

Dying and Caring for the Dying at Home



The materials in this manual are not for professional reproduction and are the intellectual property of A Sacred Passing Death Midwifery and Community Education. However, please share with the community wide and far. Share it with anyone you think may find it helpful.

Adapted for the Current Life we are Living - Edited: 03.24.2020



Introduction

We are sharing tools that those within A Sacred Passing have built through training, community building, and research. This particular document has been a work in progress that we hoped to share as soon as possible with community members.

With our networks of death professionals, doulas, and funeral directors, we have been discussing the ways folx are choosing to respond to COVID-19, with precautions like social distancing, limited gatherings including ceremony surrounding death. This virus will likely lead to an increased possibility of community members dying at home. We came together to provide a short document of resources to become more educated about death and dying at home, be a companion to someone who is dying, or prepare your own dying wishes.

The more people who engage with this practice of caring for our dead the more groundwork we will continue to build. Please reach out to us for additional resources. We want to share this knowledge authentically & with care. This document is sprouted from a group of facilitators & facilitators-in-training from A Sacred Passing's No One Dies Alone (NODA) program. A volunteer program that provides the reassuring presence of a trained volunteer companion to dying people who would otherwise be alone. We work towards building these skills collectively because we recognize that people do die alone. We build skills to participate in care using accountable, sustainable support.

A Sacred Passing acknowledges that we gather on Indigenous land: We are located on the traditional territory of Coast Salish peoples, specifically the Duwamish Tribe. Please look and see whose land you're living on, and find meaningful ways to honor and support.

Gratitude to the centuries of women of color, humans enslaved, mothers, grandmothers, daughters, servants and village witches who have been doing our birthing and dying. We hold a quiet warm space for the knowledge and the paths they have left for us to learn from.

Please share in these acknowledgements through your own ways, words, and actions. This may include:

- <https://www.realrentduwamish.org/>
- <https://apihtawikosisan.com/2016/09/beyond-territorial-acknowledgments/>
- <https://www.teenvogue.com/story/indigenous-land-acknowledgement-explained>



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Dying and Caring for the Dying at Home

If the cause of death is known and from natural causes the doctor will issue the documents to allow you to register the death. It's important not to take responsibility for the time, cause or reason of and method of dying and death. Please know you are doing the best you can.

I Will Be a Hummingbird Wangari Maathai

<https://www.youtube.com/watch?v=IGMW6YWjMxw>

- The idea of offering presence allows the dying to know they are not alone. What are some of the ways we can prepare to hold that presence?
- Taking 10 deep breaths
- Asking for nonvisual helpers, guides, Gods, and ancestors
- Listening to a song or singing one yourself
- Drinking a glass of water
- Feeding yourself something small
- The moment of death is only one part of the dying process. It is not something we can control.
- It is the connection and care that we bring into the dying's life that matters. In this spirit it can truly be said, "They were not alone." This is an emotional, spiritual, and relational reality - not just physical.
- It is not uncommon for the dying to WAIT to breathe their last breath until they are alone. It's surmised that it can be less painful for them to leave when those they love aren't right there.



The Role of the Companion

What does being a companion to the dying look like?

Social

- being with
- talking to
- reading

Medical

- Offering as much comfort care as you have access to
- Writing down all that you can as far as their wishes for a gathering after this all ends. See *Death Plan Doc in Resources*

Spiritual

- offering words that resonate with the dying
- connecting with the land, opening windows, or going outdoors
- prayer

Financial

- helping them complete a list of things to be taken care of - passwords, accounts, where they'd like monies to go. It won't be legal, but it will be something to show the dying expressed their wishes.

Emotional

- Listening
- Writing letters to say goodbye to people they might not be able to say goodbye to
- Recording their words to share with folx later



The Dying Person's Rights

- The right to be treated as a human into my death.
- The right to maintain my autonomy.
- The right to be cared for by those who can maintain a sense of presence, compassion and grace.
- The right to express my feelings and my emotions about my approach to death
- The right to participate in decisions concerning my care.
- The right to expect continuing medical and nursing attention throughout the dying process.
- The right to choose if, when and how to mitigate pain.
- The right to have questions answered honestly.
- The right not to be deceived.
- The right to have and not to have help from and for my family in accepting my death.
- The right to expect that the sanctuary of the human body will be respected during and after my death.

What rights would you add to this list?

What are ways to honor the autonomy of the people around us?

This Patient Bill of Rights was sprouted from one created at a workshop on “The Terminally Ill Patient and Helping the Person,” in Lansing Michigan in 1975 and the aforementioned A Sacred Heart Hospice and updated to honor autonomy.



Helpful Tools for Caregivers

Please prepare yourself for entering into the space of someone who is facing death. Walking into a room of someone who may be dying soon requires that you come fully into “present time.”

Your presence:

- A willingness to just “be with”
- Be there to listen, discover comfort in the silence
- Being open to follow the lead of the dying
- Answering questions honestly. It can be hard to show up authentically while navigating who you are.

Please do not offer ideals, unless asked about do not offer:

- Remedies or programs to cure or heal
- What happens when someone dies, and the afterlife
- Your stories of other death experiences
- The right ways to die
- The reason why you think this person is dying or dealing with a life threatening illness
- Asking someone: *what feels true to you right now? Why do you ask?*

Option:

- Ask the dying, what they believe, why the answer is meaningful to them, work through what they are feeling and try to move from what your beliefs are.

Whenever possible, we let the dying lead:

- If a time should come when you feel the patient/care receiver wishes need to be overridden, please consult with other caregivers.
- Ram Dass has said: “There are dying people, and there are caregivers to the dying, but they are both engaged in the same work, the work of waking up.”

Inspiration for this list has been gleaned from Doorway Into Light Bodhi Be/ Director, Interfaith / Innerfaith Minister and updated to honor autonomy.



Trying to Create a Calming Space

Creating a calm environment

- Depending on the wishes of the dying
- Crack a window for the smell, sound and airflow of outside
- Lowering overhead lights
- Think about what the dying likes and doesn't like.
- Choose the items you bring into the space according to what the dying person would want and not want.

Changing an environment with music

- What sounds are soothing? What sounds are available?
- Does the dying like the water? Do they like to hike? The sound of birds etc.
- Are there styles of music they would never listen to- don't put it on :)
- Think about the senses and what you can do to bring calm to them. Write them down as you brainstorm, think of how to be of assistance to someone who is actively dying

Meet the person where they are in their process

- Trust your intuition after checking in with the dying person
- Approach the subject of death as a natural life process and only with permission
- Be as fully present and in the moment as possible
- Allow household pets be around the dying if the dying had pets
 - If the person dying is in a home that is not theirs, be aware of any allergies that may ignite a reaction from the dying and make them uncomfortable.
- Bring a loving presence
- Normalize the environment
- Take time to access where the person is at in their dying process
- Ask how you can help
- Listen and remain open
- Ask what the person needs or desires (watch for whole body responses)
- Read from text that the person can relate to
- Use prayers, meditation, either quiet or guided
- Provide some comfort foods to eat or drink; if they still can take either
- Facilitate unfinished business (forgiveness rituals)
- Affirm visions or information shared by the dying person
- Look at photo albums

Create an intentional environment

- Create good smells (soup, cookies, homemade bread)
- Use of essential oils and/or flower essences as desired
- Music, any kind the person loves
- Change the energy in the room (move furniture or things in and out)
- Hang a favorite painting or photos
- Use calming colors such as solid pastel silks to create a soothing atmosphere
- Use the elements in the room (water fountains, wind chimes, crystals, plants, etc.)
- Use sun dried sheets on the bed
- Light candles



Body language of the Dying

- Self Stroking or Auto Contact, also called self soothing or pacifying behavior, like touching or rubbing the neck, stroking a thumb, rubbing the earlobe, rubbing the legs.
- Lip Chewing or biting. -> could also indicate interest in the conversation you're having, the music, touch etc. happening
- Sucking or chewing on any kind of object, finger or hair.
- Any kind of hand movement toward or near the mouth, also concealing the mouth.
- Playing with hair. -> could also indicate interest.
- Picking finger nails.
- Tapping of the fingers in a non-musical way.
- Sudden increase or decrease in speech rate.
- Speech hesitation, stuttering, pauses, pause filler like uhm's, delayed responses.
- Sudden increase in speech errors, like going from half sentence to half sentence, stopping half sentence and starting to talk about something completely different.
- Sudden high pitched voice.
- Furrowed forehead.
- Compressed lips.
- Covering the neck dimple (suprasternal notch) or Hand to Lower Neck.
- Crossing arms at certain topics or situations.
- Crossing arms while self hugging.
- Uneven smile, lopsided smile or a smile with some contempt.
- Compressed smile of the mouth, without wrinkling of the eye corners, also called the nervous smile.
- Fetal position, hugging the knees, pulling knees in, balling up. Also shown when there is extreme sadness or depression.
- Talking with a quiet voice, or a low volume voice.
- Sighing, deflating, exhaling.
- Blushing of the face, blushing of the ears. -> could also indicate interest.
- Swaying or rocking the body back and forth, or from side to side.
- Feet fidgeting. -> could also indicate interest.
- Crossing hands in front of the groin.
- Playing with or adjusting a bracelet, watch or cufflink.
- Checking for a purse, wallet, keys... "items to go with".
- Shifty eyes, looking over your shoulder, quickly looking away.
- Erratic movements, darting movements
- Unintelligible sounds



Body Before Death

Days to hours prior to death, known as Active Dying
Disengagement from other people Agitation
Kidney function slows, urine output is lower, urine becomes darker
Incontinence
Terminal delirium or terminal agitation
Seeing figures in room
Averse to food and drink
Significant sleeping
Blood pressure drop
Changes in breathing pattern
Open mouth breathing
Shifts in body temperature
Eyelids open, but not responding to stimulation in front of the eyes
Stiff joints
Cold extremities
Rise in heart rate
Mottling of skin-blotchy discoloration
Limited communication
Imminent Dying, hours or minutes prior to death
Complete disengagement from other people
Eyes become fixed and remain open without blink reflex
Blood pressure drops further. Pulse is irregular and very weak
Oxygen saturation is low (when measured by a medical device)
Heart rate drops
Cyanosis-fingernails, toenails, lips, nose, top of ears turn bluish /purplish
Cheynes-Stokes breathing-a pattern of breathing of breaths of differing depth followed by a pause
“Death Rattle”--fluid buildup in throat which makes noises while breathing
Breathing becomes mechanical
Urine ceases entirely
Changes in skin color
Faint pulse
Skin mottling further
Mouth agape
Right at death
Mouth open in Q or O position
No pulse
Warm body (others might already feel cold)
Slight smell of death
No breath
Purge-expectorate from the mouth -- brownish reddish fluid
Pupils dilated and do not respond to stimulus
Gag reflex is absent
Complete inability to rouse



How will you know your companion has died?

- They will have no pulse or heartbeat.
- They will not breathe.
- They will not respond to your voice.
- The eyelids may be slightly open and the eyes fixed.
- The jaw will be relaxed for the first hour or two.

What to do when your companion dies?

- Remember death is not an emergency, but in WA State you will have to call and alert the authorities and notify certain services.
- Take a deep breath
- Honor them in a way that feels good to you
- Take another deep breath
- When you are ready, notify
- If the death was expected, perhaps due to illness, you should contact your funeral home, follow the deceased's wishes
 - In Connecticut, Illinois, Indiana, Louisiana, Michigan, Nebraska, New Jersey, and New York, a licensed funeral director must be involved and sign the death certificate. It is legal in the state of Washington to keep the deceased at home (body is placed on dry ice after 24 hours). You can legally act as your own funeral director, or you can have us act as your licensed funeral director.
 - The local registrar will issue a burial-transit permit that allows you to move the body for purposes of burial or cremation. You must obtain this permit within three business days after the death and before final disposition. (R.C.W. § 70.58.230.).
- Call 911 if there is an unexpected death in your home. The medical team will help you figure out the next steps. If the deceased was receiving hospice care, call the hospice.
- Look for any written instructions (sometimes called a "Letter of Instruction," "Final Instructions", or "Disposition Authorization") for arrangements. Also look to see if the deceased is named a "Designated Agent" to take care of those arrangements (sometimes this is included in the deceased's advance directive documents such as in their Durable Power of Attorney for Health Care). If you cannot find these documents, ask close friends, the deceased's doctor, or the deceased's lawyer if they know where these instructions are.



What Is Dying?



what is dying



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Dictionary

Search for a word



dy·ing

/ˈdiɪŋ/

adjective

on the point of death.

"he visited his dying mother"

Similar:

terminally ill

at death's door

on one's deathbed

in the jaws of death



• occurring at or connected with the time that someone dies.

"he strained to catch her dying words"

Similar:

final

last

departing

deathbed



• gradually ceasing to exist or function; in decline and about to disappear.

"the dying embers of the fire"

Similar:

declining

vanishing

fading

passing

ebbing

waning



Translations, word origin, and more definitions

From Oxford

[Feedback](#)

I am standing upon the seashore.
A ship at my side spreads her white sails to the morning breeze,
and starts for the blue ocean.
She is an object of beauty and strength,
and I stand and watch her until she hangs like a speck of white cloud
just where the sea and sky come down to mingle with each other.
Then someone at my side says: "There! She's gone!"
Gone where? Gone from my sight – that is all.
She is just as large in mast and hull and spar as she was when she left my side,
and just as able to bear her load of living
freight to the place of her destination.
Her diminished size is in me, and not in her.
And just at the moment
when someone at my side says: "There! She's gone!"
there are other eyes that are watching for her coming;
and other voices ready to take up the glad shout:
"There she comes!"

And that is -- "dying."

- Rev. Luther F. Beecher 1904



Ritual Washing of the Body

At some point, usually within an hour, it is appropriate to begin a ritual washing of the body. This is done with the utmost care, respect and dignity for the person who has died. First remove the clothing using draping techniques so as to not uncover the private parts of the torso.

Supplies you may need include:

- 3-4 small washcloths
- 3-4 hand or shower towels
- A large bowl or basin $\frac{3}{4}$ full of warm water
- Shampoo
- Comb or brush
- Toothbrush and toothpaste
- A Depends, absorbent pad or a towel doubled
- A castile soap if possible
- Medical gloves (caring for any wounds)
- Dry shampoo (not all hair supports the use of wet shampoo)
- Essential oils
- Body balm
- Tea Tree spray

When washing you can add a dialogue, a prayer, a blessing, an offering of gratitude, etc. Here are a couple examples:

1. "We are going to be physically, literally washing their body. To get it clean and ready for the next step. But we are making this a special time. We are asking it to be a sacred time and a deeply intentional process. In doing that we ...
2. "We invite into this room all the ancestors and guides, guardians and loved one who have ever loved or cared for our dear _____. Join us now as we clean and bless this body which has carried them in this lifetime.
3. We are washing away the stress, the pain and any discomfort they have had in these final stages. As you wash, I invite you to please say out loud the blessings and thanks for each part of _____ body as we have experienced it in this world.
4. Beloved _____ (*Spirit*, God, Creator, Mother, Father, Universe)



Bless this mind, *which was open to new possibilities.*
Bless these eyes, *which saw such beauty and wonder in the world.*
Bless these lips and mouth, *who spoke of love and truth.*
Bless their voice
Bless their heart
Bless their shoulders
Bless their arms
Bless their hands
Bless their belly
Bless their legs
Bless their knees
Bless their feet
Bless their back
Bless the body of our beloved _____. It has served them well in this lifetime. May they be free of it now and on to their next phase of existence.
(Blessed be, Enveloped in love, amen, Ashay, Namaste) _____."

Washing the Body

1. We wash the arms and legs first while the deceased is lying on their back. Then we use respectful draping and only the most intimate caregivers will wash thoroughly the front of the groin. There may be a need to clean released urine or feces, if you are keeping your human at home for a wake. For a ritual washing, and no wake, you can skip the groin if desired.
2. Once the front has been washed then the body is rolled to their side, if you have help. One holds the waist and shoulder, the other hip and mid-thigh to knee. The farthest knee is bent slightly across the other knee towards the person holding the leg. This makes rolling easier.
3. On the count of three the body is pulled towards the two helpers onto its side. It is then supported while the third person cleans the back, removes the soiled bedding from under the person and applies the new absorbent pad/towel. The legs are separated slightly and the butt cheeks are pulled apart to thoroughly clean the rectal area. Feel free to use as many hand towels, wet wipes as necessary. Also change the wash water as necessary. After washing the rectal area it is a good idea to spray the area thoroughly with the tea tree spray or to apply tea tree or other antibacterial essential oils. Packing cotton into the rectum to avoid leakage is something that you can also do.



4. If you are using dry shampoo for hair washing, spray it 4"- 6" away from the head, and using your fingertips, massage the product into roots and scalp so that the oil-absorbing action can take place evenly across the head. If you are using wet shampoo a garbage bag under the head with the opening like a sink behind the person off the end of the bed works well for rinsing the hair and keeping the excess shampoo off the bedding.
5. The teeth are brushed or dentures removed cleaned and replaced, or not, depending. Dentures will need to be removed before cremation or green burial.
6. In the event of trauma, large wounds can be covered with gauze and taped shut for appearances, please wear gloves. If the person has had a large amount of fluid retention/edema/swelling in the legs or belly, it may be helpful to wrap these areas with chucks and secure with tape to prevent seeping fluid from soiling the clothing or draping material during the wake or vigil.
7. Once the body has been washed, we have several choices:
 - a. Dress them in the clothes for the funeral services.
 - b. Shroud them, wrap them in a sheet and blanket to be transported to the cemetery or body care facility
 - c. Cover them with linen
 - d. The body can be laid out for the home vigil or wake.



A Vigil or Home Wake

The vigil can last 1 hour to 3 days, and has many purposes. In this process we serve during the passing of spirit of the deceased, create tangible moments for the grieving process for family and friends, integrate death as a natural process into the greater human culture and support the absorption of the sacred elements back to source.

Examples:

- The body is washed by those caring for it
- A balm of herbs and oils may be rubbed into the body.
- The body is dressed as requested. Either in clothes or in a funeral shroud (a special cloth for just that purpose) or in something as simple as a sheet.
- If you have help to move the body, place it in a space that is meaningful.
- A Guide candle is lit and placed above but on the same plane as the head. This candle also can burn continually as long as it is safe. An electric candle is ok, too.
- A small altar to the elements; earth, air, fire and water, may be put in the room with the body..
- The body may be covered or not depending on the condition of the body and viewers' concerns.
- The candle is blown out when the body is moved to either be cremated or buried.
- A small ritual of gratitude for the cycle and closing is given.
- There is one vein of thought that our bodies are a collection of water; earth as minerals in our cells and bone; fire represented as electrical energy and air as our much needed gasses like oxygen. With the fifth sacred thing being spirit, that which animates the whole. When we die our elements break apart. Fire is the first to leave the being at death. Sometimes it is thrust out, sometimes leaving is its conscious choice. Then the breath stops: air leaves the body. Then the spirit leaves, then the earth and water break apart/deconstruct into simple parts. The body breaks down, decomposes. These separate elements are then allowed to be resourced back into the whole of existence and to be made ready to reform in a new collection of elements manifest as some new thing. The cycle of life continues.



NHFA's Guide on Bodycare

The purpose of preparing the body is to prevent any sights and odors that the family/community might wish to avoid during the vigil, and as a symbolic gesture of loving, hands-on care that is usually the last physical contact the family has with the deceased. Care of the body engages our hearts, minds, bodies and spirits in a compassionate fashion and usually helps to facilitate healthy grief processes. There is no right or wrong way.

The idea of providing body care may be uncomfortable for many people. Because we have become so culturally alienated from caring for our dead, this is understandable. Those who do elect to participate in body care often see their fears disappear. Rather than the mysterious and technically challenging undertaking it is made out to be, body care, like many aspects of home-based post-death care, is a simple, practical task that might be compared to caring for an infant, immobile, or bed bound person.

How to do Body Care

- Eyes — If the eyes remain open after death and you wish that they be closed, gently bring lids down over eyes and place small bags of rice or sand (or other substance that can provide a little weight) over the eyes and keep in place until lids remain closed. This usually takes a couple hours.
- Mouth — If the mouth is open and you wish it to be closed, use a necktie or long thin piece of non-slippery material (an ace bandage or a scarf work well), bring it under the jaw and tie a knot on top of the head. A second person is necessary in order for the mouth to stay closed while the knot is being tied. Keep in place until the mouth remains closed without a tie. The time varies on this, though it usually takes 1-2 hours. In some cases, it may be impossible to completely close the mouth in this way.
- Rigor mortis (stiffening of the joints and muscles) — generally sets in within the first few hours, so having the body bathed and dressed soon after death is recommended. However, if rigor mortis has already set in by time bathing occurs (or if the body, prior to death was already stiff), all of the above is possible but may be slightly more challenging. In this situation, an option for dressing the deceased (if regular dressing proves to be too difficult) is to cut the garment(s) up the back and tuck the sides



under the body. Sometimes massaging joints will help loosen them enough to make dressing easier.

- Cooling the Body
 - Dry Ice. In many parts of the country, dry ice is difficult to come by. It also requires special handling to avoid burning the skin of either the user or the deceased. Room ventilation is imperative to accommodate off-gassing for the safety of the living. The following are considerations and advice if dry ice is chosen as the primary cooling method.
 - Techni-ice or Other Polymer Refrigerants. Polymer refrigerants are highly recommended by the NHFA for their long life, reusability, absence of off-gassing or condensation, size versatility, and relative ease of activating and using for family members. Once activated, the sheets stay effective up to 3-4 hours when used beneath and on top of a cooling body. As the body cools, the time of effectiveness lengthens until, in many cases, it is no longer required. Each sheet can be cut to fit the dimensions needed for the individual, beneath and on top of the torso, and switched out as necessary with little disturbance. Some prefer to encase the activated sheets in a pillowcase or ornamental cloth, or add the changing of the ice to the ritual process.
 - Most important to cool are the trunk of the body from underneath and the head. Additionally, the areas of the body that have more tissue- ie belly and thighs.

Thank you to the NHFA for permission to include this. The direct link to this information and the state by state laws are in the additional resources section at the bottom of this page.

<https://www.homefuneralalliance.org/body-care.html>

<https://www.homefuneralalliance.org/health-and-safety.html>



Funeral, Gathering, Weaving Ritual from a Distance

Make a space in your home and fill it with items that remind you of the dead. Spend intentional time in this space. You can speak to the person, share memories, cry, laugh, read a poem, offer prayer or sit in silence.

- Create an effigy, which is a likeness of a person shaped out of wood, stone or other found materials. It can be as simple as wrapped fabric, the intention is to have a physical object to bury and let go of.
- Write a letter to the dead, send it, bury it, burn it or save it.
- Create art in a way that feels comfortable for you.
- Create a meaningful symbol or sigil. A sigil is a symbol infused with your thoughts, manifestation desires, hopes and wishes. It is a small visual reminder of something significantly larger. You can create this to represent the love and honor of the dead. Put it in a place that you see often, bury it or burn it. Further ideas on [how to create a sigil](#).

This can also be modified for a group with internet access and desire for group gathering via Facetime group calls, Skype, or Zoom if many folks want to witness and gather from afar.

- As a group of folx, set aside a time and a day to sit, wherever you may be in the world, and focus on the person. Together agree to read the same piece of poetry, scripture or sing/play a song together.
- Record a video message on your phone of a tribute to the dead and share it on a group message, email or virtual 'guestbook'



The Details: A Death Plan Worksheet

A Death Plan fills in the gaps of information not covered by a will, Advanced Care Directive or funeral plan. It is designed to tie those plans together in a cohesive way for families and friends to follow with ease.

Form checklist Durable power of attorney for Finances Durable power of attorney for Health Care Dementia & Alzheimer's Provision Last Will and Testament POLST Funeral & burial contracts/arrangements	Guiding questions/prompts <i>When you are ill, what do you want/need?</i> <i>What do you NOT want?</i> <i>When you are very stressed, what relaxes you and brings you comfort?</i> <i>When you are stressed, where do you hold or feel tension in your body?</i>
Pre Death	Post Death
Place Home, hospice, hospital, skilled nursing facility: rest home, assisted living, skilled care center, rehab	Preparing the body Cleaning, dressing, laying in honor, esthetics (makeup, hair), embalming, organ/body donation
Method natural course, VSED: Voluntary stopping eating & drinking, Medical Aid in Dying	Transportation By whom? where is your body going? in what? Do you want music? What music do you not want?
<i>Who do you want to visit you?</i> Family, friends, clergy, medical caregivers, pets (who do you not want there)	Vigil Where, how long, is there a flow? What might your family be comfortable with? Who will help?
Who will support: <i>Physical, emotional, mental, spiritual</i> Family, friends, clergy, Death Doula, medical caregivers, pets	Ceremony/Ritual Spiritual, ethnic, customary; when, where, facilitated by whom, for who?
Environment In what room or space, temperature, lighting, scents, music, noise levels, furnishings, bedding, Focal points: personal items, pictures, flowers, secular objects	Funeral/memorial When, where, how many attendees (who and who may not be invited), who will facilitate the day? a celebrant, minister, priest, friend,
Interventions Medical, comfort measures, spiritual (CPR, feeding tube, Oxygen, etc)	Deposition of the body Buried, cremation, aquamation, NOR, natural burial, sea burial
Medication Comfort care, pain management, regular maintenance medicine	Obituary Name used in obituary and announcements Pronouns, where can it be shared
Pain control What level (1-10) and how lucid/conscious Pain/Presence	Special Notes: Please don't let the room be without music, etc



Summary of Wishes for Health Care and Deathcare

For _____
[My Name]

This is not a legal document. I am creating it so that people will know what I want in the event I am unable to speak for myself, or I die without witness.

Item to think about when you are writing your wishes

Consenting/or not to medical treatments that are experimental.

Consenting/or not to donating organs/tissues.

Consenting/or not to an autopsy.

Consenting/or not to use all or part of my body for medical education or research.

Consenting/or not life support (CPR, Oxygen, Breathing machine, feeding tube)

Consenting/or not to burial or cremation

Who would you like to have your remains?

Where if you would like your remains to be scattered, if at all.

Written comments below:

Signature

Date

Witnessed by

Date



Self Compassion

Self-compassion is essential to self-care. Being kind to yourself builds the foundation to self-care. Self-compassion means giving yourself credit for the tough, complex work of caregiving, stepping away from the self-critical, harsh inner voice, and allowing yourself time — even if it's just a few minutes a day — to take care of yourself.

Lack of time or energy can make getting that time away particularly challenging. You may even feel guilty or selfish for paying attention to your own needs. What you need to know is this: in fact, practicing self-care allows the caregiver to remain more balanced, focused, and effective, which helps everyone involved.

Breath Awareness

One of the simplest deep relaxation techniques is breath awareness. (We) go over breath awareness, paced breathing, and other breath techniques in [The Harvard Medical School Guide to Yoga](#). Here is one you can try:

- Find a comfortable seated position on a chair or cushion.
- Close your eyes and begin to notice your breath.
- It is common to have distracting thoughts come and go, but just let them pass, and gently bring your attention back to your breath.
- Breathe in slowly through your nose for five counts, hold and pause for five counts,* and exhale for five counts.
- Continue for 10 minutes. You may substitute phrases for the counts such as:
 - I breathe in calm and relaxing energy.
 - I pause to let the quiet energy relax my body.
 - I breathe out and release any anxious or tense energy.
- For deeper relaxation, gradually extend your exhalation, until you reach an exhalation twice the length of the inhalation (10 counts).

Breathing exercises should not be painful or uncomfortable; if holding your breath is uncomfortable, just eliminate the pause between the inhalation and exhalation.

Try a Mindbody Practice

Mind-body practices not only build physical health, but also deepen the awareness and connection between the mind and body. Yoga has been shown to reduce stress in caregiving groups, like the families of those with Alzheimer's disease and cancer.

- Yoga breathing, poses, and meditation techniques in [The Harvard Medical School Guide to Yoga](#).
- Mindfulness meditation and deep relaxation techniques can reduce stress. Guided audio meditations are available online:
 - [UCLA Mindfulness Awareness Research Center](#)
- Smartphone apps like Headspace, Meditation Oasis, or Insight Timer.



Make eating well and getting quality sleep priorities.

We recognize that not all communities are able to access food easily. If you can, search for community groups, churches, neighbors, and others in your area that offer free meals or reduced meals. When out in public, wash your hands frequently for 20 seconds and avoid touching your face.

Maintaining adequate sleep and nutrition are key to preventing caregiver burnout. Build a daily 10-minute nighttime routine to achieve more restful sleep. Your nighttime routine can include your breathing exercises, meditation, or yoga poses. Missing meals can lead to irritability and fatigue, so it is important to eat regularly scheduled meals throughout the day.

Nutrition can also be an important factor to prevent burnout. Chronic stress has been linked to increased inflammation in the body, so it is helpful to avoid foods that are processed or high in refined sugars, which increase inflammation in the body. Avoid or reduce alcohol, since alcohol both increases inflammation in the body and disrupts quality of sleep.

Remain socially connected. Find support through local caregiver support groups or community groups that meet online.

While it can be difficult to keep social appointments with friends and family in the face of medical caretaking, it is important to maintain social connections to feel less isolated and prevent burnout.

Realizing that you're not alone and that others are going through similar experiences nurtures your ability to be self-compassionate. Hospitals and local organizations often offer caregiver support groups for family and caregivers.

Use community resources. The more you work with your community members, demand the services that you deserve, and work to create options that help you, the less you have to do. There are places to get help:

- Your local Area Agency on Aging
- Paratransit
- Meals on Wheels
- Day care programs
- Support groups

Take a break from caregiving. Make a date to go to the movies, take a walk, meet a friend for lunch. Everyone needs to get out of the house once in awhile. Do something not related to caregiving.



Get support. Attend a support group online, have a buddy you can call just to let off steam and complain. Watch for changes in your own mood or behaviors, and be honest about symptoms of depression. Talk to your doctor, counselor, community, or ministry about it, bring someone to help you advocate if you need to.

Practice communication and behavior management skills. This will make your job easier. Learn how to do this by taking a class or researching online. The best communication strategies are often not intuitive and need extra care to cultivate.

Relax (if you can)

- Read a book, meditate, pray, garden, knit, massage yourself, take a long bath. Take care of your health. Go to the doctor or call over the phone if you are able, get routine exams and flu shots, get enough sleep, and eat your fruits and vegetables.
- Exercise, take a long walk. Consider social distancing suggests 6 feet distance between other people at this time.
- Ask for and accept help when offered. No one can do this alone.
- Forgive yourself—often. You cannot be a perfect caregiver, all day, every day.
- Laugh. Find ways to keep your sense of humor on a daily basis. Watch comedies, practice laughter yoga, share jokes with friends.



In Consideration of a Dying Person's Pain

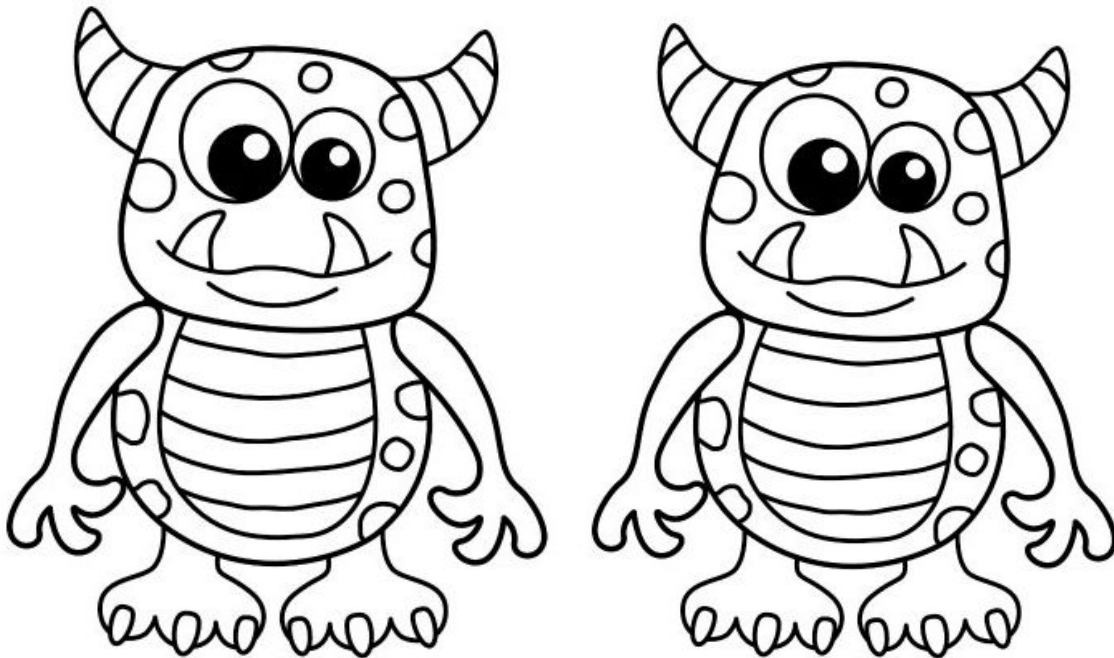
No one at any stage of life should live in pain that they do not wish to experience. Almost all pain can be alleviated with a combination of environmental changes, mind-body practices, and/or medications. With pain reduced to a tolerable level, a person may feel more comfortable with eating and sleeping, be mentally alert, and maintain a level of independence.

Mindbody Techniques

- First, find a comfortable place to sit or lie down.
Place one hand on your stomach right above your belly button.
Breathe deeply.
Hold each breath briefly, then slowly breathe out.
Notice the air entering your nose and mouth.
Try to make your breaths longer and slower.
- There are a large and diverse group of techniques that are administered or taught to others by a trained practitioner or teacher, you can find many of these practices available online.
- Examples include acupuncture, massage therapy, meditation, relaxation techniques, spinal manipulation, and yoga.
- <https://www.ncbi.nlm.nih.gov/pubmed/23529519>

There are a variety of medications used to support or aid a person's pain.

- If you or someone you love has a condition that causes acute or chronic pain and over-the-counter drugs like acetaminophen or ibuprofen are not effective, talk to your doctor if possible, there may be other options for pain medications.
- Medication is *their* choice, it is important not to encourage people into something they didn't want in the first place.
- Cannabis and psilocybin are two natural plants that can help to reduce pain and can typically be easy to acquire. Please be aware that these are not considered legal in all states.
 - Psilocybin Related research
<https://www.painnewsnetwork.org/stories/2019/5/16/magic-mushrooms-psychedelics-and-chronic-pain>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6364961/>
- Opiates, which can be taken by mouth or intravenously, include morphine, codeine, hydrocodone, oxycodone, hydromorphone, etc. Opiates are derived in nature from opium poppies. Opioids are manufactured drugs that have the same effect as the natural opiates. Both kinds of medications are strong, safe and effective painkillers when prescribed and used appropriately.







Journal Prompts for Caregiving

1. How do you want to feel when you wake up in the morning?
2. List five good things about today.
3. What are some of your values in life?
4. Did you feel stressed or anxious today? If so, what triggered that feeling, and what did you do to overcome it?
5. What is one thing you can improve on (time management, communication, etc.), and how can you do this?
6. What is one adjustment you would like to make to your morning routine?
7. What is one adjustment you would like to make to your nighttime routine?
8. What is one thing you need to let go of?
9. Make a list of twenty things that make you happy.
10. Write down the lyrics to a song that makes you happy. What is it about this song that makes you feel this way?
11. What is one place you would love to travel to and why?
12. Have you been exercising patience with others? If not, how can you?
13. What is a new skill that you would like to earn and how can you learn it?
14. Are there any areas of your life that can be more organized? How can you accomplish this? What can you do to prevent disorganization in the future?
15. What is one long-term goal you wish to work towards?
16. Draw a picture of something that makes you happy. Write about the picture.
17. What steps have you taken towards a goal of yours (short or long-term)? If you haven't taken any, what steps could you be taking to work towards it?
18. What is one thing you are scared to do, and how can you overcome it?
19. How can you be more mindful of others?
20. Was today a difficult day? If so, what made it difficult and what can you do to prevent from having days like this in the future?
21. What is one problem you had today, and what was your solution to this problem? Was this the best way you could have handled it?
22. Are you taking time to care for yourself? Do you allow yourself time to relax and breathe? If the answer is no, what can you do to give yourself this time?
23. Think about a past mistake you made. What did you learn from the experience and how can it be applied to your future?
24. Write about something that you are scared of.
25. Write a letter to your future self.



Additional Resources

Coronavirus CDC

<https://www.cdc.gov/coronavirus/2019>

The Order of the Good Death

<http://www.orderofthegooddeath.com/burials-funerals-under-covid-19>

Body Care 101

<https://www.homefuneralalliance.org/body-care.html>

Home Funerals State by State

<https://www.homefuneralalliance.org/state-requirements.html>

A Sacred Passing - K- 12 Children's Resources

<https://asacredpassing.org/resources>

Irresistible (previously healing justice podcast) has a podcast and resource list here: <https://irresistible.org/podcast/corona> and a resource list on that page.

Covid Mutual Aid regularly updates this [solidarity/collective aid document](#).

Contacts

Folx who are willing to be phoned, texted or emailed if you need moral support caring for your dying or your dead at home. Sometimes it can help to have a buddy. The people listed below are NOT funeral directors, they are Doulas, helpers, folx who are willing and able to sit and support you.

- Lashanna she/her 206-715-5265 info@antareswellness.com
- Asha she/her 425-260-0306 asha@asacredpassing.org
- Oceana she/her 415-336-4479 oceana@oceacnendoflifedoula.com
- Summer they/them summergdiegel@gmail.com
- Carrie she/her carrie@asacredpassing.org
- Paige she/her 914-772-8524 paigeloren@outlook.com
- Naomi 718-290-4095 artbynaomi@gmail.com
- Danna she/her danna@waypointceremonies.com
- Kalisto He/Ze/They (206) 920-0753

Thank you to the humans who have helped us put this together, who added, edited, cut, and grew this document with love and community care. Summer D., Lashanna W., Asha N., Sarah C., Alua A., Alice T., Paige D., Bonnie B.

Please continue to let us know how we can make it better.

MAD LOVE