

Transitioning from Caring for a Child with Special Needs to Adult Life



The transition of a child with special needs to adult life is a gradual process that seeks to prepare the young person and their family to manage their health with greater confidence and independence. With support and proper planning, continuity of care is ensured and the young person's ability to assume responsibilities related to their well-being is encouraged..

What is transition of care?

Transition of care is a planned and gradual process in which a young person transitions from the pediatric system of care to the adult system. This process not only involves changing doctors, but also gaining skills to manage your health, understand your condition, and be able to make informed decisions about your own care.

Why is transition important?

- It improves the autonomy and responsibility of the young person in their medical care.
- Enables adequate access to health services for adults caring for chronic or complex conditions.
- It reduces gaps in care when the young person stops seeing pediatricians.
- Prevents health complications by ensuring continuity of care and treatment.

When to start the transition process?

The transition does not happen quickly. Some general recommendations are:

- Initiate early planning, ideally from the age of 12, to prepare the young person and their family.
- Effective handovers to adult care usually occurs between the ages of 18 and 21 years, depending on the preparation and individual needs of the young person.

What should the process be like?

1. Gradual planning:

Starting early allows the young person to develop:

- Self-care skills.
- Understanding your medical history.
- Confidence to communicate with providers.

2. Education and self-care skills:

The young person must learn to:

- Schedule appointments.
- Understand medication instructions.
- Explain your health condition.
- Know your insurance coverage.

Important things to consider:

- **Before transitioning**, parents are often the ones who manage appointments and explain symptoms.
- **After transition**, the young adult is directly responsible for his or her health.

Support for families: Family and caregivers remain key as:

- Consultants and support.
- Help in complex or new situations.
- Facilitators of communication with suppliers when necessary.

Common Challenges in Transition

- Lack of preparation or structured support.
- Differences in how pediatric and adult services are managed.
- Anxiety or insecurity of the young person when assuming new responsibilities.
- Barriers to securing adult physicians with experience in your condition.

Practical recommendations for a successful transition

- Start conversations early and with the participation of the young person.
- Create a plan with clear goals and review progress annually.
- Include self-management skills in the young person's routine.
- Make sure the young person is aware of their medications, allergies, and medical conditions.
- Identify adult clinicians who can address your specific needs.



Social and Emotional Aspect

For tips, tools, and resources on how you and your family can cope with the emotional and physical concerns that arise during and after your medical treatment, please visit your primary care physician or call the following phone lines:

Medical Advice Line:

1-844-347-7801

TTY/TDD 1-844-347-7804

APS Health

787-641-9133

References:

<https://rcml.rcm.upr.edu/familycenter/transition-de-salud/>
<https://together.stjude.org/es-us/emotional-support-daily-life/transition-to-adult-health-care.html>
<https://www.cdc.gov/heart-defects/living-with/transitioning-from-pediatric-to-adult-medical-care.html>
<https://www.mass.gov/health-transition-for-youth-and-young-adults-with-special-health-needs>
<https://www.ncdhhs.gov/divisions/child-and-family-well-being/whole-child-health-section/best-practices/pediatric-adult-health-care-children-special-health-care-needs>

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