Planning for the Future

It can be difficult to plan for the future when you are focusing on living in the present. But giving thought to what lies ahead can help you live your best life now and provide you, and your family members, with peace of mind going forward.

**Care planning**

As your ALS progresses, you will be faced with making many decisions that have a direct bearing on your quality of life. Knowing your options for managing your symptoms in advance and having time to consider the pros and cons of each course of action can help you (or your family members) avoid being put on the spot and forced to make a difficult decision in the midst of a crisis.

Although it can be upsetting to think about declining abilities and the inevitable outcome of the disease, anticipating future challenges paves the way for handling them in a way that reflects what is most important to you. A good way to begin the process of planning your future care is to think about how you define a good quality of life. For example, you may want to consider:

- Which situations scare you.
- Your religious beliefs, and how these beliefs shape your view of your illness.
- The level of independence and free will you wish to have, and how much of this you are willing to give up.

Thinking about the care you want to receive in advance has many benefits for you, and for your family members. Care planning:

- Allows you to make decisions in advance about the care you’d like to receive, and to make the necessary arrangements for that care.
- Lets you gather information on life-sustaining treatments and decide which treatments you would or wouldn’t want.
- Allows you to share your decisions with your loved ones and put your wishes in writing, making it easier for your loved ones to make decisions about your care on your behalf if necessary.
Advance directives are legal documents that convey how you want to be cared for if you’re unable to make medical decisions or express your wishes. There are three important types of advance directives:

- A living will outlines the type of medical care you want to receive. It gives specific instructions about treatment, such as the use of invasive ventilation and tube feedings.
- A durable power of attorney for health care lets you appoint someone you trust (such as a family member or friend) to make medical care decisions for you in case you are unable to.
- A do not resuscitate (DNR) order states that you do not want to be resuscitated if your breathing stops or you go into cardiac arrest. The DNR order must be signed by a doctor.

You can write your own advance directives or get help from an attorney. Experts recommend discussing your advance directives with your doctor, who can fully explain the implications of accepting or rejecting various forms of medical care. Advance directives are legally binding once they’ve been signed and witnessed. They remain in effect unless you prepare new ones. A directive prepared in one state may not be valid in another state, so consider preparing one for each state where you spend a lot of time.

It can be difficult to think about the care you want to receive in the future and at the end of your life. But making no decision with regard to the future is, in fact, making a decision—the decision to put your family members in the difficult position of guessing what you would want. Careful consideration can help you, and your family members, be at peace with the decisions that are made, now and in the future.

**Financial planning**

Financial planning soon after diagnosis can help you afford your expenses now, as well as help to ensure your family’s future financial security. Here are some financial planning steps you should take right away:

- Consult with a financial planner who has experience helping people with terminal illnesses. You can find a financial planner by asking friends and family for recommendations or consulting a professional organization, such as the National Association of Personal Financial Advisors (www.napfa.org) or the Financial Planning Association (www.fpaforfinancialplanning.org).
- Arrange for a durable power of attorney for finances.
- Organize and review relevant financial documents, such as life insurance policies and pension and retirement plan documentation. Check beneficiary designations.
• Review the financial resources available to you to help cover health care costs, including health and life insurance policies, employee and/or retirement plan benefits, government assistance programs, and your personal assets.
• Consult with a tax advisor or accountant before filing tax returns. You may qualify for income tax breaks.

**Estate planning**

Regardless of your money situation, you and your family should know about a process called estate planning. Estate planning helps ensure that upon your death, your assets go to the people and places you choose. Your assets may include checking and savings accounts, stocks, bonds, your home, and other possessions. As part of the estate planning process, you should:

• Meet with an attorney who specializes in estate planning. You must have a comprehensive, well-crafted will. An attorney who specializes in estate planning can help you to write a will if you do not already have one, or review and update an existing will to ensure that it conveys your intentions accurately. He or she can also advise you about other estate planning documents that may be applicable to your situation, such as a trust.
• Organize documents and information that will help your loved ones to handle your affairs after your death, such as:
  ▪ Bank account and safety deposit box information.
  ▪ Information about your investments.
  ▪ Pension and retirement account information.
  ▪ Life insurance policies.
  ▪ Deeds.
  ▪ Passwords.
  ▪ The contact information for your attorney, tax professional and financial advisor.
• Leave instructions regarding your funeral and burial plans.

Planning for the future can be difficult, even under the best of circumstances. But by thinking and talking about the future now, you can make the tough journey that lies ahead a little bit easier for both yourself and your loved ones.

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**Bibliography**


