

Section 2:

After the Diagnosis

How I am feeling after the diagnosis and who can I talk to?

Being given a diagnosis can be overwhelming for the individual and their family. It can cause many emotions to come to the surface immediately or can take time and slowly overwhelm you. It's important for you to process the information you have received and create a plan for moving forward. Below are several steps you can take to help you through this new journey.

Step One - Take time to breathe and process through the information you have received. For some the diagnosis could be a shock and for others they may have questioned the possibility of a diagnosis for some time. Every individual and caregiver will handle the situation differently and it is recommended to implement self-care techniques to help navigate through the changes to your family. These techniques may feel new at the beginning but are easy additions to a regular routine moving forward.

Step Two - Knowing the disability is important, but it does not define your loved one. This step is incredibly important as you begin your journey. For many of us who have been a part of this community, we will say the person has been diagnosed with a disability and not that they are their disability (i.e., Tom has been diagnosed with autism, not Tom is autistic). You may hear people in the disability community refer to this as People First Language (PFL). This is a way for us to acknowledge the individual has a disability, but we never want it to be the sole attribute to define them. Your loved one is still your loved one and their value doesn't change with the diagnosis. Those diagnosed with the disability may choose to identify themselves as their diagnosis (i.e. I am autistic, I have down syndrome, I am deaf, etc.). This is a way for individuals to own their disability.

Step Three - Education is your greatest tool throughout your new journey. Take the time to learn everything you can about the diagnosis. Utilize the medical team who gave the initial diagnosis, your family physician, medical journals, books, websites affiliated with medical organizations, etc. Ensure you are using reputable sources when gathering information to help you through your new journey.

Step Four - Build your team of medical professionals, local providers, family, friends, educators, social media groups, local support groups. It takes a village and many people have been through the process before and want to provide any help you need. Never hesitate to ask for assistance. It is not uncommon for caregivers to seek out support from a therapist to process through the diagnosis of their loved one. This is a valuable step in your journey and talking through your feelings can help create a solid plan moving forward.

Step Five - After you have taken the time to process through the diagnosis, gathered information, and start to build your team, now is the time to talk with family and friends. Some of these conversations can be the most difficult to have but are the most necessary. Having advocates and allies allows you to know you have people looking out for you on this journey.

Self-Care Techniques

De-clutter - Being surrounded by unnecessary clutter can increase feelings of being overwhelmed. Starting small will allow you to ease into de-cluttering while relieving additional stress. Choose a closet, a corner, or a room to start small and work at a pace you feel comfortable with.

Find a hobby - Find a hobby unrelated to your career. Draw, paint, garden, woodworking, etc. Allow yourself the opportunity to engage in something to allow your creativity to come out.

Fuel your body - Find ways to add fruits and vegetables into your diet, aim to have one healthy meal each day and increase to additional healthy options weekly.

Get outside - Walk, run, bike, garden, take your dog for a walk, etc. Find any reason to get outside to reset your mind.

Listen to music - Take 30 minutes each day and listen to your favorite music. This could be while you are getting ready for the day, your commute, while making supper, etc.

Massage - Set aside time once a month and get a massage. There are many options for massage therapists in our area. Some health savings plans will allow you to utilize your funds if a note is on file from your physician. Talk with your health savings account customer service for more information. If your plan does not cover massages, we have several massage schools in the area with students who offer training massages at discounted rates.

Meditate and Relaxation - Give yourself the gift of peaceful moments. Turn off your electronics, utilize aromatherapy through oils or candles, turn on calming music or sit in silence. Allow yourself time to rest.

Move - Get into an exercise routine before and after work by joining a class, go for a walk, lift weights, dance, yoga, etc. If it helps find a friend or neighbor who can join you.

Read a book - Find a cozy place inside or go find a great space outside with fresh air. Allow yourself a minimum of 15 minutes to read each day.

Relationships - Nurture current relationships and building new friendships. Surround yourself with positive people who support where you are and where you want to be. Find people you are comfortable with to share how you are

coping with the current demands of your life and be a listener for them as well. Attend events for them or with them, spend time with them in a group or one on one. Events may include sports, concerts, plays, religious activity, movies, exercise class, coffee, shopping, etc.

Sleep - Develop and implement a regular sleep routine. If the kids go to bed at 8 PM, there is no reason you can't be close behind. You will be your best self if you can get the rest you need.

Take breaks - This applies to both 15-minute breaks, walking breaks, and/or lunches. You can only run-on fumes for so long before you need the time. Be aware of your start and stop times for work. It is easy to go in early or stay late, but self-care means you are making yourself a priority to be the best version for you and your family.

Vacation - Take time to get away. This could be a long weekend or a full week off. Allowing yourself to take time away to reset with your family will help you to re-energize and balance yourself.

Education Resources

Physicians, Specialists, and credible websites are all beneficial resources to gather information to help support you and your loved one. Below you will find a list of websites to access for disability information. This is a small selection of reputable information you can find online. If you are a reader, spend time online looking at books written by and for individuals diagnosed with a disability. You will find lots of books online for all age ranges, diagnosis, and relatable content.

ADDitude

<https://www.additudemag.com>

ADDitude is an on-line magazine that addresses issues and provides resources for people affected by or caring for those with Attention Deficit Hyperactivity Disorder (ADHD).

American Speech-Language-Hearing Association (ASHA)

<https://www.asha.org>

Members: 800-498-2071 · Non-Members: 800-638-8255

National professional, scientific, and credentialing association for 218,000 members and affiliates who are audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students.

ASK (Access for Special Kids) Family Resource Center

<https://www.askresource.org>

800-450-8667

The center can connect you with strategy, training, and education programs. Families with children who have disabilities can access their F.I.N.D. database, which connects families with similar experiences and interests.

Aunt Bertha

<https://www.auntbertha.com>

Aunt Bertha is a social services search engine helping people find referrals to free or low-cost programs and services for food, shelter, health care, work, financial assistance and more.

Birth Injury Help Center

<https://www.birthinjuryhelpcenter.org>

800-444-6443

A comprehensive website dedicated to promoting awareness of major birth injuries and related childhood disabilities. Their goal is to give parents of children injured during childbirth access to the highest quality information on the web to enable them to make informed decisions.

Brain Injury Association of America

<https://www.biausa.org>

The Brain Injury Association of America offers information about how to connect to supports and resources, including descriptions of the many symptoms and issues that may accompany a brain injury.

Cerebral Palsy Guidance

<https://www.cerebralpalsyguidance.com>

This organization's website features information ranging from cerebral palsy symptoms to financial assistance to daily living articles, covering all aspects of cerebral palsy.

Cerebral Palsy Guide

<https://www.cerebralpalsyguide.com>

866-778-5616

Read a free educational guide with information for parents and children affected by cerebral palsy, including financial options and emotional support.

Disabilities Resource Library

<https://uichildrens.org/cdd/drl>

319-356-1345

Located at the University of Iowa Hospital, the collection focuses on information regarding disabilities. Over half of the items can't be found in any other library in Iowa.

Disability Rights Iowa

<https://disabilityrightsiowa.org>

666 Walnut Street, Des Moines, IA 50309 · 515-278-2502

Disability Rights IOWA aims to defend and promote the human and legal rights of Iowans who have disabilities and mental illness. They promote safety, opportunity, access, and self-determination for all Iowans.

Disability Scoop

<https://www.disabilityscoop.com>

Disability Scoop is a conglomerate of recent developmental disability stories in the news.

Epilepsy Foundation

<https://www.epilepsy.com>

The mission of the Epilepsy Foundation is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. For more than five decades, the Epilepsy Foundation and their network of nearly 50 partners have helped to connect people to treatment, support and resources, fund innovative research and the training of specialists; and educate the public about epilepsy and seizure first aid. Their programs also shine a light on epilepsy by promoting awareness and advocating for laws that matter to people with epilepsy

Friendship Circle Blog

<https://www.friendshipcircle.org/blog>

The blog offers a number of online special needs resources including over 1,000 articles on special needs parenting, products, therapy, and more. It also offers information about special needs apps.

GeneReviews

www.genetests.org

GeneReviews, an international point-of-care resource for busy clinicians, provides clinically relevant and medically actionable information for inherited conditions in a standardized journal-style format, covering diagnosis, management, and genetic counseling for patients and their families. Each chapter in GeneReviews is written by one or more experts on the specific condition or disease and goes through a rigorous editing and peer review process before being published online..

Global Down Syndrome Foundation

<https://www.globaldownsyndrome.org>

303-321-6277

Network of affiliated organizations to improve lives of people with down syndrome through research, medical care, education, and advocacy.

MindSpring Mental Health Alliance

<https://mindspringhealth.org>

515-850-1467

MindSpring is an independent local organization providing mental health education, support, and advocacy. They are dedicated to improving the lives of individuals, families, and the community on mental illness. MindSpring welcomes anyone who shares their mission and vision.

National Alliance on Mental Illness (NAMI)

<https://namiiowa.org>

800-950-6264

Alliance for the Mentally Ill provides education and support programs.

National Council on Independent Living (NCIL)

<https://ncil.org>

844-778-7961

NCIL advances independent living and the rights of people with disabilities. NCIL envisions a world in which people with disabilities are valued equally and participate fully.

National Federation of Families for Children's Mental Health

<https://www.ffcmh.org>

240-403-1901

The National Federation of Families for Children's Mental Health is a national family-run organization linking more than 120 chapters and state organizations focused on the issues of children and youth with emotional, behavioral, or mental health needs, and their families.

Self Advocates Becoming Empowered (SABE USA)

<https://www.sabeusa.org>

Self Advocates Becoming Empowered (SABE) is the United States national self-advocacy organization. They are a national board of regional representatives and members from every state in the US. Their mission is to ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends, and to learn from their mistakes.

The Arc of the United States

<https://thearc.org>

800-433-5255

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. They serve all ages and individuals with more than 100 different diagnoses including Autism, Down Syndrome, Fragile X Syndrome, and various other developmental disabilities.

The Arc's Action Center

<https://p2a.co/IRPDZ5C>

Stay up to date on what is going on in Congress and how it impacts people with intellectual and developmental disabilities. Advocates receive a weekly policy newsletter and get action alerts that give a direct course of action, talking points, and background on breaking policy related issues.

Building a Team

When building a support team, the team will generally start small and increase in size as you learn more about the diagnosis or are referred to additional physicians and specialists. Here are some possible members of your team:

Developmental and Behavioral Pediatrician - a physician specially trained to address behavioral, developmental, and/or learning needs of children. They will provide a diagnosis, referrals, and assist in locating community resources to help support the individual.

Local Service Provider - an organization supporting individuals with a development, intellectual, or mental health diagnosis (i.e., The Arc of East Central Iowa, Abbe Center, etc.). The staff can help provide resources, education, and support throughout all stages of an individual's journey.

Medical Specialist - a medical professional focused on certain areas of the body (i.e., audiologist, cardiologist, genetics, immunologist, internal, neurologist, podiatry, etc.).

Nurse Practitioners (NP), Advanced Registered Nurse Practitioner (ARNP) or Advanced Practice Registered Nurse (APRN) - a nurse who has graduated with an advanced nursing degree. They can complete a wide range of tasks to support the individual in need.

Parent Partner Support - a fellow parent or caregiver of an individual diagnosed with a disability who can lend a listening ear, share their experiences, and offer advice as you go through your journey. If you are needing additional support contact Kristen Krambeer at The Arc of East Central Iowa at kkrambeer@arceci.org to be connected to a parent partner.

Physicians - a medical professional with a medical doctorate degree who can provide an individual with a diagnosis, care, treatment, and prescribe medication.

Physician's Assistant - a medical professional licensed to provide services under supervision of a physician.

Psychologist – a person who studies the mind and brain. A psychologist will help an individual utilize psychotherapy to adjust changes in the individual's behavior.

Psychiatrist – a person who diagnoses and helps to prevent and treat behavioral, emotional, and mental health.

School Staff – a member of a school who provides support to students and their families (teacher, school counselor, principal, etc.).

Spiritual Advisor – is anyone in your faith you acknowledge as a leader to help guide you through your journey (bishop, elder, guru, lama, imam, minister, pastor, priest, rabbi, reverend, etc.).

Therapist – a specialist who works to support an individual through the process of handling multiple emotions through a diagnosis and medical process (Occupational, Play, Physical, Respiratory, Speech, Musical).

Talking with others about the diagnosis

It can be easy to feel like it is your job to explain the diagnosis everywhere you go. Luckily, there are many wonderful resources online, books, public speakers, podcasts, etc. that anyone can access to learn more about a particular diagnosis. Never feel you are alone or having to educate everyone in every circumstance. Sometimes the best thing you can do is direct them to places where they can learn more and make yourself an open resource if they have follow-up questions.

Helpful tips when sharing a diagnosis with another person:

Make sure the information you share is accurate. With all the resources online, you want to ensure you are directing people to appropriate and useful information.

Be aware of the audience you are speaking to and how much information you share. For a friend or family member, you may be okay sharing every detail, but with a stranger, you may say, “they/I have been diagnosed with a disability” and choose to share nothing else.

If you go into further detail, it is best to provide the information in a private location to help maintain your privacy but allow time for the individual to process the information. They may begin to ask questions during the initial conversation or ask to speak to you in the future if you are open to further discussion.

It is important to remember disclosing is always a choice. You should never feel pressured to disclose a diagnosis and you are not required to disclose. This includes disclosures to current or future employers.

Additional resources for sharing someone’s disability diagnosis or how to interact with individuals diagnosed with a disability:

Center For Disease Control and Prevention: Communicating with People with Disabilities

<https://www.cdc.gov/ncbddd/disabilityandhealth/materials/factsheets/fs-communicating-with-people.html>

Cincinnati Children’s Hospital Medical Center: How to Talk to Kids About People with Disabilities

<https://blog.cincinnatichildrens.org/86/how-talk-kids-people-disabilities>

Raising Children: Talking About Your Child’s Disability

<https://raisingchildren.net.au/disability/family-life/communicating-relationships/talking-about-child-disability>

Respectability: Etiquette: Interacting with People with Disabilities

<https://www.respectability.org/inclusion-toolkits/etiquette-interacting-with-people-with-disabilities/>

After a Conversation: What are things, someone can do to help end the stigma around disabilities?

Ask questions. It is always better to ask in an open honest way about someone’s disability. Taking the time to hear people’s stories may help you understand who they are as a person, their experiences, and some of the struggles they face each day.

Never joke about having a disability and if you hear something, say something.

Using the phrase of “Everyone’s a little on the spectrum”, “I’m a little slow too”, “I couldn’t even tell”, or “I’d like to cruise around on two wheels all day too” can be extremely hurtful for those who are experiencing the real challenges of being diagnosed with a disability.