

Define Your Wishes: A Self-Assessment Tool for Healthy Patients

This self-assessment is designed to help you reflect on your values and preferences regarding life-prolonging treatments in the event you develop a serious or terminal illness.

When a person's illness is deemed terminal, the goal of treatment is to prevent or slow further damage caused by the disease, which hopefully prolongs his or her life. There is no treatment to reverse or eliminate terminal diseases (e.g., dementia, lung cancer, heart failure, renal disease).

The goal of this tool is to help you clarify your "lines in the sand" for when you would prefer to stop life-prolonging treatments and instead focus on treatments that manage your symptoms, allowing the disease to progress at its natural pace.

When you finish this questionnaire, save it where you keep your other end-of-life documents, and share it with your physician and loved ones, especially your Power of Attorney. Too often, loved ones are faced with making major healthcare decisions for a family member without knowing his or her wishes.

Please take your time to consider the following 6 factors and how they would impact your future decisions about treatment. You may print the blank version to fill out on paper, or you can fill it out electronically and save/print it after that.

1. Cognitive Clarity

How important is maintaining cognitive clarity to your quality of life?

- Very important: I want to be able to think clearly, recognize loved ones, and make decisions about my care.
- Somewhat important: I can accept some cognitive decline if I can still enjoy certain aspects of life.
- Not important: I would prefer to prolong life even if I experience significant cognitive decline.

Check any symptoms that would cause you to stop life-prolonging treatment. Check all that apply.

- If I experience regular confusion or memory loss.
- If I am unable to make decisions about my care or understand my condition.
- If I am no longer able to recognize family or loved ones.
- I would continue treatment regardless of cognitive decline.
- Not sure.

Notes: (If, for example, you would want to stop treatment if TWO or more of the above symptoms are present, note that here. If there are other symptoms of cognitive decline you'd like to call attention to, note that here too.)

2. Emotional Well-Being

How much does your emotional well-being factor into your decision about continuing life-prolonging treatments?

- A great deal: I value emotional stability and happiness, and emotional suffering would strongly influence my decision to stop treatment.
- Moderately: I can tolerate some emotional distress if other aspects of life are still positive.
- Not much: I would continue treatment even in the face of significant emotional suffering.

At what point would you prefer to stop life-prolonging treatment due to emotional distress? Check all that apply.

- If I experience intermittent bouts of deep depression, intense anxiety, or emotional breakdowns several times per week for a month or more.
- If consistent emotional distress prevents me from enjoying time with family, friends, or meaningful activities nearly all the time.
- If I experience daily or constant emotional suffering without relief.
- I would continue treatment regardless of emotional distress.
- Not sure.

Notes:

3. Quality of Healthcare

How much does the quality of your healthcare affect your willingness to continue life-prolonging treatments?

- A great deal: I only want life-prolonging treatments if they are accompanied by high-quality, compassionate care provided by providers who know me.
- Moderately: I am willing to tolerate some decline in healthcare quality as long as the treatments are effective.
- Not much: I would continue treatment even if the quality of healthcare is suboptimal.

At what point would you prefer to stop life-prolonging treatments based on the quality of healthcare you are receiving? Check all that apply.

- If I feel I am being treated as a burden or with a lack of compassion.
- If my healthcare is more about prolonging life than improving its quality.
- If I no longer have access to the treatments and care that I believe are necessary for a dignified experience.
- I would continue treatment regardless of healthcare quality.
- Not sure.

Notes:

4. Personal Autonomy

How important is it to you to maintain personal autonomy (the ability to make decisions and control aspects of your own life)?

This is related to cognitive clarity in the sense that losing cognitive clarity eventually means you lose control over decision making, but here we are focusing on your ability to make decisions around your care and daily life. For example, people often feel they lose personal autonomy over daily decisions when they move to a nursing home, even if they are still cognitively clear.

- Extremely important: I want to be in control of my life and care decisions for as long as possible.
- Moderately important: I value autonomy but am willing to relinquish some control if necessary.

Not important: I am comfortable with others making decisions on my behalf if needed.

At what point would you prefer to stop life-prolonging treatment if your personal autonomy is compromised? Check all that apply.

If I am no longer able to make my own medical decisions (e.g., able to choose a specific treatment or procedure, choosing hospice).

If I lose the ability to control some important decisions (e.g., if I can drive, where I live, how I spend my time)

If other people decide all of my daily activities (e.g., when I am fed/bathed/medicated/woken up in the morning)

I would continue treatment even if I lose personal autonomy.

Not sure.

Notes:

5. Physical Capabilities

How important are your physical capabilities to your overall quality of life?

Very important: I need to be physically active and capable to enjoy life.

Moderately important: I can accept some physical limitations as long as I maintain other aspects of quality of life.

Not important: I am willing to continue life-prolonging treatments even with significant physical limitations.

At what point would you prefer to stop life-prolonging treatments due to a decline in physical capabilities? Check all that apply.

If I am no longer able to walk or move independently without another person's help.

If I require full-time assistance with basic activities (e.g., feeding, toileting).

If I experience chronic pain or physical discomfort that significantly impacts my daily life.

- I would continue treatment regardless of physical limitations.
- Not sure.

Notes:

6. Preparatory Aspects: Family, Financial, and Personal Considerations

How important is it to you to make practical arrangements for your family and resolve personal issues before stopping life-prolonging treatment?

- Extremely important: I need to have my affairs in order and provide for my family's future before considering end-of-life care.
- Somewhat important: I would prefer to make preparations but can accept the possibility of leaving some things unresolved.
- Not important: I am comfortable stopping treatment even if I haven't completed my preparations.

At what point would you prefer to stop life-prolonging treatment based on your ability to prepare for the end of life?

- Once I have made all necessary arrangements for my family, such as financial planning, estate decisions, and resolving personal relationships.
- I would consider stopping treatment even if some things are left unresolved, provided my emotional and physical suffering is high.
- I would continue treatment until all practical and personal preparations are complete, no matter my health condition.
- Not sure.

Notes:

Reflection and Final Considerations

1. What are the most important factors influencing your decision to stop life-prolonging treatment? Select all that apply.

- Cognitive clarity
- Emotional well-being
- Healthcare quality
- Personal autonomy
- Physical capabilities
- Preparatory aspects (family, finances, etc.)

2. Which factor(s) would most likely lead you to consider stopping life-prolonging treatment? Select all that apply.

- Cognitive decline
- Emotional distress
- Poor healthcare quality
- Loss of personal autonomy
- Significant physical limitations
- Unfinished personal or family arrangements

3. Have you communicated your preferences with your loved ones or healthcare providers?

- Yes
- No, but I plan to.
- No, I am still unsure.

4. Is there anything else that would impact your decision to stop or continue life-prolonging treatments?

Conclusion

By completing this self-assessment, you've taken an important step in clarifying your values and preferences for end-of-life care. Consider discussing your responses with your loved ones and healthcare providers to ensure that your wishes are understood and respected. Keep it where you keep your other end-of-life documents, and come back to it when needed.