



The Sojourner Project

...help for the journey

What to do when you receive a devastating diagnosis?

Receiving a devastating diagnosis is a frightening and overwhelming experience, one I wish we could all avoid. But it is important to face your fears and take proactive steps to prepare for the journey ahead. Hopefully by taking some important steps today you and your loved one can avoid the stress of having to make some difficult decisions in the midst of a crisis. Decide to be proactive, put a plan in place then get busy living your life to the fullest today and every day.

Important First Steps

Get an accurate diagnosis and an education.

- Once you have an accurate diagnosis it is important to really know and understand the disease process and progression. Not everyone with the same diagnosis will experience the same symptoms in the same way or on the same timeline. But it is important to know the potential path that lies ahead. As difficult as it is to think about it is important to know and understand how the disease may progress so you can plan for any disability and its' impact on your ability to function. With this knowledge, you can begin to take the needed steps to prepare for these potential changes.

Get the paperwork in order

- Medical and disability insurance coverage
 - Review your coverage to know what costs you might incur and what income or benefits you might be entitled to receive. Be sure to research your prescription drug benefit as these costs can vary widely. For those covered under Medicare or the Affordable Care Act you can make changes to your medical and prescription drug coverage during annual open enrollment in December.
- Advanced Directives and other legal and financial matters:
 - Print out my free Caregiver's Guide to Advanced Directives worksheet and prepare or review these essential documents. Make sure they reflect your current wishes and circumstances. These must be prepared before your reasoning or judgment becomes compromised. They can be legally challenged if it is believed they were prepared under duress or when you were considered "incompetent". Have an attorney prepare or review them if this is a concern.
- Review Life Insurance and Long Term Care policies.
 - Pull out these policy documents for a thorough review. Be sure you understand the benefits available and the named beneficiary is correct. While it might be too late to put new policies in place don't let that stop you from speaking to an insurance agent about the options available.

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The goal is to provide general information so that you can seek out professional assistance from the appropriate subject matter expert
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- Financial Planning
 - Begin to document all of your financial holdings, bank accounts, investment accounts etc. Make sure you have a viable plan in place for how and who will take care of your financial affairs when you are no longer able to do this yourself. Be sure your caregiver can pay for the care you will need and that your executor has access to the funds to pay your funeral expenses. Now is the time to work with a financial advisor or accountant to be sure you have a well thought out plan in place.
- End of Life Planning
 - Thinking or talking about this topic always scares people and keeps them from making some important decisions. Discussing with your family your wishes for your final days will save them the agony of making these difficult and expensive decisions in the midst of their grief. Simply put in writing any specific wishes you have including pre-payment of or preferences for funeral home, cremation, burial, cemetery, memorial service. This scary step for you today will make that very difficult time so much easier on your loved ones.

Have a Plan B

Plan A is what is working now. Plan B is for when things change. If you understand your disease process you can probably anticipate how your daily life might change. It is important that you and your caregiver discuss how you will manage these changes and what to do next. Having a Plan B in place will avoid the stress of making difficult choices in a crisis. Plan B is being proactive and not reactive. Here are some key questions to answer to help you create a viable plan

- Who will take care of you?
 - What will they have to give up to care for you - their time? job? home? school?
 - Are you asking too much?
 - What is the alternative if that person cannot care for you anymore or at all?
- Where will you live?
 - What help will you need?
 - How will you maintain your home? Prepare your meals? Get to appointments?
 - If you can no longer live where you are (because of finances, physical or mental disability) then what are the options available?
 - Which assisted living or skilled nursing facility (nursing home) would you want to go to should this become necessary.
- How and who will pay for your care? Is that paperwork correctly prepared?
- Who or what haven't you thought about? (business ownership, pets, other property etc.)

Think about Plan C

This is the crisis plan. This is what you will do when Plan B doesn't work anymore. When there is a dramatic change in your circumstances. Use the same questions above to decide what you would want to do next.

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Give your caregiver permission

- Write a letter to your caregiver giving them permission to make those difficult decisions they will have to make in order to provide the best care to meet your needs.
- Release them from any promises they may have made before they knew the consequences of those promises. "I'll never let you go to a nursing home" when told to an Alzheimer's patient is one that severely limits some of the most helpful options available to family caregivers.
- Thank them for taking care of you. For those diagnosed with Alzheimer's or other serious dementia diseases this letter will remind them of how much you love and appreciate them and all that they are doing for you. This will be a gift they will cherish on those very difficult days when you are no longer able to tell them yourself.

And finally, but most importantly...

Don't waste a day

You are not your diagnosis - this is just something you are struggling with. Do what you need to do to care for yourself and then get busy living. Remember to live today and every day.

I hope you found this guide helpful. Until next time take care of yourself and know that there is

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