



NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Two

Obtaining a Medicaid Waiver

BY BONNIE DAVIS, ADAM'S MOM

As you are beginning to learn more about your child’s diagnosis and care, you may be wondering how you will do it all yourself, or how you will pay for all of the care your child will need. We want families to know that there is a government program that can help you with this. It is called a **Medicaid Waiver** and is available in some form in every state. According to the US government Medicaid website, “under a Medicaid waiver, a state can waive certain Medicaid program requirements, allowing the state to provide care for people who might not otherwise be eligible under Medicaid”.

In other words, Medicaid Waiver programs are based on the diagnosis, rather than the family income level. Your child will be eligible regardless of your income, and Medicaid can be used as secondary insurance to your primary private coverage. **Medicaid varies by state**, but many offer coverage for in-home care.

Some other services that may be available through Medicaid include, but are not limited to:

- A home health aide
- Nursing
- Medical supplies and medical equipment
- Chore and homemaking services, such as shopping, laundry, and cleaning
- Hot meal delivery services
- Respite care to relieve a primary caregiver
- Counseling services
- Home and/or vehicle modifications, such as ramps and safety rails,
- Support and case management.

Be aware, however, that approval for the Waiver is a process that can take months to complete. For this reason, we encourage you to apply for this program as early as possible. *continued on page 2*

"Now I don't put things in boxes anymore. I'm just focusing on right now"

- Robin Roberts

Resources:

NTSAD Information on Research

We know you're likely wondering what the status of current research is and how to find out more information.

NTSAD has the information of both past and current research efforts peratining to Canavan, Gm1, Sandhoff and Tay-Sachs available on the NTSAD website under a tab for **Research for Families**.

Contact Us:



Diana Pagonis
Director of Family Services
diana@ntsad.org
(617) 458-9013



Becky Benson
Family Services and Conference Coordinator
becky@ntsad.org

Disclaimer: The content of this newsletter is intended for support purposes only and not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your mental health provider with any questions you may have regarding a medical condition.



continued from page 2

Additionally, the process to obtain a Waiver can be complicated so it is beneficial to seek guidance from a trusted professional from your child's care team. Talk to your child's pediatrician, neurologist, palliative care team, or an Early Intervention specialist. One of these team members should be able to help you find the appropriate person who can walk you through the application process. Although obtaining the Waiver will take some time and energy, once in place, the services provided will be invaluable to you and your family.

Getting Organized

BY SARA SCAPAROTTI, JOEY'S MOM

Getting organized after your child's diagnosis is a great way to cope with the overwhelming emotions. Creating a care notebook or binder will help you record important information about your child's health care, and will make it easier to keep track of changes, share information with your child's care team, child care, school, and family members. Everyone has a different way of organizing information. The key is to make it easy for you to find again. Make sure to share new information with your child's primary care physician, therapists, family members, school nurse and school staff, daycare staff, and others caring for your child. Take the care notebook with you to appointments and hospital visits. Here are some suggestions for supplies used to create care:

- Notebook
 - A three-ring notebook to hold papers securely
 - Tabbed dividers to create your own information sections
 - Pocket dividers or sheet protectors to store reports, discharge summaries etc.
 - Plastic pouch for notebooks for holding notes, miscellaneous items
 - Plastic pages to store business cards and photographs

- The following information should be kept and updated in your care notebook
 - Where the evaluation/assessment was done, where diagnosis was made
 - Names and contact information of doctors
 - Informative hand-outs
 - Supportive resources
 - Pertinent phone numbers and addresses
 - Copies of assessment reports, diagnostic and imaging tests and laboratory reports
 - Updated list of your child's medicines and treatments
 - Insurance documents

"YOU DON'T HAVE TO SEE THE WHOLE STAIRCASE, JUST TAKE THE FIRST STEP."

– DR. MARTIN LUTHER KING JR.



An Additional Resource for Families

BY MONICA GETTLEMAN, BROOKE'S MOM

You may find that into the second month of your child's diagnosis, friends and family may have stopped bringing over meals and groceries. With so much on your mind already, the last thing you likely want to think about is grocery shopping and planning dinners.

A meal delivery service can help take this burden off "your plate." Companies such as Door Dash, Grubhub, and Uber Eats deliver ready made meals from your favorite local restaurants right to your door. A meal delivery service is one small way to help take the hassle out of planning, grocery shopping and even cooking dinner.

NTSAD would like to offer to treat your family to a gift certificate to a delivery service of your choice in the amount of \$100. Whenever you are ready, please reach out to [Diana](#) or [Becky](#) and let them know it would be a good time to utilize your gift certificate. You'll then be sent an e-gift certificate to use at your convenience.

During this hectic time of living with your child's new diagnosis, we hope this gift card can help alleviate the burden of worrying about a few upcoming meals.

Common Emotional Responses to Serious Illness

AN EXCERPT FROM HELPGUIDE.ORG

- Anger or frustration as you struggle to come to terms with your diagnosis—repeatedly asking, "Why me?" or trying to understand if you've done something to deserve this.
- Facing up to your own mortality and the prospect that the illness could potentially be life-ending.
- Worrying about the future—how you'll cope, how you'll pay for treatment, what will happen to your loved ones, the pain you may face as the illness progresses, or how your life may change.
- Grieving the loss of your health and old life.
- Feeling powerless, hopeless, or unable to look beyond the worst-case scenario.
- Regret or guilt about things you've done that you think may have contributed to your illness or injury. Shame at how your condition is affecting those around you.
- Denial that anything is wrong or refusing to accept the diagnosis.
- A sense of isolation, feeling cut off from friends and loved ones who can't understand what you're going through.
- A loss of self. You're no longer you but rather your medical condition.

For more information on emotional responses to serious illness and how to navigate them, please view the full HelpGuide.org article, [here](#).

"Whenever grief tries to steal the beauty of your memories,
just remember, love never dies." - Unknown