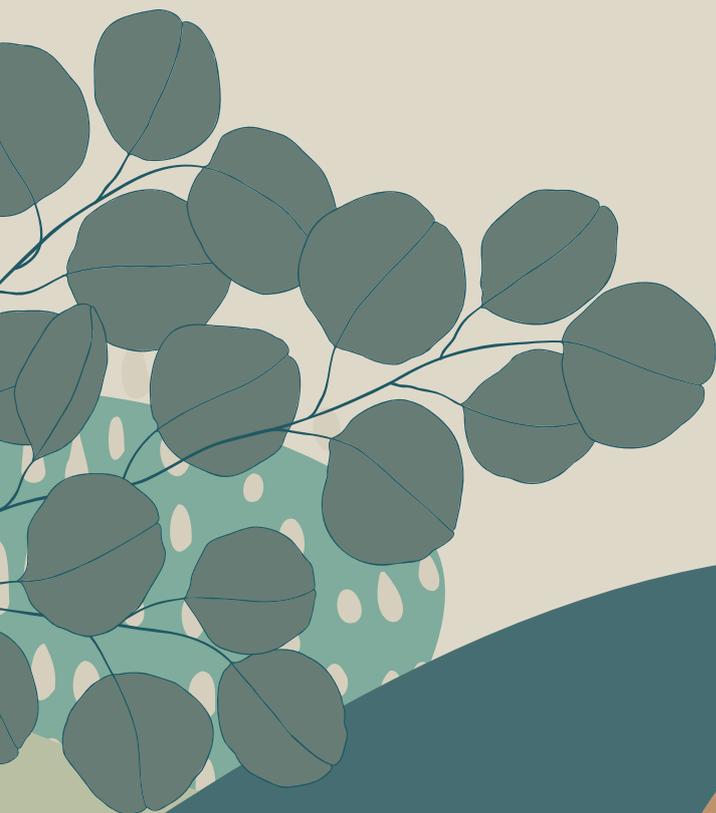




Voicing

My CHOICES

A Planning Guide for
Adolescents and 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 and you can make changes at any time. 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 letters 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.

Any term that is **bold and underlined** throughout this booklet is defined in the glossary on page 21. On this page you will also find a list of terms that may provide additional clarification for you.

Table of Contents

Say what makes you feel supported, write what decisions bring you peace.

Choose what provides you the most comfort, voice your thoughts and needs.

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Stuff you need to know About Me



What do I need to know about you as a person
to give you the best care possible?

My Voice

My funniest memory is:

.....
.....
.....

My favourite trip or holiday was:

.....
.....
.....

My greatest achievement is:

.....
.....
.....

My best childhood memory is:

.....
.....
.....

The things I'm most grateful for are:

.....
.....
.....

My fondest memories with family and friends are:

.....
.....
.....

How I want to be Cared For

These are a few of the comforts important to me

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 Voice

Ways to bring me comfort are (e.g. food, music, podcasts, TV/movies, books, activities, games, aromatherapy, places to visit):

.....
.....

Preferences I have for my room/space include (i.e. lighting, sounds, decoration, bedding, photographs, etc.):

.....
.....

Other things that are important to me are:

.....
.....

If I am in pain, I would like:

- or,
- 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.
 - 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 (i.e., timing, pain severity, other methods of pain control, or subcutaneous versus oral medication) are:

.....

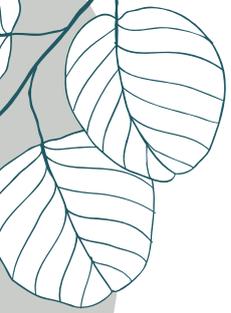
My Choice

Other things I would be interested in to improve my comfort are:

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

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:



How I would like to be Supported when I'm really Sick

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.

So I don't feel alone

My Choice, My Voice

The ways I like to be supported are:

- I would like my family to be with me when:
- I would like my friends to be with me when:
- I would like visitors when:
- I would like to be alone when:
- If I am sleeping, I would like to be:
- If friends are coming to visit, please help me get dressed and whatever else is needed to help make me look my best
- If people are very upset or crying, I'm ok if they:
 - Share their feelings with me
 - Visit me at another time
 - Cry in front of me
- If people are unable to visit, I would like them to communicate with me by:
- How I want other people to be informed of my preferences about getting visitors:
- It is important to me that my friends/family respect my wishes, decisions and choices even if they don't agree with them.*



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 counselling or find a support group for themselves and/or my brother(s) and sister(s) if they are having a hard time
- Pursue the things that bring them comfort and happiness

My Voice

I want my family to know that I am thankful for their love and support. I am especially thankful for:

.....
.....
.....

I want my friends to know that I am thankful for their love and support. I am especially thankful for:

.....
.....
.....

I want my family and friends to know that I regret:

.....
.....
.....

If I have been hurt or upset by my family, friends, or others, they should know I forgive them for:

.....
.....
.....

The things I value most in my life:

.....
.....
.....

My Spiritual and Cultural Thoughts and Wishes

Not everyone has a religion or spiritual or cultural 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 Choice

- I would not like to have spiritual/religious activities incorporated into my care at this time.
- 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 other spiritual beliefs and questions I might have about death
 - A hospital-based spiritual leader such as a chaplain, rabbi, imam, priest or pastor to visit me while I am sick
 - Every day
 - Once a week
 - Just when I ask
 - Spiritual/religious support for my family

My Voice

I identify with the following spiritual and/or cultural group(s):

The meditation/prayers/religious songs/chanting I find useful are:

.....

People from my spiritual or cultural 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:

.....

Based on my personal beliefs, I would not like people to talk about death or the afterlife as:

.....

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

.....

Other thoughts or preferences I have related to spirituality, wellbeing or peace of mind I'd like honoured (including things to do with medicines or treatments):

.....

.....



Who 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, or persons, your 'decision-maker/s' would make sure that your thoughts or wishes are respected. If you are happy with how your healthcare decisions are made now, you can skip this page. Please keep in mind that this page is not legally binding.

Things to Consider When Choosing Your Decision-Maker:

It can be helpful to choose people who know you well, care about you, live 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(s) you recommend can be your parents/guardians or someone you would like your parents/guardians to work with, like your partner, carer or siblings.

Remember, Your Decision-Maker:

- 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 wishes.

I give my decision-maker permission to make these choices for me about my medical care or services, if I am unable to do so myself. (Please check all that apply)

To allow or refuse:

- Tests (like blood tests or CT scans)
- Medicines
- Surgeries
- Other care that can help keep me alive (like dialysis or antibiotics)
- Medication(s) or procedure(s) to help with pain
- Stop previously started treatment
- Donate usable organs and/or tissue of mine if it can help others
- All of the above**

Act on my behalf to:

- Determine which health care worker(s) should take care of me
- See and approve release of my medical records
- Apply for **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**

Arrange for:

- Hospital or palliative admission
- Admission to a facility in another state to get the care I need or to carry out my wishes
- Hospital discharge to take me home
- My decision-maker is also allowed to make decisions based on conversations we have had about my wishes and what they believe my wishes to be.
- All of the above**

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

First Person (Full Name): Relationship to me:

Address:

Phone: Email:

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:

Address:

Phone: Email:

Third Person (Full Name): Relationship to me:

Address:

Phone: Email:

How I want my decision-maker/s to make decisions:

.....



The types of Life Support Treatment I want, or do not want

Some of the questions on this and the next page can be confronting. If you are feeling upset, talk to your medical team for support.

A time may come when you are very ill and not able to speak for yourself. If this happens it will be important for your decision-maker/s to know your preferences on **life-support treatment**.

Life-support treatment means 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 opt for a **natural death** by completing a **Not For Resuscitation (NFR)** 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 health care 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, prolongs the dying process without offering benefit, or adds to the perception of a poorer quality of life.

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*
- Nothing will be done or withdrawn with the intention of taking your life

Examples of Life Support

Interventions to treat life-threatening conditions such as infections or failure of the bone marrow to make blood cells. Machines or devices that support injured organs and allow them to recover function:

- 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
- Antibiotics to treat **infections**
- Medications to treat **pain and anxiety**
- Transfusion of **blood** or blood products
- Perform **surgery** if needed to help increase survival
- Perform **CPR** if the heart stops
- Machines or devices to support **injured lungs** (oxygen therapy, mechanical ventilators, breathing tubes)
- Machines to replace **kidney** function (dialysis)
- Medications or devices to help injured **heart** functions

My Choice

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

Some of the questions on this and the next page can be confronting. If you are feeling upset, talk to your medical team for support.

- 1** 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

- 2** 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 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

- 3** If life support is unsuccessful to stabilise 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 decision-maker/s reassess the goals of my care
 - I would like to continue life support

I have discussed this decision with my doctor and/or my decision-maker/s

My Voice

Describe here if you have other preferences for when or how long you want life support measures to be used/not used:

.....

You may have preferences around what happens to your body if you die. You can express those preferences below:

- I would like an **autopsy**, if relevant and possible
- I would like to donate my body to science, if possible
- I would like to be an organ donor, if possible
- I would like my decision-maker/s to make these decisions as they see fit

The place I want to be if the end of my life is near is: at home at the hospital not sure

Other:

Other decisions I would like respected:

.....
.....

I have completed a **NFR (Not For Resuscitation) Order**:

yes, it is located no

Other options such as an Ambulance Plan may be available in your state. Check with your medical team for more information.

How I Wish to be Honoured and Remembered

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.

My Choice

- I prefer not to be a part of planning my service
- I prefer to be part of planning my service
- I prefer to have my family make choices about my service

There are many different types of services. Some services include:

Funeral:

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

Memorial service:

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

Celebration of my life:

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

The type of service I would like is:

My Voice

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

.....

The music/videos/photos I want at my service are:

.....

The food I want at my service is:

.....

The people I would like to be present are:

.....

I would like these readings at my service:

.....

Who I would like to perform these readings:

.....

I would like these other arrangements at my service:

.....

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

.....

Some of the questions on this and the next page can be confronting. If you are feeling upset, talk to your medical team for support.

I would like:

- An **open casket**
- A **closed casket**
- To be buried

This is where I prefer to be buried:

.....

- To be cremated

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

.....

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 wishes that you have for how 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 what you desire and how you would like to be remembered so that they can fulfill your wishes and know that by doing so, they have your special approval. You might choose to create a legal will or document that sets out how you want the things you own to be distributed when you die. Please talk to your medical team for more information.

This is how I would like to share My Belongings

My Belongings

Clothes:

Games:

Art:

Photographs:

Computer:

Furniture:

Car:

Pets:

Books:

Music:

Phone:

Other electronics:

Money/savings/superannuation/insurances

.....

Other heirlooms or belongings:

.....

I would like my belongings sold and proceeds donated to the following charity:

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

I would like the following person to decide how to distribute my belongings instead:

Special Days

How I would like to be remembered on my birthday:

.....
.....

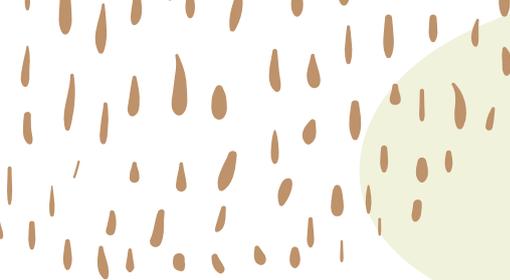
How I would like to be remembered on other important days:

.....
.....

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

.....
.....

The people I want looked after are:



My Personal information

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

.....
.....

Passwords/Pins:

Phone:

Bank accounts:

Other financial accounts:

Computer:

Other:

.....
.....

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

I want to distribute them.

They are located

.....
.....

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

.....
.....

How I would like My Online Presence to be managed

Our social media presence is an important part about who we are. Below, you can select how you would like your social media accounts to be handled if you were to die, like who you want to give your passwords to, and what you want to happen with your accounts.

Facebook

I want
to manage my account.

Email/username:

Password:

I would like my account to be: deleted kept active memorialised

Instagram

I want
to manage my account.

Email/username:

Password:

I would like my account to be: deleted kept active left alone

Twitter

I want
to manage my account.

Email/username:

Password:

I would like my account to be: deleted kept active left alone

Other:

I want
to manage my account.

Email/username:

Password:

I would like my account to be: deleted kept active left alone

Other:

I want
to manage my account.

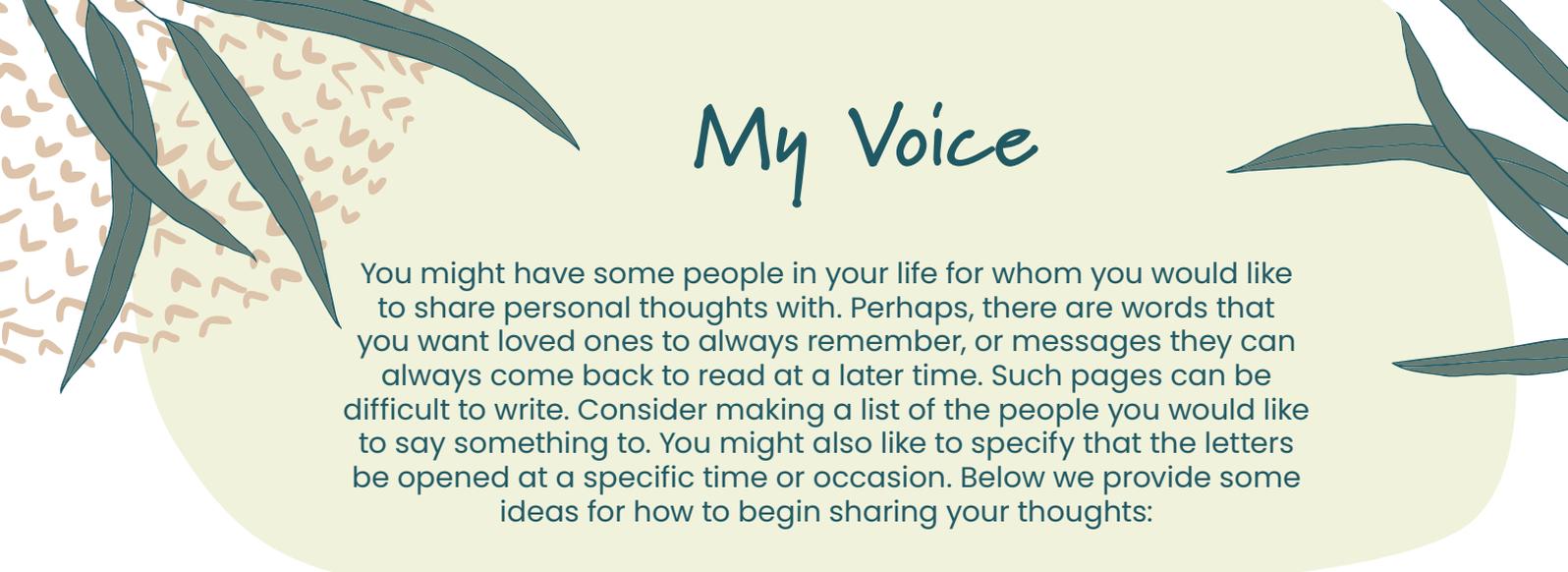
Email/username:

Password:

I would like my account to be: deleted kept active left alone

You can write any other instructions here:

.....
.....
.....
.....



My Voice

You might have some people in your life for whom you would like to share personal thoughts with. Perhaps, there are words that you want loved ones to always remember, or messages they can always come back to read at a later time. Such pages can be difficult to write. Consider making a list of the people you would like to say something to. You might also like to specify that the letters be opened at a specific time or occasion. Below we provide some ideas for how to begin sharing your thoughts:

Dear

Writing this letter is really hard to do. You have been so important to me because...

I will especially always remember...

One thing I want you to always know...

In the future, if you ever get very sad...

I want you to always remember...

Something I hope for you is...

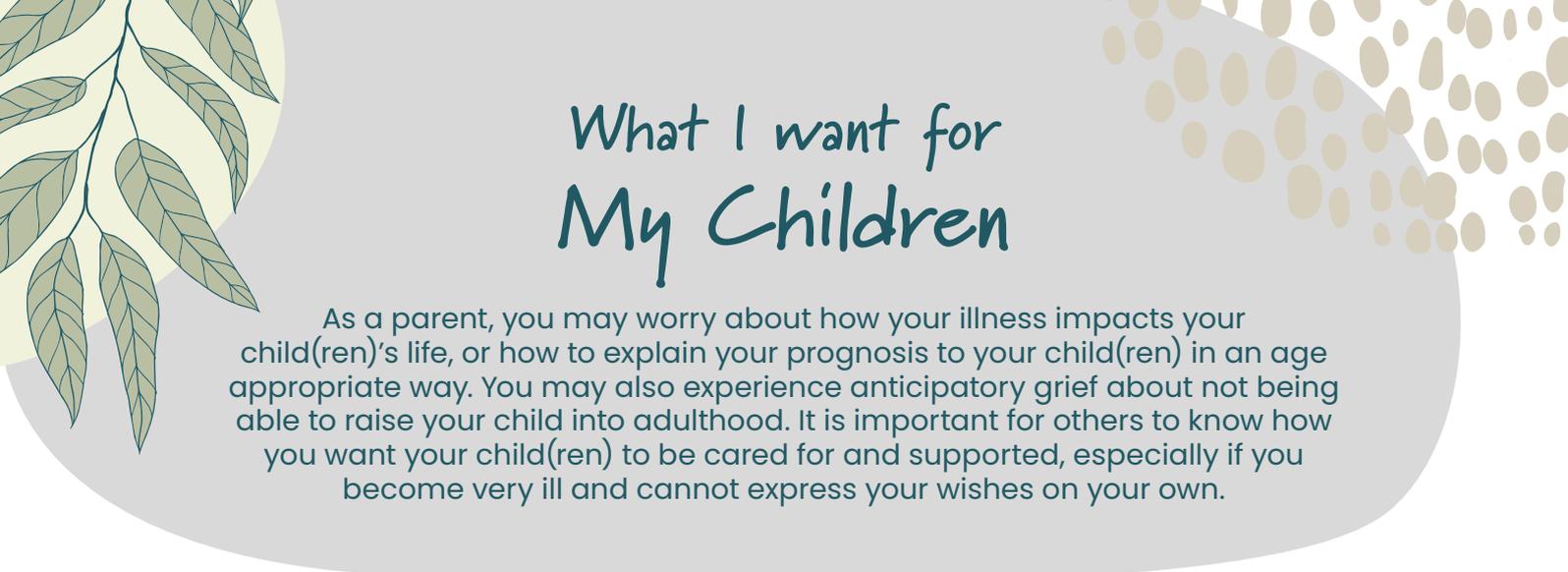
My Reflections

This is a space to **share additional thoughts** or to provide more detail to questions within the document.

A series of horizontal dotted lines for writing reflections.



A series of horizontal dotted lines spanning the width of the page, providing a guide for handwriting practice. The lines are evenly spaced and extend from the left margin to the right margin, leaving a small gap for the decorative illustration.



What I want for My Children

As a parent, you may worry about how your illness impacts your child(ren)'s life, or how to explain your prognosis to your child(ren) in an age appropriate way. You may also experience anticipatory grief about not being able to raise your child 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 wishes on your own.

If I am too sick to care for my children:

Who I want to take care of my child(ren) when I am not able:

.....

Ways I want my child(ren) to be comforted and supported include:

.....

Preferences I have for my child(ren) visiting me:

.....

How I want my illness and prognosis to be communicated to my child(ren):

.....

If I am very ill or on life support, I want my child(ren): To be with me To not be with me Other:

.....

When the end of my life is near, I want my child(ren): To be with me To not be with me Other:

.....

After my death:

Rituals or activities I would like to be continued with my child(ren) to keep my memory alive include:

.....

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

.....

Wishes I have for my child(ren) include:

.....

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

.....

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

.....

Other arrangements I have made or would like made for my child(ren) include:

.....

Other things that are important to me are:

.....

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.

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.

Healthcare Providers

A person or organisation 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.

Medicare

A federal system of health insurance.

Natural Death

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

Not for Resuscitation Order (NFR)

An NFR is a legal document that is signed by your doctor. If you think a NFR may be appropriate for you, discuss this with your doctor or medical team.

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 organisation 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 health care providers follow my wishes as communicated in this booklet. This booklet is only to be used in the case I can no longer communicate my wishes myself.

My Signature:

My Date of Birth:

Address:

Phone: Today's Date:

I would like this booklet stored in:

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, wishes, 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

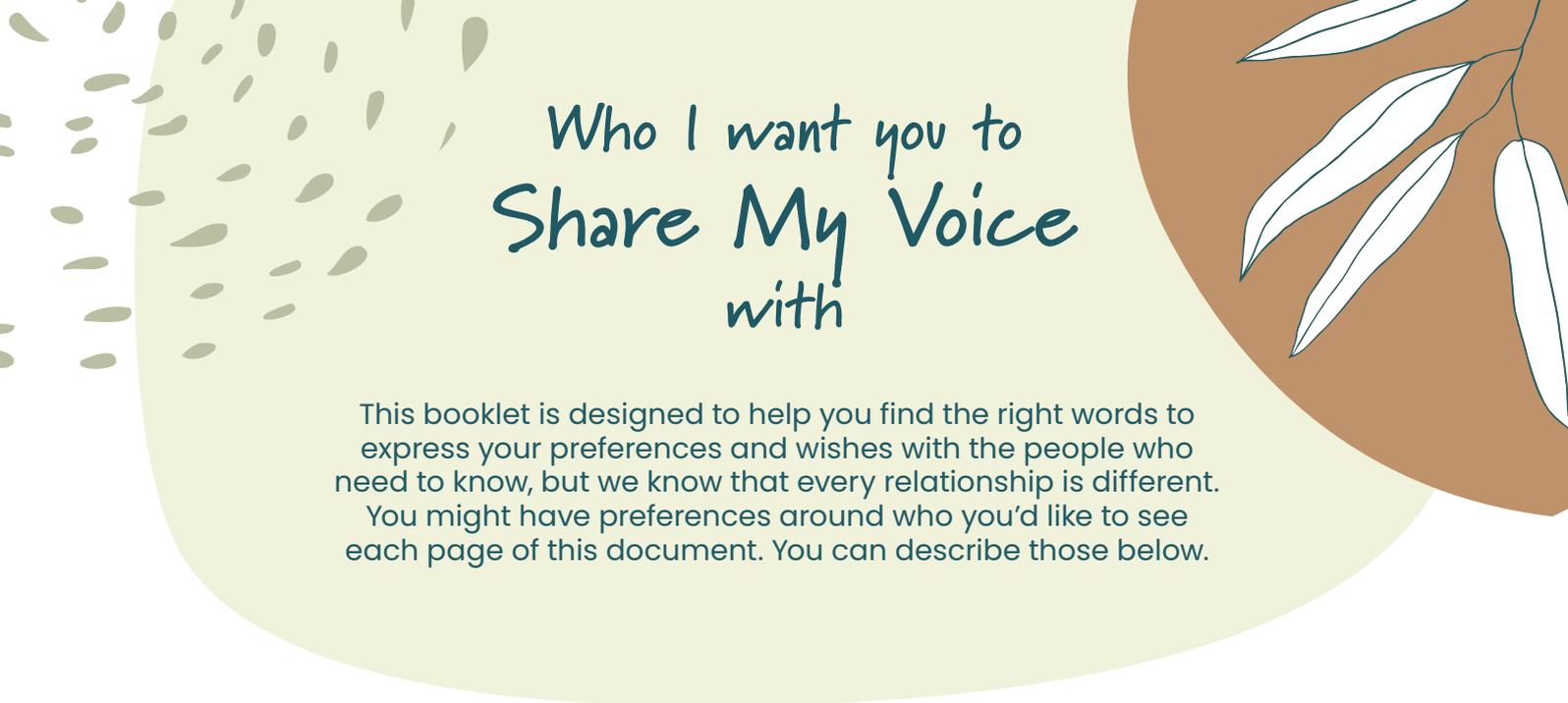
.....
Address

Notarization (if required by the state you live in)

Voicing

My CHOICES

A Planning Guide for Adolescents and 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 honour your wishes no matter how you express them. **This booklet is not a legal document.** If you are age 18 or older and want your wishes to be legally binding, you should consider completing an advance directive, or a will. 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.



Who I want you to Share My Voice with

This booklet is designed to help you find the right words to express your preferences and wishes with the people who need to know, but we know that every relationship is different. You might have preferences around who you'd like to see each page of this document. You can describe those below.

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About Me, page 4:

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Voicing

My CHOICES

A Planning Guide for Adolescents and Young Adults was originally 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 research using the Five Wishes advance directive and incorporating the extensive feedback of many treasured colleagues, adolescents and young adults. Special thanks to Lori Wiener, PhD, in addition to Sima Bedoya, PsyD; Abigail Fry, B.A.; Maryland Pao, MD.; Kathleen Samiy, and Anthony Suffredini, MD.

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