

Most families are uncomfortable talking about what will happen when their parents are no longer able to take care of their adult child with Down syndrome. It is your responsibility as a sibling to discuss options, make informed decisions and *really* get to know your brother or sister. Be proactive!



How well do I really know my brother?

Do I have all the information I need to provide the very best post-parental care for my sister?

Adult Sibling Toolkit™ Purpose

The reality is this: your parents are not getting any younger. They may be slowing down. What will happen when Mom and Dad are no longer able to care for your sibling with Down syndrome?

The adult sibling toolkit provides families with an easy-to-use resource which will facilitate family conversations about their loved one with Down syndrome and lay the groundwork for making a plan for the future.

Use this notebook:

- As a guide in talking with your parents about uncomfortable topics
- To record contact information for doctors, specialists, support staff and friends of your sibling
- To track your sibling's daily routine and weekly activities
- To list current medical conditions and medications
- To provide basic information about the "system"
- To find local resources specific to your family situation

This is an overview of possible issues you may encounter as your family develops a plan for the future. It is not intended to be an exhaustive resource on any particular topic or to give professional legal, financial or medical advice. Laws vary from state to state; you should consult a professional in the state of your sibling's residence.

Post-Parental Care: Will Your Family Be Ready?

1. Sit down with your parents, your sibling with Down syndrome and other interested family members and friends.
2. Decide who should take your parents place as the **key** support person.
3. Determine the roles of the others present.
4. Go through this toolkit page-by-page with your parents and fill out the information to the best of your abilities.
5. Gather the important documents or at least identify where to find them.
6. Which documents are missing? For legal and financial documents make a plan for creating them.

"Vision without action is a daydream. Action without vision is a nightmare."

-Japanese Proverb