

When you're better prepared for the predictable, the surprises can be less overwhelming.

A helpful 10-point checklist for caregivers

Generally speaking, parents everywhere want the best for their children – from infancy through old age. They want them to be as happy as they can be, as healthy as they can be, as successful as they can be. And for children with disabilities or special needs? The wishes are the same, of course! It just may take more time and effort to try to turn those wishes into reality.

If you're new to the world of caring for a person with a disability or if you're worried that you may not be doing all you should be doing, this checklist could help. It touches upon some important factors related to caring for a person with special needs.

1. Getting the right guidance

Each of us has our own personal support group – those we know we can lean on and learn from. But when it comes to making the big decisions and long-term plans regarding a person with a disability, it's best to seek out the experts. Just as you choose medical professionals who specialize in the particular disability or condition your child has, so too should you choose financial services professionals and attorneys who have the knowledge and experience to serve the special-needs community. They are most

aware of ever-changing laws, regulations, benefits, and programs that can affect you.

A Massachusetts Mutual Life Insurance Company (MassMutual®) Special Care Planner¹, or a financial services professional who has a focus on special needs will work with you and your advisors – your banker, accountant, or financial services professional, your special needs attorney, social workers, and health care providers – to help you develop your life care plan that best suits your loved one's needs – now and far into the future.

2. Creating a life care plan

What exactly is a life care plan? It's a comprehensive, all-encompassing plan that incorporates basic needs, goals and strategies for achieving the best quality of life in every area of life – food, clothing, shelter, health, finances, family life, entertainment, employment, retirement, and so forth – now and for the long-term. Taking time now to consider your loved one's current and future needs will help you to realize what aspects need attention. A Special Care Planner can help you design the right life care plan for your family.

¹ The Special Care Planner is a title used by MassMutual financial professionals who have received advanced training and information in estate and tax planning concepts, special needs trusts, government programs, and the emotional dynamics of working with people with special needs and their families.

3. Include yourself in your plan

It's just as important to take care of yourself and other family members' needs. For example, you'll want to ensure that siblings get a fair share of your attention and that you include them in your financial protection strategy — saving for college, for instance. Make time for yourself, as well. Getting out to participate in an activity you love to do will help prevent burn out that can take a toll on relationships, careers, and family life. In the long run, it will help you be a better caregiver. And a careful financial protection strategy that incorporates the entire family could mean having money for your own retirement and your loved one's future financial needs, instead of one using up funds meant for the other.

4. Estate planning

Estate planning is part of the life care plan, and the complexity depends on your financial situation. Some families may be interested in tax-saving advantages, establishing a third-party trust for the person with special needs, providing inheritances for their other children in carefully-drafted wills, and more. Others may realize they simply need to purchase life insurance policies or change beneficiaries of policies already in place, and ensure that eligibility requirements for public benefits their loved one currently receives (or may receive in the future) continue to be met. Many parents want to name guardians to care for the person with special needs after their death, or find that assigning durable powers of attorney and health care proxies are smart measures to take. Estate plans vary, and they're not only for the most affluent. Your attorney can help you with your estate planning process.

5. Guardians

A great deal could be said about naming a guardian for your child. First, you must determine whether or not your child will need one. A Special Care Planner can explain the role of a guardian and walk you through “what-if” scenarios to give you a better idea of whether or not this is something you should include in your life care plan. If so, your next step will be to consider exactly what responsibilities that person would have and the financial support a guardian would need to fulfill those responsibilities. For example, if you died and your child moved into the guardian's home, would the home need to be renovated to accommodate your child's needs? Would child care services be needed if the guardian worked full-time? What additional income might the guardian need to continue to provide care at the level you currently provide?

6. Government benefits

To learn about state and federal benefits your loved one may be eligible to receive, begin with a visit to the Social Security Administration (SSA) web site www.ssa.gov. You'll find information about Medicare², Medicaid², Social Security Disability Insurance (SSDI), and more, including how to qualify and how to apply. You may also want to check the web sites for the State Children's Health Insurance Program (SCHIP) (www.cms.hhs.gov/home/schip.asp) and the Children with Special Health Care Needs (CSHCN) provision of the Social Security Act (www.amchp.org/policy/specialneeds.htm). Receiving these benefits can help enhance your family's and your loved one's quality of life.

² For more information regarding benefits provided by Medicare or Medicaid, visit www.cms.hhs.gov. Medicaid guidelines vary by state. Contact your local Medicaid office for details.

7. Open Communication and letters of intent

Once you've completed your life care plan (actually, it's continually a work-in-progress because it should be reviewed periodically), it's valuable to let close friends and relatives know that you have a life care plan in place. Their love for the person with special needs may compel them to name your loved one in their will or as beneficiary to a life insurance policy they acquire, or they might wish to give them a monetary gift. However, this generous act could cause your loved one to become ineligible for public benefits being received. There are ways to accept these types of gifts without such consequence, though, and a Special Care Planner and an attorney skilled in serving the special needs community can show you how.

Another wise step is to develop a Letter of Intent. This is a document you keep in a safe place that records everything you'd want someone to know about your loved one if you should suddenly become unable to provide care (a serious accident or illness that incapacitates you, or death). It includes the obvious information – names and contact information for everyone involved in your loved one's medical, educational, and financial well-being, family and hereditary information, medical history, medications and dosage amounts, educational plans, work arrangements, religion and practices, and so forth. But a letter of intent goes further. It provides your loved one's caregiver with an immediate insight into who that person is and what a typical day might be like. You'll include such things as lists of favorite games, foods, people, music, and movies; sleeping and grooming habits; dreams and goals; special talents; and even dislikes. You'll work on this document over time because each day's events

will remind you of something you'd want to add, and you'll want to keep it up-to-date. To make this easier for you, the SpecialCare Program includes a Letter of Intent document for you to complete.

8. Health Plans

Because medical care costs can be high, be sure you have the best health care plan available to you. If you and your spouse both work, annually review the health plans your employers offer and choose the one that provides the benefits your family needs at the most affordable price. Understand which services and procedures are covered, and appeal if claims are denied. And don't forget to check the eligibility requirements for government benefits, such as Medicaid or Medicare.

9. The age of majority

When your child reaches the age of majority (18, 19, or 21; it varies by state), he or she is legally considered an adult (for most purposes) and will be expected to make decisions on his or her own behalf. If your child will continue to need you to be the decision-maker, you must file for legal guardianship and be appointed by the court as guardian. Keep in mind, too, that becoming an "adult" may make your child newly-eligible for some government benefits, or require your child to reapply as an adult for benefits now being received.

10. Moving out, moving on

Becoming an adult may affect your child's housing situation. If he or she is living outside the home, does the facility have an age requirement? If your child is able to live independently, will he or she want a place of his or her own, or to move into an assisted-living residence? Begin looking for alternate accommodations well in advance. Some facilities have long waiting lists. If your child will be college-bound, begin researching schools that accommodate special needs during the first year of high school. When your child decides what to study, this pre-work will make the task of visiting and choosing a college easier.

Need to fill in the gaps?

If this sounds overwhelming it certainly can be. But a Special Care Planner can help you take it one step at a time, working with you and others you rely on to provide the best care for your loved one and your entire family. Talk with a Special Care Planner today to get started on your life care plan or address specific issues you may have overlooked.

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