friends will appreciate knowing your preferences and being able to honor you in a way you find meaningful.

My Belongings

This is How I Would Like To Share My Belongings

Clothes: _____ Pet(s): _____

Games: _____ Books: _____

Art: _____ Music: _____

Photographs: _____ Phone(s): _____

Computer(s): _____ Other electronics: _____

Furniture: _____ Money/savings: _____

Car(s): _____ Other heirlooms or belongings: _____

The person(s) I would feel most comfortable going through my belongings is:

Special Days



How I would like to be remembered on my birthday:

How I would like to be remembered on other important days:

Things I would like people to do to keep my memory alive:



My Personal Information



Passwords/Pins:

Phone: _____

Bank accounts: _____

Other financial accounts: _____

Computer: _____

Other: _____

The persons(s) I would like to trust to keep this information safe include: _____

Medical:

The person(s) I would like to keep informed of my medical status include:

*If I have participated in fertility preservation, and I am unable to use the collected eggs/sperm,

I would like: _____



Social:

How I would like my social media account(s) to be handled:

If I have written letters/recorded audio messages for my loved ones.

I want _____ to distribute them.

They are located _____

** If you have participated in fertility preservation, it is important to take appropriate legal steps that may vary from state to state, to designate how your sperm/eggs will be used after you die*



As a parent, you may worry about how your illness impacts your child(ren)'s life, or how to explain your prognosis to you child(ren) in an age appropriate way. You may also experience anticipatory grief about not being able to raise your child(ren) into adulthood. It is important for others to know how you want your child(ren) to be cared for and supported, especially if you become very ill and cannot express your preferences on your own.



What I Want for My Child(ren) If I am Seriously Ill

What I want for my child(ren):

If I am too sick to care for my child(ren):

When the end of my life is near, I want my child(ren):

Traditions or activities I would like to be continued with my child(ren) include:

I want my child(ren) to remember me as:

I have arranged for the care of my child(ren) after my death. My preferences include:

In addition to the primary caregiver I have designated, I would like these other important people to carry my memory and remain involved with my children.



Glossary

Autopsy

A standard autopsy is a medical procedure that consists of a thorough examination of your body to determine the specific cause of death or to evaluate any disease or injury. There are 3 types of autopsies: 1) a limited autopsy (a specific part of the body or body system); 2) a full autopsy (studies most organs); and 3) a Research Protocol Autopsy (conducted for research purposes).

Body/Tissue Donation

You can choose to donate either your whole body, or some of your tissue for medical research and education after death.

Burial

The act of placing a body into its final resting place. An urn or special container can be used to store remains from cremation.

Celebration of My Life

A gathering of your family/friends that is planned to honor and celebrate your life. Some choose to have a gathering yearly or just once after their death.

Closed Casket

When the casket is closed at a funeral so that those present do not view the body.

Cremation

The process of reducing the body by intense heat. Cremated remains are typically placed in a container (urn) and can be placed or buried at memorial sites or kept by relatives/friends. If you choose to be cremated, it is still possible to have a viewing of your body (open casket) before the cremation process.

Funeral

A ceremony used to mark a person's death. A person's body is typically at the funeral.

Healthcare Agent

The person chosen, legally named, or designated under state law to make healthcare decisions on behalf of a person who is no longer able to make their own decisions.

Healthcare Providers

A person or organization that provides healthcare in any way, including: doctors, nurses, administrators, and other staff who are affiliated with your care or your care facility.

Insurance Benefits

Payments or compensation provided to assist with costs of healthcare.

Life Support Treatment

Any treatments used to maintain the vital

functions of the body in order to sustain the life of someone who is critically ill or injured.

Medicaid

A federal system of health insurance for those requiring financial assistance.

Medicare

A federal system of health insurance for people over age 65, or qualified young people with disabilities.

Memorial Service

A service or ceremony performed to honor a deceased person. The body or cremated remains are typically not present. More than one memorial service can be held.

Natural Death

When life support treatments are not used and everything possible is done to provide comfort and support.

Open Casket

When the casket is left open during a funeral in order to allow for a viewing. A mortician at the funeral home will prepare and dress the body for viewing.

Organ Donation

The removal of the tissues (organs) of the body from a person who has recently died to a living recipient in need of a transplant.

Terms to talk to your healthcare provider about

Artificial Pacemaker

A small battery-operated mechanical device, which uses electrical impulses to keep the heart beating regularly. They can be internal (surgically implanted) or external (attached with wires to the skin). Pacemakers are usually only for temporary use.

Blood Transfusion

The process of transferring blood or any of its components into the bloodstream of a person who has lost blood because of illness, an accident or surgery.

Brain Damage

An injury to the brain caused by trauma to the head, infection, hemorrhage (bleeding), inadequate oxygen, or other complications, which results in significant loss in brain functioning or consciousness.

Cardiopulmonary Resuscitation (CPR)

An emergency procedure performed on a person who has no pulse and has stopped breathing. CPR consists

of external cardiac massage and artificial respiration (breathing) in an attempt to restore circulation of the blood and prevent death or brain damage.

Coma

A state of unconsciousness, lasting more than 6 hours, in which a person cannot be awakened, fails to respond to external stimuli, including pain and light, lacks a normal sleep-wake cycle, and does not initiate voluntary actions.

Dialysis

A medical treatment in which an artificial filtering system removes waste from the blood, performing the functions of the kidneys if they are not working.

Feeding Tubes

A medical device used to provide nutrition to patients who cannot obtain nutrition on their own.

Hospice

An organization or facility that provides care for the terminally ill focused on

palliation (comfort) when curative treatment is no longer an option. Hospice care involves medical care, pain management, and emotional/spiritual support. It can be provided inpatient or outpatient and focuses on maintaining quality of life and symptom control.

Insurance

A program used to assist with costs of healthcare.

Mechanical Ventilation

The medical procedure used to aid or replace breathing when someone is unable to breathe on his or her own. A machine called a ventilator forces air into the lungs via a tube that is inserted in the nose or mouth and down the windpipe.

Tracheostomy

A surgical operation that creates an opening into the trachea (windpipe) with a tube inserted to provide a passage for air in order to help someone breathe.



Voicing My CHOICES My SIGNATURE

I, _____, ask
that my family, my doctors, my friends, and my healthcare providers
follow my preferences as communicated in this booklet. This booklet is only
to be used in the case I can no longer communicate my wishes myself.



Signature: _____

Date of Birth: _____

Address: _____

Phone: _____ Today's Date: _____

Witness Statement:

I, the witness, declare that the person who signed or acknowledged this
booklet is known to me, that they signed this booklet based on their own thoughts,
preferences, and desires, and that they are of sound mind and no duress, or undue
influence.

Signature of Witness #1

Signature of Witness #2

Printed Name

Printed Name

Address

Address

Notarization (If required by the state you live in)

Voicing My CHOICES is not a legal document. It is A Planning Guide for Adolescents & Young Adults helps young people living with a serious illness to communicate their preferences to friends, family and caregivers. Most health care providers want to honor your preferences no matter how you express them. If you are age 18 or older and want your preferences to be legally binding, you should consider completing an advance directive, such as Five Wishes. This planning guide is not meant to give you legal advice. If you have a specific question or concern, talk to a medical or legal professional for advice.





Voicing My CHOICES

A Planning Guide for Adolescents & Young Adults was developed by researchers at the Pediatric Oncology Branch, National Cancer Institute, and the National Institute of Mental Health at the National Institutes of Health. The development process included extensive research using the Five Wishes advance directive and incorporating the feedback of many treasured colleagues, adolescents and young adults. Special thanks to Lori Wiener, PhD, in addition to Sima Bedoya, PsyD; Anthony Suffredini, MD; and Maryland Pao, MD.

National Cancer Institute
National Institute of Mental Health
National Institutes of Health
Department of Health & Human Services



National Institutes of Health
Turning Discovery Into Health

Version Date: August 2, 2024
