

The Passing of Parents for a Person Who Uses AAC:  
Preparing For A New Life  
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This is a topic that is in the back of everyone's mind. How do you adjust to life without your parents by your side. How can I adjust to the inevitable fact of facing life without those that gave it to you. Ask anyone. The question is difficult to answer. The hand that held you at birth, the primary influence in your early life, the roots to the tree that has become you. How do you adjust to this? Take a moment and ask yourself this question. Now, place yourself in the confines of a severe physical disability and you have a whole new set of questions to be answered.

I have been asked to discuss the adjustment process from the perspective of my disabilities and the loss of both of my parents. How do you adjust? How do you cope? Many people have asked me this question. I don't know what to tell them other than to get their act together and move on with their life. But, most want more from the answer than the obvious cliché.

When looking at my adjustment to the passing of both my parents, I realize that they took the time to prepare me throughout my whole life. They protected me through my early years and ingrained in me the independent thought that has served me my whole life. As I progressed to adulthood, I acted on the independence by taking time to myself. I took frequent trips to the movies, away trips to the mall by myself, trips around the neighborhood in my chair. All of this helped to foster in me the independence and desire to expand my mind and spirit contained in my disabled body and chair.

With this in mind, the preparation for separation begins early. As difficult a thought as this may be, you need to consider life in the role of decision maker, case manager, social secretary, planner, communicator - without a parent there as a helper or facilitator. Preparation and planning before you are thrust out on your own is an important component. I was in a situation where I knew who I was and where I wanted to be before the passing of my parents. Many people with disabilities cannot make the same statement. They are dependent on their parents to provide all of their needs. This security is wonderful, but the individual becomes vulnerable when this security is removed. The time to act is now. You need to begin to develop your independence. These can be small steps such as staying at home when they are out, visits to friends or neighbors, or trips to local events or functions to allow you your own identity.

Another important factor to consider is using the resources in the community to discuss options for independence. Investigate your options. Find ways to meet your needs. My

situation consists of a modified van to provide transportation. With this in mind, I realized that I needed aid with its operation to maintain my independence and mobility. Finding appropriate aids that can be trusted with my safety was a process that can, and should, take time to insure that you can continue to function. You need to investigate what options work for you. They may be public transportation, state funded transports or friends and family.

When the parents are gone, people often feel very vulnerable and helpless and cannot even begin to know where to start to make the adjustments needed. You have to find a way to manage your grief and at least continue with those things that give you security and normalcy. You need to carry on by asking your family, friends, neighbors or service providers. You have to find a way to work out your primary needs. Once these are established, you need to determine what you want to do and what is the best way to achieve these goals. You need to create back-up emergency support for yourself to address your personal health and welfare concerns. This is dictated by your own personal disabilities and health needs. Emergency services, contacts and medical records need to be accessed and located where you and others can assist you with a plan to retrieve and use them when necessary.

If a parent or caregiver passes away to hopefully a better life, your life is now in limbo. You are placed in an extremely difficult situation of finding a new caregiver. The process can be stressful and frightening since you may have to deal with complete strangers. If you are fortunate enough to have family to help you through this tough time, you may have a better transition when finding a caregiver. But, if this task is left up to you alone, it is an uphill battle until you can find a caregiver you can trust. It is essential that you try and take care of as much personal business as you possibly can so that you will not be taken advantage of. Handling your own banking, paying your own bills and other personal matters would be beneficial to your increasing independence. The risk of someone mishandling your money would be diminished if you take on your own financial responsibilities. Consulting with a lawyer would be to your advantage if you are on public assistance. Possibly a trust fund could be set up to protect your assets.

The most significant thing that you can do is to discuss your future with your parents or caregivers. Most likely the parents would die before the person with the disability. With this in mind, discussions must begin to remind the parents that if future plans are not in place, the person with the disability would be put in a very vulnerable position – emotionally, psychologically, physically and financially.

As for the psychological aspect of losing a parent, this event will leave a huge gap in the disabled person's life. Parents are the emotional support and life-line of the disabled person, and losing them will be a tremendous shock. You will need to find inner strength to deal with all of life's trials and find support from other people to fill the void.

Remember, the most important thing you can do for yourself is to move forward in a positive way if you should ever lose your parents, and prepare –prepare – prepare in advance so that the loss does not have devastating consequences to your future wellbeing.