

Issue 3

# Livingwith™

LGS • DRAVET • TSC



## IN THIS ISSUE

### *Empowering Your Child*

Information about transitioning to adult healthcare using this helpful toolkit

### *Words of Advice*

Insights from caregivers about common challenges

### *Siblings Speak*

Answers and advice from one sibling to another

## FROM HELPLESS TO SCIENTIST

How epilepsy pushed one mom to fight for a cure

Pictured here: Tracy, mother of Savannah, living with Lennox-Gastaut syndrome

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AT OUR CORE	3
MEET THE CONTRIBUTORS	4
WORDS OF ADVICE from families living with LGS, Dravet syndrome, or TSC	6
8	PATIENT ADVOCACY GROUP NEWS: Ambassador Programs
12	FROM HELPLESS TO SCIENTIST: The story of a mom who refuses to back down to LGS
18	EMPOWERING YOUR CHILD through transitioning to adult healthcare
SIBLINGS SPEAK: Answers and advice from one sibling to another	24

## AT OUR CORE

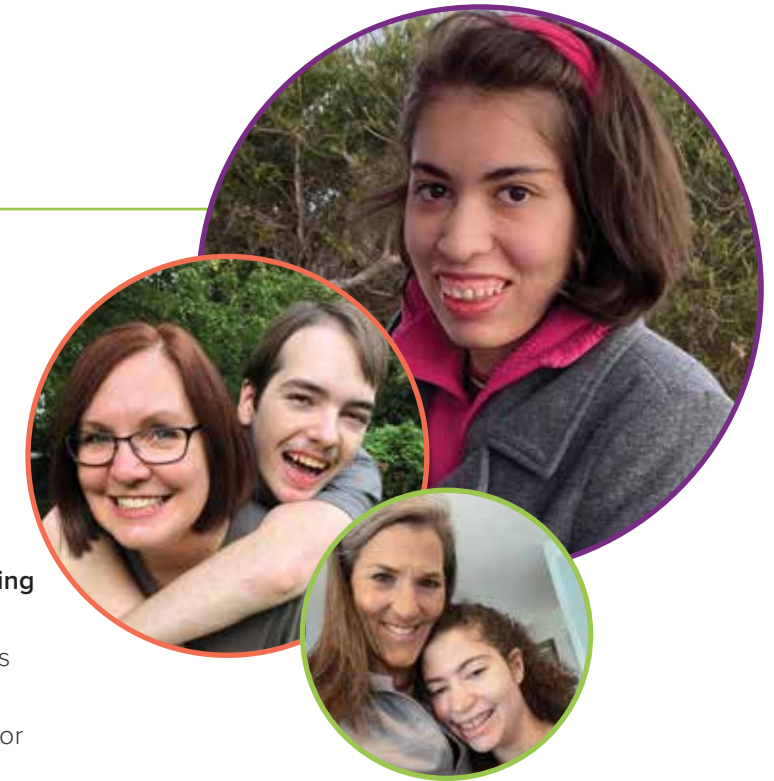
*It brings us great joy to bring you the third issue of Living With Magazine—created for and by families living with epilepsy.*

At Greenwich Biosciences, which is now part of Jazz Pharmaceuticals, **families living with rare neurological diseases are at the center of everything we do.** We are honored to be able to partner with parents, caregivers, and siblings to create resources for families living with rare forms of epilepsy like Lennox-Gastaut syndrome (LGS), Dravet syndrome, or tuberous sclerosis complex (TSC).

**This third issue focuses on the theme of family empowerment,** with articles about a mom's inspiring journey, advice from caregivers on finding quality family time, questions and answers from siblings, and ambassador programs to support you and your family. As you read through, we hope you will find encouragement, inspiration, and guidance.

*From Helpless to Scientist* highlights the journey of Tracy, a mom and caregiver, whose life changed completely after her daughter Savannah was diagnosed with LGS. Tracy wasn't going to give up, so she made it her mission to fight for her daughter by waging a war on LGS.

In *Empowering Your Child*, the Child Neurology Foundation (CNF) provides information and guidance about transition of care—the process of moving your child from pediatric to adult care. You'll learn about how it's never too early to start the process with your



child and how using the CNF's Transition of Care Toolkit can help. Included with this article is a tear-out of the Self-Care Assessment, one of the tools in the Transition of Care Toolkit.

Thank you for reading *Living With*. We hope you enjoy it as much as we enjoy learning from you. We would love your input for future issues of the magazine—you can select topics you are interested in by visiting [LivingWithMag.com](http://LivingWithMag.com)



To download previous issues, visit [LivingWithMag.com](http://LivingWithMag.com)





## MEET

# THE CONTRIBUTORS

Meet the caregivers behind this issue. We thank them for partnering with us to develop the magazine by sharing their stories.



### LISA S.

Mother of Haley, living with Dravet syndrome

#### My family includes...

...My husband, Bobby, our daughter, Haley, 21, and our twin boys, Peyton and Parker, 18. We also have 2 chocolate Labrador Retrievers.

My husband is a general contractor who owns his own business. To meet the needs of our community and to meet Haley's needs as well, my husband and I also started a Montessori School in our area with a few other parents. Haley started Montessori at age 5 and stayed for 3 years. The twins started at age 2 and completed it at age 8. Peyton and Parker have now graduated high school. Parker is in Florida for a post-grad baseball program and Peyton is home attending community college and is in an electrician apprenticeship program.

#### Haley has had seizures...

...Since she was 5 months old, but was not diagnosed until she was 7 years old. We saw 3 different neurologists, tried 2 medical diets, and more than 17 pharmaceuticals until she was diagnosed properly at age 7. She is now 21 years old.

#### Our family mantra is...

"Life is not what it's supposed to be. It's what it is. The way you cope with it is what makes the difference."  
—Virginia Satir

We are a family of faith. We see each of our children for who they are and for their unique qualities. We strive to teach the boys that family is forever. Friends may come and go, but family will always be there.



### ERIN R.

Mother of Leonel, living with Dravet syndrome

#### My family includes...

...My husband, Leo, and our 2 children, Leonel, 8, and Eloise, 6. We also have one dog, Elyssia, who is Leonel's service dog.

#### Leonel has had seizures...

...Since he was 11 months old. At that time, we did not know that what he was having was a seizure. He had his first recognizable seizure at 14 months old when an EEG test revealed that what he had been experiencing were seizures. At 20 months old, he began having a variety of seizure types every other week. He was later diagnosed with Dravet syndrome. He is now in the 2nd grade and loves books, playing soccer and flag football, and riding his bike.

#### My favorite quote is...

"We can do hard things." —Glennon Doyle

No one chooses to be in the situation that rare epilepsy caregivers are in, but when it comes to doing whatever we need to do to care for our children, choosing to be strong is our only choice.



### LISA M.

Mother of Evan, living with TSC

#### My family includes...

...My husband, Rob, and our 2 children, Evan, 18, and Aria, 20.

I am the Vice President of Donor Relations for the TSC Alliance and my husband and I co-founded a comprehensive web-based electronic seizure diary. Our daughter, Aria, is a super sibling and has been Evan's biggest supporter. She is interested in a career in neuroscience.

#### Evan has had seizures...

...His entire life. He has had 2 brain surgeries and has been on multiple medications. He was initially diagnosed with epilepsy as an infant, and then when he was 2 years old, he received a specific diagnosis of TSC. Most recently, he has had some success with managing his seizures and we knock on wood every time we comment on that.

#### My favorite quote is...

"Life isn't about waiting for the storm to pass...It's about learning to dance in the rain." —Vivian Greene

Our family has a knack for finding humor in the toughest situations. If we are still able to laugh, we know everything will be okay.



### TRACY D.

Mother of Savannah, living with LGS

#### My family includes...

...My husband, Ruben, and our 2 children, Talon, 30, and Savannah, 28. We also have Freddie D, Savannah's service dog.

We all have our own relationship with Savannah. My husband is a retired Marine and police officer—he is now Savannah's main caregiver. Talon is an EMT who works in the emergency room and is a very caring soul. Growing up with Savannah prompted his career choice. Talon lives across the street, and we see him regularly—he is a wonderful big brother.

#### Savannah has had seizures...

...Since she was 2 years old, but she wasn't diagnosed until the age of 5. LGS evolves over time, which explains her later diagnosis. Savannah had 16 years of uncontrolled seizures and then 10 years of a few seizures a week. She functions at a 2- to 7-year-old level depending on the skill. She is very social and likes to use her vocabulary.

#### Our family mantra is...

"Live in the now."

We try to laugh as much as possible because life is hard. Savannah lives right now; she doesn't fret about the future and doesn't fret about the past. To remind myself to live in the now, I often tell myself to breathe, unclench, and relax.



# WORDS OF ADVICE

## FROM FAMILIES LIVING WITH LGS, DRAVET SYNDROME, OR TSC

It's always beneficial to hear from other families living with rare forms of epilepsy, as they may go through similar challenges. Here, you'll read how 4 families address some very common challenges, like finding ways to spend quality time with your family and embracing your child's diagnosis. **We hope you will find inspiration from their experiences.**



Erin R. with her family | Husband, Leo, daughter, Eloise, and son, Leonel, living with Dravet syndrome



### What does quality time look like for your immediate family?



**LISA S.**  
Mother of Haley,  
living with Dravet syndrome

*In the summers when Haley and the twins were young, we did an annual summer beach week in the Outer Banks. With the twins specifically, I was very aware that although they are twins, they are 2 unique individuals. **When they were small, elementary school age, I made a point of taking them out individually.** Either my husband or I would take them to dinner and a special treat, like a shopping trip or a movie.*



**LISA M.**  
Mother of Evan, living with TSC

*We eat dinner together at the table every night. We also enjoy card games, having a game night, and planning outings for hiking. **Most of all, we laugh together all the time.***



**ERIN R.**  
Mother of Leonel,  
living with Dravet syndrome

*Since we have very young children (and a child who requires constant supervision), we spend a lot of time together. As a family, we like to watch movies, read stories, listen to music and podcasts, play board games, have fun with building blocks, and do puzzles. We are proud Seattle sports fans and enjoy cheering for our teams. **We love evenings around the fire pit making s'mores.***



**TRACY D.**  
Mother of Savannah, living with LGS

*We are a home-based family. We try to hang out together and have fun. We have dinner together with some good food and we have game nights where we do puzzles, play video games, and dance together. Savannah also loves using her play kitchen to make us food. **We have lots of laughs together, and we try to carve out some time to just enjoy each other and the simple things life has to offer.***



### Thinking back to when your child was first diagnosed, how did you embrace the diagnosis and foster acceptance from those around you?



**LISA S.**  
Mother of Haley,  
living with Dravet syndrome

*When we got the diagnosis, Haley was 7 years old and we had been searching and searching for someone else in the same situation. So, when we heard it was Dravet syndrome, we were relieved to finally have a name and were encouraged that there was a community that understood what we were going through. We did not yet know or had digested the full spectrum of her syndrome. **It was just comforting to stop searching and find a "home" and our "tribe" of people.***



**LISA M.**  
Mother of Evan, living with TSC

*As a family, we were very open with our son's diagnosis with our friends and larger family, but it took some time to share all the details with our young children. **We were always open and honest with our answers to their questions, understanding this is what we thought worked best for our family, and that may not be the case for others.** That's okay. We also always alerted our eldest when Evan had an upcoming doctor's appointment to allow time to prepare appropriately.*



**ERIN R.**  
Mother of Leonel,  
living with Dravet syndrome

***A Dravet syndrome diagnosis is not an easy diagnosis to accept or embrace.** We accepted that Leonel had a gene mutation, but we were in denial about the severity of what that meant for his and our family's future. At the time we received his diagnosis, we also learned about the Dravet Syndrome Foundation (DSF). We quickly volunteered to do a fundraiser and were overwhelmed with the outpouring of support from our family, friends, and community at the fundraiser and beyond.*



**TRACY D.**  
Mother of Savannah, living with LGS

*We really didn't have time to embrace it. The seizures took over our lives, and we were just surviving. We had no choice but to accept it. We spent our time trying to keep her alive and safe. We honestly didn't have time to look up and see how others were reacting to our situation. Now, things are more predictable. We have a community of support for Savannah, but it's pretty small. Many don't accept her or know how to interact with her because she is intellectually disabled due to the brain damage from all those years of seizures. **So, we focus on the people who do accept her. And we try to raise as much awareness as we can about seizures, LGS, and intellectual disability.***



Lisa S. with her family | Husband, Bobby, twin boys, Peyton and Parker, and daughter, Haley, living with Dravet syndrome

# Ambassador Programs

Patient advocacy groups are a great resource for you and your family as you navigate the epilepsy journey. These groups can support you by connecting you with other families impacted by epilepsy, finding support services and events in your area, giving you access to the information you may need, and so much more.

Patient advocacy groups also help the epilepsy community stay connected and informed through their ambassador programs. Ambassadors are volunteers who support their community by advocating, empowering, informing, and offering hope and guidance. **On the following pages, you'll learn about some advocacy groups and their specific ambassador programs.**



## EPILEPSY AWARENESS AMBASSADORS

Epilepsy Awareness Ambassadors are passionate and dedicated Epilepsy Foundation volunteers tasked with virtually growing epilepsy awareness across their community. Ambassadors engage in activities that promote all areas of the Epilepsy Foundation's mission to both people living with epilepsy and the general public. Although this ambassador program was initially launched as a way for volunteers to continue spreading awareness about epilepsy despite COVID-19 restrictions, it has now grown into a national and connected community of over 300 ambassadors.

The ambassador initiative is a "choose your own adventure" volunteer opportunity designed to provide options for ambassadors with different interests and availability, allowing them to incorporate epilepsy awareness into their daily life by participating in activities provided by the Epilepsy Foundation. Activities focus on educating their local community through social media, participation in and promotion of Epilepsy Foundation programs and resources, and organization and execution of awareness-based activities and events. The Epilepsy Foundation is constantly in awe and inspired by all the ambassadors accomplish and is tremendously grateful to them for sharing their passion, talents, creativity, and enthusiasm.



**LEARN MORE**  
[www.epilepsy.com/ambassador](http://www.epilepsy.com/ambassador)



Scan the QR code



**LEARN MORE**  
[www.lgsfoundation.org/get-connected-and-supported/connect-with-an-ambassador/](http://www.lgsfoundation.org/get-connected-and-supported/connect-with-an-ambassador/)



Scan the QR code

## FAMILY AMBASSADOR PROGRAM

The LGS Foundation is firmly grounded in the belief that everyone who is living with LGS should have access to the information, resources, and support they deserve, including a connection with others. In 2015, the Family Ambassador Program was established to help build positive and lasting relationships between families who share similar journeys.

Our families are at the heart of everything we do at the LGS Foundation. Being at the center of helping families connect is rewarding for both parties. We are happy to be able to provide access to emotional support, encouragement, and information when needed.

The Family Ambassador Program is made up of family caregivers who have experienced the highs and lows of living with LGS. Our Family Ambassadors listen and support others on the LGS journey while sharing a wealth of helpful resources, tips, and ideas. Our goal is to empower each family to be a strong voice for LGS awareness and become the best advocate for their loved ones. No matter what point of the journey you are on, LGS is life-changing. Our family volunteers are here to support those impacted by LGS.








## DSF PARENT AMBASSADORS

The Dravet Syndrome Foundation (DSF) Parent Ambassadors are fellow parents who have volunteered to help support the Dravet syndrome patient community, and they are integral to the growth and development of our family support and advocacy programs. From helping to plan and execute events to fundraising and supporting the implementation of our programs, our Parent Ambassadors are an irreplaceable part of our community.

Each Parent Ambassador has their own personal experience of caring for a loved one with Dravet syndrome. They are not medical professionals, nor are they trying to be. They are here to offer hope and guidance to those affected by Dravet syndrome by sharing their stories and experiences to reassure families that they are not alone. They have the ability to connect families with one another and guide them regarding local services and resources.

### How do our Parent Ambassadors assist our community?

-  They are available to communicate with newly diagnosed families.
-  They are an ongoing resource for families in need of information or regarding new challenges they are facing.
-  They help to create unity within our community on a regional level.



#### LEARN MORE

[www.dravetfoundation.org/dsf-parent-ambassador-program/](http://www.dravetfoundation.org/dsf-parent-ambassador-program/)

Or email **Erin Reoyo**  
erin@dravetfoundation.org



Scan the QR code



They are a conduit to help families to help them get involved with DSF and stay connected.



They help families better understand the programs and materials that the DSF offers and the work we do.

## THE COMMUNITY ALLIANCE CHAIRS

The Community Alliance Chairs are a key element of the peer-to-peer support and resources offered through the TSC Alliance. They work closely with staff members, especially within the Community Programs Team, to connect families and individuals impacted by TSC to local resources, including educational programming, professional and support services, and TSC Alliance programming. They are also a key part of the TSC Connect program, a network of volunteers who assist in providing the latest medical information, education, and support, as well as awareness to families and individuals impacted by TSC. They are also responsible for organizing social activities like picnics, holiday parties, support groups, or educational sessions with featured speakers.

Community Alliance Chairs also act as the local or regional point of contact for families looking for more information about TSC, and they communicate feedback, community needs, and other asks back to the TSC Alliance, as well as manage an operational budget for community activities provided by the TSC Alliance. Finally, Community Alliance Chairs monitor social media pages, where relevant, to make sure that community members are able to access resources and connect with other families for peer-to-peer support.

Chairs are expected to attend leadership training meetings and the annual March on Capitol Hill each spring and/or participate in government relations efforts. Chairs are primarily supported by the Community Programs team and participate in regular check-ins and training to ensure they are equipped with the necessary resources to support their local communities.



#### LEARN MORE

[www.tscalliance.org/engage/volunteer-opportunities/community-alliance-chair/](http://www.tscalliance.org/engage/volunteer-opportunities/community-alliance-chair/)



Scan the QR code





# From Helpless to **SCIENTIST**

*By Tracy, mother of Savannah, living with Lennox-Gastaut syndrome (LGS)*

The story of a mom who refuses to back down to LGS

“*Being Savannah's caregiver became front and center. Our life consisted of my husband and I trying to keep her from having frequent, non-stop seizures and keep her from having to constantly go to the hospital.*”

**W**hen LGS came into our lives, it completely changed everything. Our introduction to this new world came when our 2-year-old daughter Savannah, who had been totally healthy since birth, had her first seizure. Up until that point, we didn't even know what seizures were. One night, I woke up to what I thought was the sound of Savannah choking in her room. My husband and I thought she must have randomly choked on something in her sleep—until the paramedic uttered something that changed the course of our lives, “**Her airway is clear, but what you just described sounds just like a seizure.**”

That was our harsh induction into the world of epilepsy, and living in that world hasn't been any

easier. It first started with a few seizures, but by the time she was 3 years old, Savannah was having hundreds of seizures a day and multiple types to the point where she had to wear a helmet. By age 4, she began to have clusters of seizures that would last for hours. By age 5, she was seizing dozens of times a day, and delays in her overall development were becoming apparent. **No matter what we tried, these seizures were unstoppable.**

Being Savannah's caregiver became front and center. Our life consisted of my husband and I trying to keep her from having frequent, non-stop seizures and keep her from having to constantly go to the hospital. There wasn't time for anything else.







I realized I didn't have the ability to stop my daughter's seizures, but I did have the ability to continue studying it. Twelve years later, I had earned my associate's degree, bachelor's degree, master's degree, and graduated with a PhD in Neurobiology.

**It is my deepest desire to help the next generation of children like Savannah live a better life.** It has been devastating to watch what LGS has done to my child. She has experienced over 40,000 seizures to date and the condition has left its mark. Her face bears the scars from falls caused by seizures. At age 28, Savannah has the developmental age of a 5 year old. She will most likely be dependent on others for her well-being. I continue to live in fear of Savannah's death. The first thing I do every morning is place my hand on her chest to see if she's breathing.

Even with her circumstances, I often think Savannah is one of the "lucky" ones. Through the years of trying different treatments, we were able to find a treatment regimen that helps her. Savannah will always have her challenges, but she is growing and developing in ways we never thought possible.

And while she will never live independently, she is still thriving. When I look back now, **I wish someone had told me that despite what I'd read, my child would be a beautiful, funny, sassy person who could teach me how to be the best kind of human being I could be.** Even at age 28, with her childlike happiness and infectious giggles, Savannah is the most loving soul I've ever met. **Every day, my daughter fuels my desire and hope of finding a cure for LGS.**

As both a scientist and a caregiver, it is so important to me to share my story—my story of never giving in to the identity of a helpless mom and never giving up the fight to stop seizures. There is a war being waged on LGS both in the lab, with groundbreaking research and new treatments, and at home in the trenches, with each family going to great lengths to care for their loved ones. **No matter how we fight it, we must never surrender to LGS.**

**“ There is a war being waged on LGS both in the lab, with groundbreaking research and new treatments, and at home in the trenches, with each family going to great lengths to care for their loved ones. ”**

At the age of 5, Savannah was diagnosed with LGS, a severe epilepsy syndrome with lifelong seizures. Despite dozens of tests, we did not find a cause for her seizures, and there was no family history or precipitating event. Right after this diagnosis, we started reading everything we could about LGS. We learned that Savannah would have seizures for the rest of her life, and the seizures would cause progressive intellectual disability. And when we found out that she may die young or may not live a full life, we were devastated.

After feeling so helpless following her diagnosis, we picked ourselves up and said, "Okay, this is our life now." I wanted to have an identity other than a mom who couldn't help her child, **so I enrolled in college to be a part of the group of people helping to find the answers to solve LGS.** I attended classes while my children were at school and did my studying while they were sleeping. Soon, I fell in love with the science, and at a certain point, it became my purpose.

### Scan the QR Code



to find more information and support on LGS

or visit [lgsfoundation.org/](https://lgsfoundation.org/)







## Introducing a new interactive resource for individuals and families affected by tuberous sclerosis complex (TSC)

**TSC NAVIGATOR** is an easy-to-use, interactive, online tool to help guide individuals and families through the complexities of TSC across the lifespan, proactively manage their care, and live their fullest lives.

### TSC NAVIGATOR INCLUDES SECTIONS ON:



#### BEGINNING YOUR JOURNEY

Information about prenatal, childhood, and adult diagnosis of TSC to empower you



#### MEDICAL CHALLENGES

Guidance on how to overcome medical access issues and address insurance hurdles



#### SUPPORT NAVIGATORS

A team of professionals to help answer your questions about diagnosis, finding the right specialist, and treatment options



#### RESOURCES

Caregiver and patient resources to support you throughout your journey



#### STORIES OF HOPE

Short profiles of patients living with TSC, from newborns to adults

Scan the QR code to start using this tool or visit [tscalliance.org/TSCnavigator](https://tscalliance.org/TSCnavigator)



# SEIZURES™ ARE SIGNS

Lili, living with LGS, with her dad, John

## A specific diagnosis for uncontrolled seizures can make a difference

### IT CAN OPEN A DOOR

to treatment options from medicine to therapy, help you find patient advocacy groups and resources, connect you with a supportive community of other people who can share their experiences, and much more.

If you or someone you know is still seeking a specific diagnosis, take a short assessment and receive access to:



A customized PDF of your responses and why the questions asked are important to discuss with your doctor



A discussion guide and tips for talking to your doctor about a diagnosis

SCAN THE QR CODE to take the assessment



or visit [SeizuresAreSigns.com/Assessment](https://SeizuresAreSigns.com/Assessment)

# EMPOWERING YOUR CHILD

through transitioning to adult healthcare

*Article and Transition of Care Toolkit provided by the Child Neurology Foundation*

## **It's never too early or too late to begin learning about transition of care.**

As early as age 12, it's important to know how adult healthcare can empower your loved one and what steps to take to learn more. In this article, the Child Neurology Foundation (CNF) shares information and resources about transition of care, including how to prepare, questions to ask, and a downloadable toolkit. We encourage you to save this article and refer to it any time you have questions.

## **What Is Transition of Care?**

Transition of care is the process of discussions and evaluations that begins with a pre-teen's healthcare provider for their eventual transfer to adult medical care. It can be difficult to recognize that your 12 year old will one day become an adult, but this is the age when you should start preparing for this transfer.

For some parents and caregivers, this means preparing your child to become an independent young adult who may move away from home, begin dating, and find employment. For others, this means negotiating the legal challenges of guardianship\* and supported decision-making† in your home state.† Regardless of your family's circumstances, resources are available to support you and your child's move to adult neurology care.



*Transitioning to adulthood is never a one-size-fits-all process for families, but one thing that can be universal is prioritizing your young adult's wishes and goals for their adulthood, beginning with their medical care*



## Where Do I Start?

The CNF, a national nonprofit supporting 1 in 5 children experiencing neurologic conditions and their families, suggests **beginning the conversation about your child's medical transition as early as age 12.**<sup>2</sup> "It's never too late to start the process, but we can be better teammates if we start early," says Dr. Ann Tilton, co-chair of the Transition Project Advisory Committee at CNF and a pediatric neurologist. "Ideally, the transition process with your child's neurologist will center around their needs and goals, and ultimately will improve their communication, decision-making, assertiveness, and self-care skills, enhancing their control and independence over their lives."

## Use the CNF Transition of Care Toolkit

The CNF's Transition of Care Toolkit is a resource you, your child, and your child's clinician can use to prepare for their eventual transfer to adult neurology care. This fillable tool is a conversation guide and resource, asking questions about the young adult's medical history, prescriptions, emergency action plans, and other pieces of noteworthy medical information. Families and their children living with neurologic conditions often share that the most successful transfers of care happen after they have spent many years preparing using the toolkit. This is because the toolkit guides young adults and their families through the multiple parts of the transition process, including the family's expectation of transition, starting the conversation, and completing annual assessments and evaluations about the young adult's medical and social concerns.

## Addressing Challenges

Unfortunately, for some young adults, the transition process and the accomplishment of their medical goals can be complicated by a lack of adult providers who feel confident treating certain childhood-onset conditions or young adults with behavior challenges. This reluctance can be mitigated by early, consistent, and clear communication with the young adult's pediatric provider. Using discussion tools, like toolkits, can drive these conversations in a meaningful way that is helpful for you, your child, and their providers.

Of course, some young adults with disabilities and other complex health needs may not become fully independent. Still, the Self-Care Assessment can serve as a tool for your family and caregivers to determine areas where your child can assert more independence and continue to work on those areas into adulthood. Traditionally, providers and researchers have concluded that patients with intellectual disabilities have a "less successful" transition. **But, by collaboratively working on goal setting with your family, your young adult, and their provider, you can reframe what "success" means for them, resulting in a happier, healthier adulthood.**

For most parents and caregivers, your child will be an adult before you know it. Empowering them to take control over their medical care at a developmentally appropriate rate is one of the best things you can do for your child. It is our best shot at getting them the healthcare they deserve to have the kind of adulthood and quality of life they want.



## Setting Goals With the Self-Care Assessment

(see tear-out)

A particularly helpful section of the transition toolkit is the Self-Care Assessment for youth and young adults, which you can find as a tear-out after this article. **The Self-Care Assessment portion of the toolkit aims to set goals as a family that centers on the young adult's wants and needs.** Intended to be completed annually with caregivers, the Self-Care Assessment evaluates the many aspects of independence throughout a healthcare transition. After a series of clarifying legal questions and personal care questions, the young adult establishes how important specific skills and goals are to them. There are 2 versions of the tool—one that the child can complete and one that a parent or caregiver can complete.

Allowing the young adult to score the importance of their goals for their future highlights which conversations about medical transition require more urgency and dedication. This is particularly true for young adults who are expected to live without complete independence. For example, suppose it's not possible for the young adult to have full control over their medical decisions. In that case, the caregiver can direct their focus to other aspects of the transition that fit the young adult's goals.

The complete toolkit is available at [childneurologyfoundation.org/transitions](https://childneurologyfoundation.org/transitions), or by scanning the QR code



SCAN ME



### References:

1. National Resource Center for Supported Decision-Making. Accessed April 12, 2022. <http://www.supporteddecisionmaking.org/>
2. 8 Common Principles to Assist with the Transition of Care. Child Neurology Foundation. Accessed April 12, 2022. [https://www.childneurologyfoundation.org/wp-content/uploads/2020/10/TransInfoGraphicTools\\_2020-updates.pdf](https://www.childneurologyfoundation.org/wp-content/uploads/2020/10/TransInfoGraphicTools_2020-updates.pdf)

## Identifying Skills With the Self-Care Assessment

The rest of the Self-Care Assessment document focuses on the assessment itself: a series of statements with the individual identifying their confidence in particular facts and skills for navigating medical decision-making. Examples include assessing whether the individual knows how to call their doctor, find their health insurance information, and refill prescriptions. Each topic area emphasizes learning over completion. This is an ongoing process that has taken place over many years, and the assessment is meant to facilitate necessary discussions. Annually revisiting the discussion provides an opportunity to check in and identify which resources an individual needs. These frequent conversations allow you and your child's providers to share tips and tricks for gaining important skills for adulthood. Examples of simple ideas include your young adult keeping a list of their medications on their phone or programming their doctor's office as one of their "favorite" phone numbers.

Ultimately, this document is intended to clarify which parts of the transition process a young adult can take charge of and what aspects they will need assistance with moving forward. By framing these discussions around the young adult's wants, needs, and capacity, you are advocating for them to have a successful medical transition to adulthood where their greatest needs are met.

Along with the Self-Care Assessment, the complete toolkit includes other tools to be completed yearly, such as the Transitions Checklist and Plan of Care.

On the next page, you will find a tear-out of the Self-Care Assessment.

The tear-out will also include a quick guide of the complete Transition of Care Toolkit.



## Helpful Terms From the Article

### \*Guardianship

A legal process that allows an individual to make decisions for a person with disability, including decisions about medical treatment.

### \*Supported decision-making

A way for people with disabilities to make choices about their own lives with support from a team.

# A QUICK GUIDE: TOOLS IN THE TRANSITION OF CARE TOOLKIT



SCAN ME FOR THE COMPLETE TOOLKIT

It's never too early to prepare and think about the future. The CNF has put together a toolkit that you, your child, and your child's doctor can use to prepare for their transition to adult care. Below is a highlight of the specific documents included in the toolkit.

## Assessments and Summaries

Documents to be completed by or in collaboration with the transitioning youth and their parents/caregivers



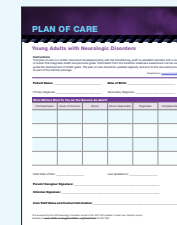
### Self-Care Assessment (Youth/Young Adults)

This document, included in this tear-out, is to be completed by the transitioning young adult to clarify which parts of the transition process they can take charge of and what aspects they will need assistance with



### Self-Care Assessment (Parents/Caregivers)

A version of the Self-Care Assessment for parents and caregivers to complete if their child or loved one has intellectual disabilities that limit or prevent their completion of the Self-Care Assessment



### Plan of Care

A written document for the transitioning youth to set up priorities and a course of action that combines their health and personal goals

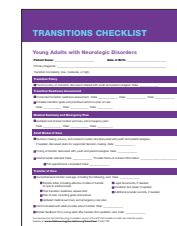


### Medical Summary (Transitioning Patients)

A medical summary of the patient that should be completed by the patient's medical provider in collaboration with the young adult and their caregivers

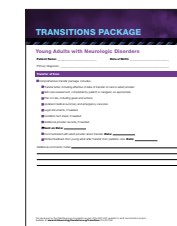
## Checklists

Organized record of items to be checked off as you complete them



### Transitions Checklist

A list to check off the necessary discussions and items that need to be completed throughout the years leading to the transfer

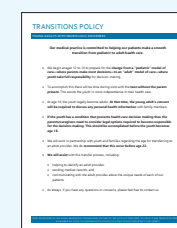


### Transitions Package Checklist

A checklist of everything that is needed for the transfer package

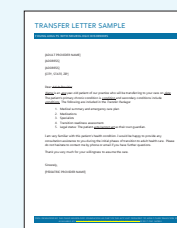
## Sample Documents

Examples of documents that you or your child neurology team should have



### Transitions Policy Example

An example of a child neurology practice's policy that outlines the office's approach to transition



### Transfer Letter Sample

A sample of the transfer letter to be sent to the adult provider




## Identifying Skills With the Self-Care Assessment

The rest of the Self-Care Assessment document focuses on the assessment itself: a series of statements with the individual identifying their confidence in particular facts and skills for navigating medical decision-making. Examples include assessing whether the individual knows how to call their doctor, find their health insurance information, and refill prescriptions. Each topic area emphasizes learning over completion. This is an ongoing process that has taken place over many years, and the assessment is meant to facilitate necessary discussions. Annually revisiting the discussion provides an opportunity to check in and identify which resources an individual needs. These frequent conversations allow you and your child's providers to share tips and tricks for gaining important skills for adulthood. Examples of simple ideas include your young adult keeping a list of their medications on their phone or programming their doctor's office as one of their "favorite" phone numbers.

Ultimately, this document is intended to clarify which parts of the transition process a young adult can take charge of and what aspects they will need assistance with moving forward. By framing these discussions around the young adult's wants, needs, and capacity, you are advocating for them to have a successful medical transition to adulthood where their greatest needs are met.

Along with the Self-Care Assessment, the complete toolkit includes other tools to be completed yearly, such as the Transitions Checklist and Plan of Care.

On the next page, you will find a tear-out of the Self-Care Assessment.

 The tear-out will also include a quick guide of the complete Transition of Care Toolkit.



## Helpful Terms From the Article

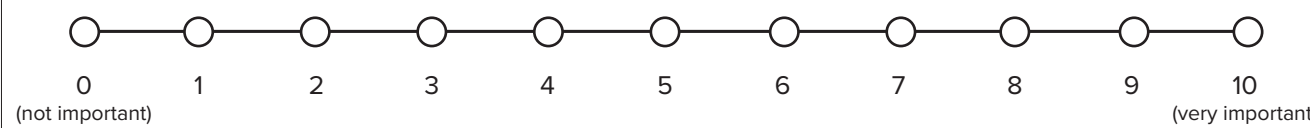
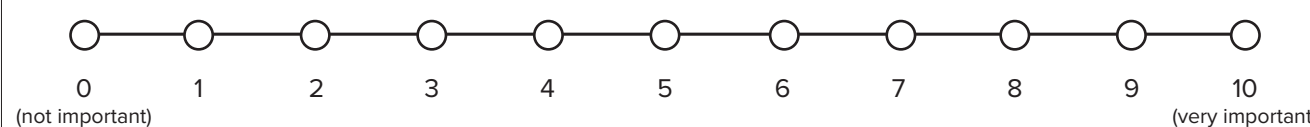
### \*Guardianship

A legal process that allows an individual to make decisions for a person with disability, including decisions about medical treatment.

### \*Supported decision-making

A way for people with disabilities to make choices about their own lives with support from a team.

My Health			
<i>Please check the box that applies to you right now.</i>	Yes, I know this	I need to still learn this	I will need help with this (who):
I know what medical conditions I have			
I know what my medications are for			
I know what to do if I have a medical emergency			
I have an emergency care plan documented			
I take my medicines without someone reminding me			
I know what medicines I should not take			
I know what I am allergic to			
I can name at least 2 people who can help with my health goals			
I can explain to people how my beliefs affect my care choices			
<b>Other Comments:</b>			

Self-Care Importance	
<i>On a scale of 0 to 10, please pick the number that best describes how you feel right now.</i>	
How important is it for you to take care of your own healthcare?	
	
How confident do you feel about your ability to take care of your own healthcare?	
	

### Personal Care

- I care for all my needs.
- I care for my own needs with help.
- I am unable to provide self-care but can tell others my needs.
- I require total personal care assistance.

Using Healthcare			
<i>Please check the box that applies to you right now.</i>	Yes, I know this	I need to still learn this	I will need help with this (who):
I know or I can find my doctor's phone number			
I can make my own doctor appointments			
Before a visit, I think about questions to ask			
I have a way to get to my doctor's office			
I know I should show up 15 minutes before my visit to check in			
I know where to go or call when my doctor's office is closed			
I can provide my medical information to healthcare staff (including a summary of my medical history and emergency care plan)			
I have a copy of my plan of care			
I know how to fill out medical forms			
I know how to ask to be seen by another doctor or therapist			
I know where my pharmacy is and what to do if I run out of my medicines			
I know where to get a blood test or x-rays if the doctor orders them			
I carry my health information with me every day (eg, insurance card, allergies, medications, and emergency phone numbers)			
I have a plan so I can keep my health insurance after 18 or older			
<b>Other Comments:</b>			



SCAN ME FOR THE COMPLETE TOOLKIT

## Young Adults With Neurologic Disorders

### Instructions

This document should be completed by youth and young adults (ages 14 – 25 years old). However, if the youth/young adult is unable to complete this document, their parent or caregiver should fill out the form: Self-Care Assessment (Parents/Caregivers).

### Intent

This form helps document:

1. What you already know about your health
2. What you already know about your healthcare
3. What areas that you think you want or need to learn more about

Today's Date: \_\_\_\_\_

Patient Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Primary Diagnosis: \_\_\_\_\_

Caregiver Name: \_\_\_\_\_ Relationship to Patient: \_\_\_\_\_

Are you the main caregiver? Y  N

### Legal Choices for Making Healthcare Decisions

- I can make my own healthcare choices.
- I need some help with making healthcare choices.  
Name: \_\_\_\_\_ Consent: \_\_\_\_\_
- I have a legal guardian.  
Name: \_\_\_\_\_
- I need a referral to community services for legal help with healthcare decisions and guardianship.

## Greg Grunberg hosts The Care Giver

A series about navigating the complexities of living with rare forms of epilepsy

Greg Grunberg, an actor and advocate for his son living with a seizure disorder, is taking a trip across the country to connect with caregivers and hear their incredible stories.

### Join Greg on an incredible journey of care

- ✓ Meet caregivers of families living with rare forms of epilepsy
- ✓ Hear stories from diagnosis to treatment
- ✓ Find out how other families have advocated for their loved ones
- ✓ Learn the importance of taking the time to care for yourself



*These stories will bring you hope and strength in knowing you're not alone on this journey.*



SCAN ME

Scan the QR code to watch the series or visit

[TheCareGiverSeries.com](http://TheCareGiverSeries.com)





# SIBLINGS SPEAK

## Answers and advice from one sibling to another

In families living with epilepsy, siblings may not always get the spotlight, but they play important roles and are often caregivers themselves. **In this article, we feature 4 siblings who answer questions about their stories, their interests, and their advice to other siblings.** You'll read about the bond they share with their brother or sister and you'll be inspired by their positivity, gratitude, and wisdom.



*"Where there's a will there's a way."*

### William

Age: 17 | Younger brother of John, 18

William's older brother John lives with TSC. William is a high school senior who hopes to study psychology and neuroscience in college. He's also interested in the research of students with autism and other developmental delays like TSC.

#### 1. How has your sibling influenced you?

*Because much of my parent's attention is focused on my older brother John, this has given me room to become more independent. My brother's TSC is what sparked my interest in the brain and led to my exploration of certain aspects of TSC, such as the relationship between genotypes and phenotypes.*

#### 2. What do you enjoy doing with your sibling?

*My brother and I enjoy watching movies and TV shows. **We love watching our favorite shows together, though my brother loves "studying" them on his own too.** We also love playing video games together.*

#### 3. What should people know about you?

*I wish people knew that I enjoy caring for others. At school, I sometimes find myself shutting out others and focusing on my work. I wish I could show these people that **a major part of my life is serving others through the TSC Alliance and other organizations.***

#### 4. What advice would you give to other siblings?

*I would recommend seeking out the help of the TSC Alliance. As part of the Future Leaders Program, I have had the opportunity to speak with numerous siblings and teenagers with TSC and offer advice on how to handle seizures and other stressful situations. **Never be afraid to ask for help!***

#### 5. What advice would you give to parents?

*I would recommend discussing epilepsy with others from the TSC Alliance. From personal experience at TSC events and activities, the TSC community has so much experience in helping others with epilepsy. Because of the wide variety of TSC cases, parents may feel unable to get the help that is specific to their child's needs. Therefore, it is important to ask a lot of questions and look for similarities in other people living with TSC rather than differences.*





## Emily

Age: 18 | Older sister of Caitlin, 16

Emily's sister Caitlin was diagnosed with TSC at age 1. Emily is a sophomore in college majoring in marine and environmental science and minoring in outdoor studies. She's involved in organizations at her school and loves to stay busy with hiking, photography, and dog training.

*"Worrying only makes you suffer twice."*



## Cab & Gabi

Age: 10 & 8 | Older brother and sister of Myla-Rose, 2

Cab and Gabi's sister Myla-Rose was diagnosed with Dravet syndrome when she was around 5 months old. Cab and Gabi both love playing sports. Cab especially loves to play football, baseball, basketball, and soccer, while Gabi loves dance, gymnastics, soccer, softball, and volleyball.

*"Our family is stronger than the storm."*

### 1. How has your sibling influenced you?

Along with the obvious introduction to advocacy and all the beautiful people I've met from working with the TSC Alliance, **I also owe my love for travel, sports, and working dogs entirely to Caitlin.** Caitlin's service dog Zinger pushed me into a love for working dogs. I would never have had the love and respect for the sheer effort and bond that goes into training and working with dogs if it wasn't for Zinger, and I wouldn't have met Zinger if it wasn't for Caitlin.

### 2. What do you enjoy doing with your sibling?

**I love traveling with my sister.** Typically, I'm more of a camper, and Caitlin enjoys staying in hotels. I do enjoy traveling around in hotels and going for drives as well, though nothing beats sleeping in a tent. We also travel to Denali National Park in Alaska occasionally and drive through.

### 3. What should people know about you?

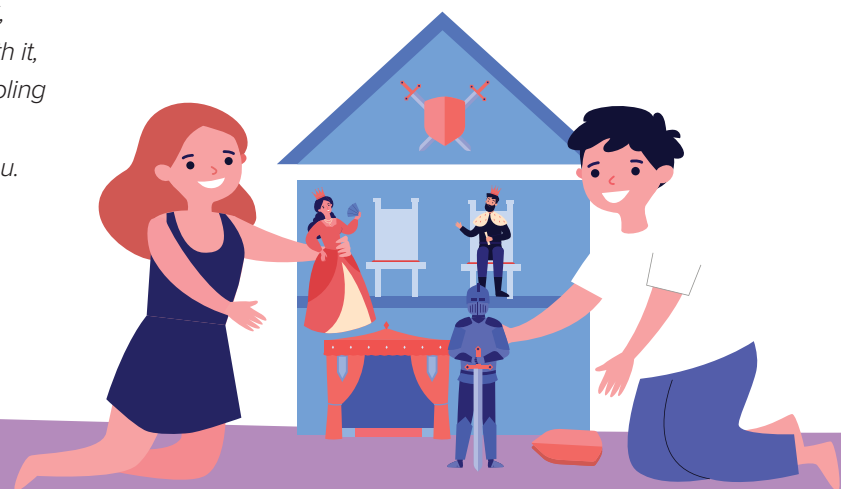
I understand what it's like going through the challenges that come with being a sibling of someone with TSC, and the mental health struggles that come along with it, like anxiety and depression. Even if you are not a sibling of someone with TSC or a person with TSC, if you're struggling, please reach out to someone close to you.

### 4. What advice would you give to other siblings?

Keep yourself busy and active. Find something that interests you and make it a hobby. During tough times, try not to take it personally. **Do what brings you joy and spend extra time taking care of yourself and your mental health.** Try to keep in mind that your parents are trying to care for you and your siblings, even if it feels like they are ignoring you. It will get better.

### 5. What advice would you give to parents?

Though I don't know what it's like to be a parent, I do know every parent tries very hard to provide for their children. My advice is to keep pushing through. If you can find additional resources such as the TSC Alliance, please use them! If you have multiple children and have the capability to distribute your attention to the siblings, please do. **Please also prioritize your own mental and physical health as much as possible.**



### 1. How has your sibling influenced you?

Myla makes me want to spend time with my family more and makes me want to be the best player I can be in the sports I play. –Cab  
Myla makes me want to help her learn. –Gabi

### 2. What do you enjoy doing with your sibling?

I love to dance with Myla and teach her how to play sports like football and basketball. –Cab  
I like to play baby dolls and kitchen with her. –Gabi

### 3. What should people know about you?

I want people to know I'm an athlete. –Cab  
That I am sweet and love to give out hugs. –Gabi

### 4. What advice would you give to other siblings?

I would tell them to stay brave and that they will be okay. –Cab  
It's okay that your sister or brother has seizures. –Gabi

### 5. What advice would you give to parents?

Find the right medicine to help [their child]. –Cab  
Make sure you have an [emergency] bag. –Gabi







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