

Building A Care Notebook for Your Child's Needs

As the primary caregiver, family members are often responsible for providing the supports in their child's life. When you have a child with complex medical needs, it can often mean lots of paperwork to organize. One way families can maintain a record of their child's care, services, providers, and other notes is a care notebook.

The care notebook can be customized to fit your family's needs and an excellent way to keep track of all your child's health history and other records. You can personalize your child's care notebook to include information about your child for other family members or caregivers. A detailed care plan helps to ensure better communication and consistent care.

There are many sources online to help create this care notebook. Most of the sources include to list a few: emergency information, emergency medical forms, emergency plans for seizures, daily schedule, current medications, daily nursing needs, central line care, daily routine, therapy routine, equipment descriptions and instructions, computer instructions, cognitive and communicator instructions, bathing needs, TPN preparation and pump use, medication preparation, important phone numbers, insurance information, copy of insurance card, medical history, medical consent form and etc.

Keeping a physical Care Notebook and on a portable device such as a USB flash drive will allow you to have immediate access to all of your children's information. Start one today because an accurate and updated Care Notebook is one of the most important things you can have ready for your child.

Sources to check out:

<https://www.navigatelifetexas.org/en/diagnosis-healthcare/care-notebook>

<http://www.familyvoices.org/work/caring?id=0052>

Reference Source: F2F Michigan



Information about Epilepsy for WV

The Epilepsy Foundation of West Virginia with the National Epilepsy Foundation shares Information about what is epilepsy and how you can help to make a difference.

What help can be found for a person who suspects or knows they have epilepsy?

- Toll-Free Helpline: 1-800-332-1000 (English) or 1-866-748-8008 (en Espanol)
Note: Please be aware that the 24/7 Helpline is an information and referral line. It is not staffed by clinical professionals. The staff only provide information based upon published materials that have been approved by the Foundation's Professional Advisory Board and referrals are to independent resources.
- Current research and the basic information about "What Is Epilepsy?" and "What is a Seizure?" <http://www.epilepsy.com/learn/epilepsy-101/what-epilepsy>
- Seizure First Aid Information <http://www.epilepsy.com/learn/treating-seizures-and-epilepsy/seizure-first-aid>
- Advocate for the cause is a link Speak Up Speak Out advocacy network: <http://www.cqrcengage.com/efa/home>
- Management Tools with forms are available to help manage seizures. <http://www.epilepsy.com/get-help/managing-your-epilepsy>
- Two epilepsy centers in West Virginia:
 - Cabell Huntington Hospital Epilepsy and Seizure Center (304) 526-6387
 - West Virginia University Hospital Epilepsy Center (304) 598-6150



**EPILEPSY
FOUNDATION**

Apps Help Your Child Bridge the Gaps

With back-to-school planning in full swing for parents and children, one important item must be added to the checklist— technology apps which helps your special needs child succeed in school.

Technology has been and continues to be a boon for children/adults with disabilities. Mobile devices such as iPads enable child with developmental delays and other special needs to acquire life skills, engage in self-directed play and most importantly, facilitate communication with their caregivers.

"There's been a democratization of communication and learning software except now we call them apps," stated Dr. Howard Shane. "The rapid-fire speed in which apps are being developed has made it difficult to distinguish the good from the bad, he stated. To help you make your decision, there is a fillable online paper "Apps Consideration Checklist" by M.T. Tamaro and M.K. Jerome which you can download to help you decide the best app for your child <https://tri-ipad1.wikispaces.com/file/view/Fillable+Form+Apps+Checklist+Locked.pdf>.

The other option to watch is free vs. fee with the apps. Many of the apps will provide a 'lite' version which is free and usually a marketing technique. The more in-depth versions which cost

allows the user allows them to customize and provide more options in items such as games, exercises, colors, etc. If you visit the internet, you will be overwhelmed with the apps which can be purchased. You might ask a friend who has a special needs child

Care.Com in an article by Julie Rosenberg recommends some of the following apps:

Talk Tablet (79.00 for communication needs)

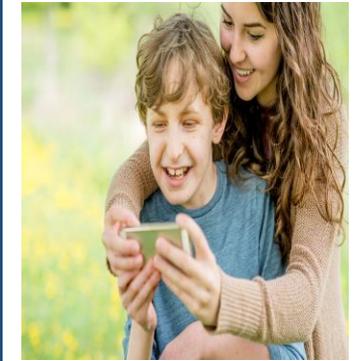
Social Skills Builder (Interactive videos teach key social thinking that are critical to everyday living.)

Splingo's Language

Universe (iTunes \$2.99) and others on the site.

Also, you can access a community forum at:

<http://bridgingapp.org>



Family-to-Family HIC Offers Training

Looking for information, you have found the correct spot. Family-to-Family Health Information Center has four new trainings available to you. The list and summary is below:

On Track- Navigating the Healthcare System for Children and Youth

If you have questions about the Healthcare System for a child with special needs; then, you need to check this training out.

Family Leadership and Engagement

The role of the family of a child with special health care needs and the role which the family plays in their child's health care plan.

Advocacy and Self-Determination- Knowledge is Power!

How you can advocate for your child with special health care needs and find how to become knowledgeable about speaking up for your child with special health care needs in the health care system.

We've Been Denied Services! Now, what do we do?

Tools for Appealing Denials of Services

This training is about the tools that you have as a parent of special health care child who needs information about what you can do after your claim has been denied.



Family Voices

West Virginia Parent Training and Information, Inc. is the Family Voices State Affiliate Organization for National Family Voices. As West Virginia's statewide Family-to-Family Health Information Center (F2FHIC), we are part of a federal initiative which funded F2FHICs in every state, providing information, and education on health issues for children and youth with special health care needs (CYSHCN). The statewide F2FHIC reflects a family focus. Family Voices-WV, affiliated with National Family Voices, works to "keep families at the center of children's healthcare."

<https://www.facebook.com/WVPTI.INC/>



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For more information:
<http://www.wvpti-inc.org/family2family/>

Call WVPTI.Inc's number: 800-281-1436

or call the CSHCS Family Phone Line at:
(800) 642-8522 in West Virginia

"WV Family-to-Family Health Information Center provides family-friendly healthcare information. We work to ensure that all West Virginia families of children and youth with any kind of disability or special health care need are empowered with the knowledge and assistance they require to make informed decisions."

Family-to-Family Health Information Center (F2FHIC)

works with families of children and youth with special health care needs (CYSHCN) to be able to participate in decision-making at all levels and be satisfied with the services they receive.

How Can F2F HIC Help?

F2F HIC can help families with children with special health care needs because families need people who can assist with the experience. Navigating the maze of health care services and programs for families with children with special health needs can be frustrating. WV Family-to-Family HIC is here to help the families.

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Disclaimer: The WVPTI, Inc. and Family-to-Family newsletter includes information and links to internet and other resources. These resources are for your consideration only and are not endorsed by WVPTI, Inc. or WV Family to Family Health Information Center or our funders. The information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care.

How to contribute to upcoming newsletters:

WVPTI, Inc. and F2F are interested in sharing on topics of interest to families of children and youth with special health care needs across West Virginia. If you have an upcoming event, learning opportunity, educational resource or other items you would like to share, please contact us at WVFamily.to.Family@gmail.com