

Pediatric to Adult Healthcare Transition for Children with Developmental Disability

As patients with developmental disabilities get ready to transition from pediatric to adult care, it's important for families to understand that the adult model of care is different.

Starting at an early age, teach your child about their body and areas that need special attention. Each child has their own way to communicate so choose a method that works for your family.

HELPFUL TIPS

Personal safety

- Teach your child how to communicate their name and how to reach caregivers. This can be out loud or by pointing to a medic alert bracelet
- The alert bracelet should have patient name, date of birth, allergies, and name and contact number for their caregiver
- They should also have a printed medical summary with them
- You may consider a safety tracker App on your phone that can track their location. One example is called Life360
- If the caregiver is the patients' only form of communication, consider having an "in case of emergency" (ICE) number in your phone for an alternative person, when the caregiver isn't available

Learning

- Using pictures can help children with developmental disabilities understand information
- Use a visual schedule to build routines. This helps children cope with change and increases their ability to do tasks independently
- Make a schedule for morning and bedtime routines to build habits around taking medicines and personal hygiene.
- A picture schedule for taking medicine, brushing teeth, and medical chores such as GT cleaning and catheter care, can help children remember how to do each task
- Repeating these routines every day is important for building habits
- Your child's behavior, speech, and occupational therapists, or teacher can also help with using visual cues and schedules

Communication

- Use the same words each time to name body parts or medical equipment. For example, the feeding tube is always a "GT" or "your tube" and the stomach is always "their tummy" or "their stomach".
- Use simple words for medicines and what they are used for
- Go over their medical condition and how treatments work
- Have your child practice talking with family members and their care team about their condition
- Encourage your child to slowly take on the responsibility for communicating with their care team

Be prepared

- A medical summary is helpful for both the caregiver and patient to always have on hand. The summary must include diagnosis, medicines, allergies, doctor's names, and important phone numbers.
- Teach your child how to tell someone they aren't feeling well. Use words they can repeat in the future or nod in agreement to describe changes in their health

Caregiver responsibilities

- Caregivers must ask for access to a child's health record after the legal age of adulthood (usually 18 years)
- This includes a letter from the child's doctor saying they meet the criteria for sharing health information with a caregiver
- Medical Durable Power of Attorney (MDPOA) is a legal document that gives permission to another person to make medical decisions if the patient can't speak for themselves
- Guardianship a legal process where an adult is chosen by a judge to make medical and other decisions for the patient. This process can take a long time and should be started before the patient turns 18.

Useful Links

- GotTransition (National Center for Transition Support and Information)
www.gottransition.org
- Children and Young Adults: <https://www.gottransition.org/youth-and-young-adults/>
- Parents and Caregivers: <https://www.gottransition.org/parents-caregivers/>

Driving

Organizations that check cognition, reaction time, reflexes, and other skills needed for driving

- Spaulding Rehabilitation Center has a driving exam program (<https://spauldingrehab.org/conditions-services/driving-assessment>)
- Penrose-St. Francis Hospital Fitness to Drive program offers clinical checks plus behind-the-wheel tests for people with disabilities (www.centura.org/Locations/Penrose-St-Francis-Health-Services/medical-services/rehabilitation-services);
- Driver Safety Consultants Inc. offers clinical checks plus behind-the-wheel exams for people with disabilities (www.adulldriverservices.com)
- Rocky Mountain Therapy offers an OT test/pre-driving/cognitive skills check, and behind-the-wheel exams (www.rockymountaintherapy.org/adaptive-driving) for Wyoming
- Shift to Independence offers a driving test and training program with a three hour clinical exam plus behind-the-wheel exams (www.shiftoindependence.com) for the Western slope

childrenscolorado.org

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Public Transportation

The public transportation system for metro Denver, RTD, has services for people with disabilities. This includes classes for groups as well as personal trainings on-site. To learn more, please visit: <http://www.rtd-denver.com/Accessibility.shtml> or call RTD Training at 303.299.6071