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# Supplemental Instructions for End of Life Care with Amyotrophic Lateral Sclerosis

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This document can be used to help you think about what you do or do not want at end of life. You can fill it out and attach it to your Advanced Directive or just use it as a tool to help you have end of life discussions with your health care representative, family, friends and loved ones.

There are a number of factors to consider when discussing end of life care with your family, friends and loved ones. Such as:

- **Quality of Life:** What will be most important to you at end of life?
- **Legacies and Bucket List:** Are there particular things you want to do or pass along to family or friends before you die and how can you accomplish these items?
- **Family Caregiver Burnout:** What are your expectations of your family providing caregiving and what are their expectations of the situation? How will you and your family address the needs of everyone involved?
- **Cost of Care:** Providing caregiving for a person living with ALS can be financially expensive, especially if hiring caregivers or moving into a facility where care is provided. What sort of expenses are possible for you and your family? What are the costs around some of the following decisions?
- **Cognitive Ability:** Would your decisions change or be different if your behavior or thinking abilities were diminished?

**Death with Dignity:** This is an option for people that are terminally ill to end their lives through voluntary self-administration of lethal medications, prescribed by physicians for that purpose, as outlined in the Death with Dignity law. Is using Death with Dignity at end of life something you want to consider and be prepared for or is it of no interest to you?

**Remember that this is a tool** to help you have hard conversations with your family, friends, and healthcare representatives. **You may also want to reach out to healthcare professionals** such as your neurologist, social worker, nurse practitioner, palliative care team, or hospice team to help answer questions and/or fill out the following pages.



## Quality of Life:

This concept differs for each person. It is important to spend some time thinking about what means the most to you in life and what areas you want to focus your time and energy, (i.e. spending time with family and friends, pets, hobbies, working/volunteering, independence, not burdening family/friends, religion/spirituality, etc.)

**What things are you looking forward to in life?** (Use this space below to share what things you are looking forward to accomplishing or experiencing)

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**What matters most in medical care decisions?** Some people choose time over comfort and others comfort over time. There is no wrong or right answer, it is deciding what is most important to you.

(Use this space below to share your answer, feel free to be as general or specific as you want in this section)

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# Making Medical Decisions with ALS at End of Life

Making end of life medical decision is hard. Although end of life decisions are not easy to make, they are important ones. As long as you are able to make your own decisions and communicate them, you will always be in charge of your care. If the time comes when you cannot communicate or make your own decision, it is most helpful for your family/loved ones/healthcare representative to know how you feel about end of life matters. This section will ask you to consider whether your focus will lean more towards time or comfort. There is also a section to share any experiences you may have had with end of life and other people.

Put a mark on the line where your focus is today.

**I want to stay alive as long as possible no matter what.**

**Somewhere in the middle.**

**I want to put my energy into being comfortable.**

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Put a mark on the line where your focus would be if you were close to death

**I want to stay alive as long as possible no matter what.**

**Somewhere in the middle.**

**I want to put my energy into being comfortable.**

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Use this space to write about any experiences you have had with others at end of life and how you felt during those times. Consider what you wish may have gone differently with the person or people you are thinking of, the things you think went well and things you would like to discuss further. Please include things you would want your family to know about how you want to experience end of life and what you would want them to know or do during that time.

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## End of Life Choices and Medical Care Decisions

While looking at the following areas it is important to consider where you would like to be during later stages and end of life. Mark which locations would be ok with you.

\_\_\_\_\_ At home

\_\_\_\_\_ In a facility, such as an adult care home or nursing home.

## Nutrition and Hydration:

ALS will eventually impact the muscles involved in safe swallowing, which will limit the amount of nutrition and hydrations you can safely take in by mouth. There are 2 options when it comes to nutrition and hydration choices. Below you will find the options available and the information around end of life and each of those decisions.

**No Feeding Tube** — Making the decision to not get a feeding tube at any point is your decision to make. For some the surgery or invasiveness they feel around a feeding tube does not fall in line with their ideas of quality of life. In making this decision it is important to know the risks. Not having a safe swallow and continuing to eat by mouth can create a very high risk for choking and aspiration (inhaling food or liquid into your lungs), both which can lead to illness or death. If you are considering using the Death with Dignity medications, it is important to note that state laws say they must be self administered by swallowing or through a feeding tube.

\_\_\_\_\_ I do not want a feeding tube and understand the risk associated with this decision.

\_\_\_\_\_ I want to pursue a feeding tube option.

*Please add any notes, concerns, or added instructions:*

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**Feeding Tube** — The decision to get a feeding tube is yours to make at any point. Most people with ALS will decide to get and use a feeding tube prior to end of life. During the end of life transition, you have a few options to think about around your feeding tube and end of life care. Some people will want to continue tube feeds and water until the end of their life. If unable to swallow, others may want to stop getting nutrition and/or water through their feeding tube to bring end of life sooner, depending on how they are feeling around their quality of life. Others may choose to access medications for ending their life or for comfort through a feeding tube, if unable to safely swallow.

\_\_\_\_\_ I want to use my feeding tube for nutrition, hydration, and medications until my life ends.

\_\_\_\_\_ I want to stop using my feeding tube for nutrition/hydration when I feel my quality of life is poor.

\_\_\_\_\_ I want to stop using my feeding tube for nutrition and hydration if I become unconscious at end of life.

\_\_\_\_\_ When I have decided to stop using my feeding tube for nutrition and hydration, I still want to access it for comfort medications or Death with Dignity medications.

*Please add any notes, concerns, or added instructions:*

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# Breathing:

ALS impacts the breathing muscles which makes breathing more difficult. There are 3 major options when it comes to breathing. Below you will find the options available and the information around end of life and each of those decisions.

**No Respiratory Support** — This option would mean not using any sort of breathing equipment at all and to let the disease progression occur naturally. The reality of this decision is likely a shorter life expectancy. Once breathing muscles weaken and respiratory testing numbers drop to a particular level, individuals will likely be eligible for hospice, which is a medical program that can support end of life transitions with comfort medications to ease passing away.

\_\_\_\_\_ I do not want any respiratory support.

\_\_\_\_\_ I want to pursue other options around respiratory support.

*Please add any notes, concerns, or added instructions:*

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**Non-Invasive Ventilation** — This option is to use non-invasive ventilation, also known as an AVAPS or BiPAP machine. These devices are used with face masks, which come in a variety of options. Respiratory equipment works to support the diaphragm muscles by helping maintain natural breathing with pressurized room air to give breathing muscles a break. These devices are often used early on in ALS when breathing muscles weaken and respiratory testing numbers begin to decline. Respiratory devices are initially worn/used at night and as breathing muscles continue to weaken and breathing becomes more difficult they can be used more often, even up to 24 hours a day. Again, when respiratory reserve drops significantly and you are not opting for a tracheostomy and ventilation, hospice will become an option. At that time hospice can support you in using your device comfortably and can support in stopping the use of devices when ready.

Hospice can support by offering comfort measures to make the transition off of breathing devices to death more peaceful. You will likely want to have conversations with your family, healthcare representatives and medical team on when you would prefer to stop using your non-invasive ventilation.

I want to use noninvasive ventilation and at end of life would prefer...

\_\_\_\_\_ To decide about removing noninvasive ventilation when I am still conscious.

\_\_\_\_\_ When I am unconscious, I want my healthcare representative to ask for my mask to be removed.

\_\_\_\_\_ Other: \_\_\_\_\_

\_\_\_\_\_ I would want to move from non-invasive ventilation to getting a tracheostomy and being on a ventilator.

*Please add any notes, concerns, or added instructions:*

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**Invasive Ventilation** — This option involves having a procedure to have a tracheostomy (tube in throat) and having that tube connected to a ventilator. A ventilator is a breathing machine that breaths for you. Tracheostomies and ventilators do not necessarily increase quality of life but typically extend quantity of life. This option comes with a need for 24/7 care due to the seriousness of having a machine breath for you and the skilled care needs that are required. The amount of caregiving required may be more care than just family and friends can provide due to the skilled nature of the care and high likelihood of caregiver fatigue. Hired caregiving is almost always needed and can also become very expensive, which is important to consider. Many people that choose invasive ventilation may have to move to a facility that can properly care for and manage a ventilator, which can also be costly.

Invasive ventilation can allow for more time with friends and family.

Ventilators can run off batteries for a few hours and are portable.

A ventilator used with a tracheostomy will continue to keep an individual breathing and alive even after the loss of physical mobility. There may come a time that you are “locked in” meaning the outside world may not be able to discern any reliable movement from you, including eye movement, to communicate effectively.

If you decide to get a tracheostomy and be connected to a ventilator for breathing, that is normally not something that can be reversed.

This is an important discussion to have with family, loved ones and your health care representative so they will know what you would prefer in regard to your respiratory status and in an emergency if you were not able to communicate or make decisions for yourself.

\_\_\_\_\_ I want to get a tracheostomy and ventilator; I want to live in all situations.

\_\_\_\_\_ I want to trial a tracheostomy and ventilator. Knowing it will likely not be able to come off without causing my death.

\_\_\_\_\_ I do not want a tracheostomy and ventilator; I want to focus on being comfortable and dying naturally.

If you have made the decision knowingly or had a tracheostomy and were vented in an emergency, it is important to discuss when you would not want to use it anymore at end of life.

Depending on your situation you may already be accessing hospice services, if not you may call them in when you are ready to turn off your ventilator. They will assist with comfort care to make the transition less stressful.

If you have a tracheostomy and are connected to a ventilator, which of the following would you want at end of life, when deciding to come off the ventilator.

\_\_\_\_\_ I want to decide about discontinuing the ventilator while I am still conscious.

\_\_\_\_\_ I want the ventilator removed when I am unconscious.

\_\_\_\_\_ If I am unable to communicate by any means (locked in), I want removal of my ventilator.

\_\_\_\_\_ None, I want to stay on my ventilator in all situations.

\_\_\_\_\_ Other: \_\_\_\_\_

*Please add any notes, concerns, or added instructions:*

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Please sign and date this document. You may want to review this document often to make sure it reflects your current thoughts and feelings. Feel free to request a blank form from the ALS Association or your medical team any time you want to make changes. Please make copies to keep with you and to share with your medical providers.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_