

Guest Post – Top 10 Tips for Adult Siblings of those with Additional Needs



TOPIC:

Top 10 Tips For Special Needs Siblings (from a sibling!)

WHAT:

When we are children, there can be a variety of emotions regarding our siblings. Maybe you were jealous because they got to do all the fun stuff such as horseback riding and playing in a really cool looking gym?

Maybe there were times that the sibling did something embarrassing in front of your friends or peers? Maybe there were just feelings of anxiety or loneliness because you were the only sibling at your school? These are all normal emotions of a child sibling but as we age, there are new roles that emerge when we become adults and those feelings are set aside.



We now become advocates and sometimes guardians over our siblings. Here is a top 10 list of things to help start

conversations with parents and caregivers as the sibling enters adulthood.

Cheryl's TOP 10 TIPS:

1. Learn to communicate:

We have to get our parents to communicate what the wants/needs are for our sibling. There are also professionals in our siblings lives and it's incredibly helpful to know the language of the professional whether it be a psychologist, therapists, day program or job trainers, etc. The needs of the sibling should be clearly listed on an Individualized Service Plan or some other document. If the sibling is staying at home with the aging parent, ask why and what is the plan.



The single biggest problem
in communication is the illusion
it has taken place.



George Bernard Shaw

2. Support Networks:

Growing up I never had a support network. I was the only sibling in the town. I typically end up in parent support groups because there really isn't many sibling supports. There are a few organizations like the American Association of Intellectual and Developmental Disabilities that hold

conferences for siblings. There is also the Family Cafe in Orlando Florida that you will meet other siblings. I started asking parents if they had other children that I could talk to. This is so important. Times will be stressful. You will be sandwiched between taking care of an aging parent, special needs sibling, and your own family.

3. Have A Plan:

Have a plan! Have a plan! Have a plan! Start talking about the wishes for everyone involved prior to an emergency. This is not just for the sibling but your parents as well. Know where legal documents are located, where everyone is going to live, know facilities in the area if needed and get on waiting lists, etc. No one wants to have this conversation and our parents don't think they will ever age but it's much easier on you the sibling if there is one. From experience, when the plan is not in place it is chaos. Can you afford to leave your family and job for 2 months to sort these items out?

4. Financial Needs:

These will vary from state to state (and country to country) but at this point most US states have special needs trust accounts as well as ABLE accounts. Money can be placed in these accounts and will not go against your siblings benefits. For more information, I recommend finding a special needs law attorney and they will let you know what is available in your state/ country.

5. Guardianship/Power of Attorney/Health Care Proxy:

Know what legal documents you need. For your parents, make sure you know who the power of attorney and health care proxy is. If these documents have not been generated, make sure you do so. Wills are also needed. You can not will a human so your sibling oversight can not be written it. Financial needs can be as mentioned in number 4 but not who will take care of the

siblings or where they go. This is where guardianship if needed and POA and HCP need to be done prior to parents passing.

6. Know your own limits:

If you can not handle or want legal responsibility for your sibling, that is fine. Just make sure this is communicated. There is nothing wrong with knowing your limits. There are professional guardians if needed. You can also review our blog post about when to ask for help [here](#).

7. Connection:

You may have to take on a new role. You aren't a brother or sister anymore if you take on guardianship of your sibling. This is all legal responsibility. You may have to establish a different connection with your sibling and that's ok.

8. Take care of your own mental health:

This falls under self care. When the time comes, you will be juggling a lot. It really is a much easier transition when you have a plan and take on the responsibilities when it's not an emergency. Seek someone to talk to and a professional if needed. There is no shame in that.



Everyone needs a little therapy.

9. Service Above Self:

Just remember it's not about you. If parents shut down and don't want to talk – it's not about you. If you sibling begins to display behaviors, it's not about you and they just want to communicate. This is the hardest one to remember.

10. You still have a life:

When everything is said and done, you still have your life. You may have a family or responsibilities to an employer. Once again, this is why it is helpful when a plan is in place.

FURTHER INFO:

Check out our siblings page [here](#).

In Australia: Contact Siblings Australia

In the US: Contact The Sibling Support Project

In the UK: Contact Sibs UK

Siblings



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