

## Growing Up, Growing Well: Transition to Adult Medical Care

Dr. Garey Noritz, Complex Care

Happily, the vast majority of children with severe illnesses in childhood will grow up and become adults. Many diseases, previously only known within Pediatrics, are now associated with longer and better lives. These include Cystic Fibrosis, Sickle Cell Disease, Duchenne Muscular Dystrophy and many others.



medical care and takes more responsibility for managing their own lives. This includes things like knowing which medications they take, why they take them and how to order refills, how to make an appointment to see the doctor and report symptoms and how to choose what

kind of care they want to get. “Transition” is also an important task for the family, as they need to let the child learn these skills. Sometimes, that is the harder part of transition!

Our success in treating these illnesses has presented us with new challenges — namely to plan the transition and transfer of care out of the children’s hospital to physicians, hospitals and systems that specialize in treating adults.

On the other hand, “transfer” of care is the process in which a patient leaves the pediatric health care system and enters the adult world. This should be planned, deliberate and individualized. The timing and method for this is likely to be different for each condition and clinic.

The American Academy of Pediatrics recommends that these discussions begin quite early, as early as 12 years of age. This is a process that continues until the adolescent has established care with “adult” doctors and is thriving in the adult system. This may not happen until beyond the age of 18 or 21.

Since there are many different adult hospitals that serve our area, your team at Nationwide Children’s Hospital should work with you and your family to identify the best adult team to take care of you.

First, some definitions: “Transition” is the process in which a child learns the important aspects of their

[Continued]

---

### IN THIS ISSUE

Growing Up, Growing Well: Transition to Adult Medical Care.....	1-2
A Parent’s Perspective: Transition to Adult Care.....	2-3
MyChart Makes Life Easier for Families.....	3
Big Lots Behavioral Health Pavilion Coming Soon.....	3-4

Know Your Colors! .....	4
Connecting Families: Peer Mentors Offer Guidance and Support.....	5
Partners in Care, Partners in Hope Award.....	6
Attend the Annual Pediatric Homecare Conference.....	6



**NATIONWIDE CHILDREN'S**  
*When your child needs a hospital, everything matters.™*



They should transfer records, discuss important health information, and be available to smooth any bumps during the transfer process.

This kind of discussion is often stressful for patients, families and their doctors.

We've worked hard to build valuable relationships over time; as doctors, we miss patients and families when they have moved on. Transition and transfer will happen at a different pace depending on the underlying condition, the preferences of the doctor and family, and the developmental level of the patient.

A great resource for patients, families, and physicians can be found at [GotTransition.org](http://GotTransition.org). This website has tools to help adolescents and families thrive through this process. If your medical team has not begun these discussions with your adolescent, please ask them to help plan their next phase of care.

---

## A Parent's Perspective: Transition to Adult Care

Jen Welday, Parent

My son Caleb has been a patient of Nationwide Children's Hospital for more than 19 years. He is one of triplets who were born three-and-a-half months early. After seven months of NICU and step-down care, he came home with a VP shunt, a feeding tube, on oxygen and with developmental delays. Eventually he was diagnosed with cerebral palsy and epilepsy. Through the years, I became a "Caleb expert." I knew all about the diagnoses, medications, therapies and habits that, in conjunction with his medical care team, helped Caleb thrive at home.

And then, all of that expertise was put on the back-burner as we were introduced to a new concept. It was in middle school that we first heard the word: Transition. It's a common word, really, but in the world of special needs, it's a heavy, important word. At this point, it really only related to Caleb's

education. How will his move to high school look? Would he participate in regular education or special education programming? School administrators told us that when he turns 14, he transitions onto the Individualized Education Program (IEP) team. What will his contribution be? What happens after his four years in high school? He can remain in public education until he turns 21 or 22, but then what? We have options such as college, a day program or working. What would his living situation look like? So many questions!

And then, the word cropped up in relation to his medical care. Will we transition his medical decision making power to him, or retain it for ourselves? Because in some capacity, he functions at a grade school level, our family had to ponder the decision to pursue guardianship. In order to continue to assist Caleb with his medical care, I became his legal guardian. This is essential with HIPPA (Health Insurance Portability and Accountability Act). Another question was asked of us: When will he transition to adult care?



The Welday Family. Back row: Sarah, James and Joey. Front row: Rob, Caleb and Jen.

Hold on... We have to leave Nationwide Children's? That cocoon of family-centered care will no longer be an option? Well, honestly, that is frightening. At every specialist visit after Caleb turned 18, I asked when that transition will happen. Surprisingly, each department had their own timeline.

[Continued]

Some say we can stay on their service until he turns 21 or 22. Another told us we should start the process of finding a new doctor when Caleb nears 30. I realize now we will need to create a “Caleb Transition Plan” for our family, complete with lists of possible providers, target dates for the transition, and tasks that will be required to make the moves. We plan to work with Caleb’s current providers to help make the transition as smooth as possible.

---

## MyChart Makes Life Easier For Families

Do you use MyChart? MyChart gives patients and families even greater access than ever before to their health information. This helps them take a more active role in improving and managing their health from any location at any time. Here are some reasons to use the tool:

- 1) Save time. Log on any time of the day and send a message to your child’s care team at your convenience, instead of calling during office hours.
- 2) View and print your child’s eye prescriptions to order glasses or contacts.
- 3) Keep track of past and upcoming appointments within MyChart.
- 4) Need a copy of your child’s school excuse or gym absence letter? Print a copy of provider letters at your convenience.
- 5) Review test and lab results quicker than waiting for a phone call.
- 6) View the full picture of your child’s health. Keep a record of medications, allergies, immunizations, current health issues, additional information, visit notes and instructions all in one place.
- 7) Schedule and cancel primary care appointments on your mobile app or desktop.
- 8) Request prescription refills. Send a refill request for any of your refillable medications (some limitations apply).

- 9) MyChart holds other great resources to help you manage your child’s care. From a pediatric health library to links to Nationwide Children’s 700 Children’s blog and information, exploring this site can benefit you.
- 10) Don’t have a MyChart account for your kids yet? Now you can sign up for one online and start the quick process of setting up your free account without the need for an activation code.



Make your life easier at  
[MyChart.NationwideChildrens.org](https://MyChart.NationwideChildrens.org)

---

## Big Lots Behavioral Health Pavilion Coming Soon

In June, Nationwide Children’s Hospital broke ground on the Big Lots Behavioral Health Pavilion. Thanks to a transformational \$50 million gift from Big Lots, it will be American’s largest behavioral health treatment and research center just for children and adolescents on a pediatric campus. The Pavilion is slated to open in 2020.

[Continued]

On the first floor, you'll find a first-of-its-kind Psychiatric Crisis Center dedicated to treating behavioral health at a children's hospital.



A rendering of the Big Lots Behavioral Health Pavilion.

The Pavilion is designed with our families and our community in mind. With 386,000 square feet, open spaces will be a key part of therapy and treatment with a focus on natural light to help with the healing process. On the top level, patients will have a multifunctional rooftop play area. Creatively designed peaceful courtyards will bring the outdoors to our patients.



The proposed rooftop play area.

The building will feature 48 inpatient beds with capacity for more in the future. Five outpatient programs will also be featured (Outpatient Crisis Clinic, Mood & Anxiety, Family Based Intensive Treatment, General Psychiatry and a Partial Hospitalization Program), as well as The Center for Suicide Prevention & Research.



A rendering of an inpatient room.

**You can learn more and experience the virtual tour of the Big Lots Behavioral Health Pavilion at [Nationwide Childrens.org/Pavilion](https://www.nationwidechildrens.org/Pavilion). And, join the discussion using the hashtag #starttheconvo. Together, we can break the stigma.**

## Know Your Colors!

Did you know groups of our clinical staff wear uniform pants in certain colors to help identify their role? Here's who you'll find wearing what:

- Registered nurses wear marine blue pants
- Respiratory therapists wear dark grey pants
- Unit coordinators wear purple pants
- Licensed practical nurses wear cranberry pants
- Patient care assistants wear green pants.

Knowing these colors can help you identify the type of clinicians on your care team.



# Connecting Families: Peer Mentors Offer Guidance and Support

Amanda Kennedy, Connecting Families Program Coordinator

When a family learns their child has a serious medical condition, they grapple with what a new “normal” will look like. Next steps can seem overwhelming and isolating. Because of how life-changing this experience can be, the Connecting Families Program at Nationwide Children’s Hospital provides emotional support and helps calm the fears of parents and patients as they start their journeys. Connecting Families trains parents and adult patients to become peer mentors. These volunteers are then matched with other families so they can listen to their story, provide wisdom, normalize feelings and concerns, and answer questions about how to navigate hospital and community systems.

The program began in 2013 as a hospital-wide peer mentoring effort after the GI Clinic and the Heart Center had established their own peer support services. Chief Nursing Officer Linda Stoverock, along with invested parents and a hospital steering committee for the program, championed the cause to make Connecting Families available to any family in the hospital who could benefit from participating. Since then, mentors have become active in 40 different specialty areas around the hospital, including the NICU, endocrinology, neurosurgery, oncology and cerebral palsy. The program has more than 100 active parent and patient mentors who live both in and out of Ohio, and 390 mentor-mentee matches have been made in the past two years.

While matches are often made based on similar diagnoses, parents can request a mentor for other reasons. They may have questions about an upcoming surgery or new course of treatment, how to bond with their newly adopted child while learning about their medical needs, or how to work with their child’s school on IEP or 504 plans. Mentors and their mentees communicate via email, phone, or in person. Where a family lives doesn’t

limit the ability to participate – for instance, a mentor from South Carolina was recently matched with a mentee living in California.

The meaningful contact Connecting Families provides is evident in the words of the program’s mentors and mentees. One mentor shared, “I...thoroughly enjoyed connecting with a mother, father and grandmother who just needed some hope that their child would live and be able to thrive in an otherwise difficult situation. Sharing my daughter’s story...gave them hope that their son would also be able to get past this early phase of extreme medical distress to live a fully functioning life.”



And a mentee stated, “My mentor has been amazing! Very supportive! She has been helpful with ideas and suggestions on people to talk to and how to solve problems. She has been exactly what I needed. Our children have similarities and major differences and that has never gotten in the way.”

Connecting Families believes that every family deserves the support of someone else who truly understands their experience.

**If you would like to find out more about becoming a mentor or getting a mentor through Connecting Families, please contact Amanda Kennedy, Connecting Families Program Coordinator at (614) 722-6747, or visit our website: [NationwideChildrens.org/ConnectingFamilies](http://NationwideChildrens.org/ConnectingFamilies)**

# Partners in Care, Partners in Hope: Family Advisory Council's Award of Excellence in Family Centered Care

The Family Advisory Council at Nationwide Children's Hospital is pleased to announce the annual Partners in Care, Partners in Hope Award of Excellence in Family Centered Care.

This award will be presented to an employee, health care provider or department of Nationwide Children's Hospital in recognition of their outstanding achievement in care that reflects excellence in the core concepts of family centered care. Patients and/or family members of patients who have been treated at Nationwide Children's are invited to submit nominations.

## Core concepts and criteria by which nominees are judged:

**Dignity and Respect** – Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

**Information Sharing** – Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

**Participation** – Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

**Collaboration** – Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation: in health care facility design; and in professional education, as well as in the delivery of care.

The Partners in Care, Partners in Hope Award will be given at the Annual Employee Recognition Dinner and Awards Ceremony in January. Nomination forms are available in the Family Resource Center or online. **The deadline for nominations will be December 1, 2017.**

Recipients will receive a beautiful piece of artwork designed and created by a local artist with a connection to Nationwide Children's Hospital. Selection will be by the Partners in Care, Partners in Hope Award Committee composed of patients, caregivers, family members and select staff members.

Visit [NationwideChildrens.org/Partners-in-Hope-Partners-in-Care](http://NationwideChildrens.org/Partners-in-Hope-Partners-in-Care) to learn more.

## Attend the Annual Pediatric Home Care Conference

The 2017 Pediatric Home Care Conference at Nationwide Children's Hospital is taking place on Thursday, November 2 from 8 a.m. to 4 p.m. The focus of this year's conference is Patient and Family-Centered Care in the Home. Speakers include Juliette Schlucter, nationally known for her leadership in Patient-Family Advocacy, and Nationwide Children's Director of the Complex Health Care Program, Dr. Garey Noritz. Families, don't forget you can recommend your current home health company to attend. **If you are interested in attending, visit <http://tinyurl.com/pedshomecare> to RSVP.**