

FAMILY CARE TOOLKIT

PARENT GUIDE



Use this notebook:

- ✚ To record information about your children's likes, dislikes; devices he/she can use, and other key information
- ✚ To help the caregiver understand daily routines and weekly activities
- ✚ To provide a list of current medical conditions and medications
- ✚ To provide your caregiver with the information to maintain your home and guide your family members

The toolkit has been created so it can be used for a planned event or in an emergency. It is not intended to be an exhaustive resource on any particular topic or to give professional legal, financial or medical advice. The Family Care Toolkit Parent Guide is removable and specifically created for completing the caregiver portion of the Family Care Toolkit.

Extra copies of each form in the toolkit can be downloaded and printed from our website at www.ndsccenter.org

PARENT GUIDE -WELCOME

When we arrive in a new environment we are often provided with a welcome, this is how the Family Care Toolkit begins. Welcome to our home.



As you go through your house, think of what will impact your child with Down syndrome and his/her brothers and sisters. What will your caregiver need to understand about your home environment? **House Notes** provides the space to explain how to use the coffee maker, how remotes work, whether the lights stay on or off, what doors to lock, and more. Remember to only let caregivers have access to what pertains to taking care of your children.

In the event you are traveling, provide any details on the **Travel Plans** form. Provide hotel, and flight information. This will help the caregiver be able to answer questions from your children.

The **Friends and Family** page provides a place for you to list people that are close to you that help you out in your daily living: friends, family that a caregiver can reach out to for guidance, or even for your child to have a playdate.

PARENT GUIDE- OUR FAMILY

The **Our Family** section is a way for you to acquaint the caregiver with the people in your home. It is helpful for the caregiver to know who lives in your house - grandparents, older siblings, stepchildren. A picture would be beneficial to identify children. Do you have a cat, dog, or even a turtle? They are also family.



To soften the ease of transition to caregiver, it is important to identify the likes and dislikes of your children. Be sure to indicate whether your child has a favorite stuffed animal or a book they like to look at. Is there a particular friend that they hang out with? Are there suggestions for calming temper tantrums? Does your child with Down syndrome have a particular “groove”? Do they need help with hygiene? A list of questions is available on **Who Am I?** for you to answer that will guide your caregiver to a better understanding of your children.

I’m Working is a page that explains where and what kind of work your adult child with Down syndrome may be doing. Not everyone will need this page, but many adult children live at home with family members and go to work, post-secondary programs or day programs. Please fill out the I’m Working section if necessary.



If your child with Down syndrome goes to school, or if your adult child with Down syndrome goes to work, there are often routines that dictate the weekdays. On the weekends and in the summer there may not be such a need for structure. Either way the care provider for your children will need to know how to plan the week for your children.

The **Daily Schedule** and the **Daily Routine** were created to help you organize the days for your caregiver. Use either form, or both, dependent upon how detailed you like to be. The **Daily Routine** form includes an area for car/bus information for school or work. Include all info, such as if your caregiver needs a tag for picking up your child from school. If you are traveling during the school year, remember to contact the school, both the front office and the teacher. This helps the school know about changes that may impact your child with Down syndrome.

The **Daily Meals and Allergies** form identifies times, allergies, typical food, snacks and EpiPen information for your child. The **Menu Ideas** form allows you to write down a week of meals for breakfast, lunch and dinner.

Children tend to stay busy and sometimes have more extensive social calendars than we do. Does your child go to scouts? Swimming practice? What time do they go and who is the main contact? The **Social Activities** form provides a space for the various details about your children's activities. The forms in this section should guide your caregiver through their days and help your children's week go smoother.

PARENT GUIDE- HEALTH & MEDICAL



Healthcare for your child with Down syndrome is of utmost concern, along with the healthcare of your other children. Does your child have chronic conditions? Are diet and exercise a priority? Are there any allergies? Do they have Psoriasis? Are there medicine allergies?

The documents in the **Health and Medical** section were created to provide space for medical history, information, and medication. By completing the **Health and Medical** form for your child, your caregiver will be better informed on specific daily medical care. The **Medical History** page includes whether any of your children have Epi Pens and where they are kept, as well as other vital information.

Does your child with Down syndrome take medicine with apple sauce or water? Does it need to be taken with food or without? The **Medication Information** page is for medicine, dosages and any comments that might help the caregiver better care for your son or daughter. Identify where over-the-counter medicine is located in the house in the event your child needs it.

In the Emergency section of the Family Care Toolkit you will find a medical consent form. More information can be found in the Emergency section of the Family Care Toolkit.

PARENT GUIDE - RESOURCES

In your community there are activities and restaurants that may be someplace that your family enjoys going. The resource section is for:

- brochures
- restaurant guides
- notices for festivals

Do you live in an area with a pool that the kids like to go to? This is the section where you would leave the key card, etc. that the caregiver would need. A pocket folder has been provided for this purpose. Within the **Resource** section there is an additional area for numbers for teachers, coaches, friends, that may be a part of your family's life.

The Family Care Toolkit is a resource for your caregiver, as well as you, the parent. It is essential to think about the legal and financial implications of not having documents when needed for the care of your children. When an emergency arises it is unexpected and many people are often caught unprepared. Every state has its own rules when it comes to financial and legal matters, which is why it is beneficial to understand them in advance of any unforeseen emergency. Things that need to be considered are a Letter of Intent, guardians, life insurance policies, financial plans and more.

Guardianship can be tailored to the needs of your child with Down syndrome such as healthcare. A Letter of Intent is a statement of need that is not legally binding, but can provide directions regarding your children. Explore and consult with someone in your state for the regulations in your state and the best strategy for your family.

For more information with help identifying a special needs attorney, or for a sample Letter of Intent provided by Attorney Dana Young, please contact us.

PARENT GUIDE- EMERGENCY



Emergencies are never something we welcome, but when the unexpected does happen it is best to be prepared ahead of time. Your caregiver may need to be able to notify emergency personnel and know medical information at a moment's notice. If the power goes out, who does your caregiver contact? Where is the first aid kit located? These details can help aid in the caring of your child with Down syndrome and his/her siblings. Use the **Emergency Information** page to complete this information.

A **Medical Consent** form is included in this section. The following is required:

- medical consent form for every child
- medical consent for older adult who has a legal guardian
- Current dates of consent
- Photo copies of insurance cards (medical and dental)
- Allergy information

In the Family Care Toolkit there will be a pocket folder for you to leave insurance cards and identification cards. Any medical doctor or hospital will require these documents. The consent form is not meant to take the place of sound legal advice. You may consult with an attorney to be sure it fits your family's needs.

In the emergency section you will also find a page for **Emergency Contact Information**. Consider local grandparents, friends, close neighbors, ex's, that can help in an emergency situation. It is in the best interest of your child with Down syndrome and his/her siblings to notify the people that you are adding them to the emergency contact list. Regularly review and update your emergency information.



The National Down Syndrome Congress (NDSC) is a membership-sustained not-for-profit organization dedicated to an improved world for individuals with Down syndrome. Founded in 1972, we are the leading national resource of support and information for anyone touched by or seeking to learn about Down syndrome, from the moment of a prenatal diagnosis through adulthood.

The purpose of the NDSC is to promote the interests of people with Down syndrome and their families through advocacy, public awareness, and information. When we empower individuals and families from all demographic backgrounds, we reshape the way people understand and experience Down syndrome.

We understand that parents travel for business, events, and rest & relaxation. We also recognize that people may want a break and need respite to care for their child with Down syndrome; or unexpectedly need care in the event of an emergency. The Family Care Toolkit was designed to provide families with a document of care for your child or adult with Down syndrome, siblings and others in your home. A caregiver will be able to use this toolkit to help guide your child with Down syndrome, along with brothers and sisters, through their day. Use this toolkit to reassure yourself that your caregiver is prepared with the necessary information to take care for your loved ones.

Empowering individuals with Down syndrome and their families since 1972