

Tips on Staying Organized when Managing the Affairs of a Loved One with Disabilities

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Becoming and staying organized has taken off in popularity, generating millions of social media posts, magazine articles, reality TV series, certificate programs and seminars. Managing the affairs of a dependent can be challenging but managing them for a loved one with a disability can be stressful, overwhelming, and exhausting.

One of the most important things family members can do is to recruit help wherever you can find it. Often people offer help in the passing comments of 'let me know what I can do to help', but just as often it can feel too cumbersome to identify what needs to be done and also reach out for help.

From the time a special needs diagnosis is shared, the initial reaction can be one of shock and disbelief, yet for millions of Americans the reality is that there is more support than ever before, and resources to ease the stress of managing a loved one with special needs.

A first step should be identifying health and medical needs, and then reviewing your estate plan with a qualified attorney to ensure benefits and coverage. Primary caregivers might need to be made aware of state-assisted resources, and a case manager or specialized individual can assist in making sure the special needs dependent has the supports and services they need.

It can be paralyzing for a caregiver to know what to do to support their child, from scheduling the plethora of medical appointments to notifying teachers, friends, and other family members. Recruiting help where parents can find it is crucial to help offset the stress and anxiety a new diagnosis can bring and being willing to let people help can ease the burden, while allowing others to feel useful.

Simple tasks like back-to-school shopping, driving to and from appointments, and having a synced schedule with other household members can provide comfort during this time. Avoiding burnout by keeping track of medical files, making electronic copies of important documents, and noting future appointments and meetings can help the primary caregiver retain a sense of control and organization.

We often find the primary caregiver has fatigue in general and decision fatigue. We can paralyze ourselves with so many options and so much to do that we can't move forward so we don't stay as organized as we want to be, so we must get help in a way that means we can move on to other tasks and also communicate so that our helpers know exactly what their tasks are so that we can be successful.

It can sometimes take years for the primary family caregiver to understand and deal with the complexities of dealing with a special needs diagnosis. A worst scenario is when the primary caregiver burns out and the entire family suffers, so it's important to help support them by asking questions, checking in frequently and providing clear definitions of what is needed.

For families with the financial ability to hire someone, a care manager, personal shopper, or house manager can be beneficial in dealing with the daily routines. This can also provide some stability to the special needs child, and take the burden off the primary caregiver, who is often also a working parent.

Other situations require extended family support, by means of grandparents, aunts, uncles, neighbors, community, and church members who are all eager to help in some way. The trick is knowing how to be proactive in asking for support, and then allowing loved ones to take responsibility for their designated task.

Most people have a support system around them, but the supporters don't know how to volunteer, and the primary caregiver doesn't know how to ask. It's about connecting those two things, so the task is aligned with what the caregiver needs most at the time.

For documents and files, it can be helpful to have a shared document system and utilize different email addresses for various needs. Having separate email addresses for school requests (such as brynlearns@gmail.com) and one for shopping (brynsmedical@yahoo.com) can create some needed structure. This system can prevent overwhelming inboxes and even be shared with grandparents who might need access to a google spreadsheet for back-to-school shopping needs or a reoccurring grocery list. Sharing calendars and reminders for tasks can also keep helpers organized, and changes can be made in real-time with updates provided directly via email or text messages.

While every person will have their own organizational system that works for them, it's important to remember to manage your expectations and let people help in the way that works best for both of you. If loved ones are willing to share some of the workload it can be one of the greatest gifts when a family receives a special needs diagnosis and

understanding the new reality while accepting that help can make a lasting difference for everyone involved.

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