Checklist for Transitioning to Adult Healthcare

Someday your child will need to transfer their care to doctors and other providers who see adults. Maybe this moment seems like a long way away, or feels like it's just around the corner. Wherever you are, planning ahead for this transition will help make this big change smoother and easier.

This checklist was made by parents of children who have gone through the process of transitioning to adult care. It was created to help you know what to expect and how to plan. Some questions may apply to you and some may not.

Use this checklist as a tool to talk with your child's providers. Your child and family will have unique needs for transition that are best planned for with your current providers. It also provides suggestions and resources to help you and your family.

Tips for using this checklist

- Take your time. Ideally, this process will occur over a period of years.
- Start these conversations with your child's providers starting around age 13. Include your son or daughter as much as possible and appropriate for them.
- Take this checklist with you to clinic visits and start asking questions that you need help with.

Planning the move to new providers and clinics

- ❑ What are all the clinics and departments where my child receives care?
- ❑ For each of these specialties, where will they receive this care as an adult? (Where will my young adult be living? What will their insurance be? What is important to them in this choice?)
- ❑ What medical records will need to be transferred, and how is this done?
- ❑ Is there information that may not be part of the medical record, but is important for the new provider to know? (i.e., my child needs sedation for blood draws or my son needs a sign language interpreter).
- ❑ When and how will this information be communicated to the new provider?
- ❑ Keep in mind it may take up to a year to get into see an adult specialist for your child so you may need to schedule this appointment well in advance of their transition.

Tip: Visit www.gottransition.org for resources to help you and your doctors plan this transfer of care. They have sample care plans, transfer letters, medical summaries and emergency care plan forms.

Preparing to manage adult care

- ❑ Who will be my young adult's primary care provider (PCP)? What role are they prepared to play in coordinating and managing their care? How important is it that they understand my young adult's conditions and diagnoses?
  (Even if your child does not currently have a primary care doctor, in the adult care system the PCP often plays a key coordinating role. If your child's PCP is a pediatrician, they will need an adult provider for primary care.)
- ❑ At age 18, will my young adult be managing their own care, or do they have developmental, mental or cognitive disabilities that mean they will they need a legal guardian or other form of support?
- ❑ How do I transfer or manage prescriptions if my young adult can't?
- ❑ How will our current provider help my child develop self-management skills and maximize their independence in managing their medical care?
- ❑ What advocacy might my young adult need for their healthcare (for example, needs medication or sedation for procedures such as blood draws)? Will their PCP help advocate for them?
- ❑ If my young adult is not independent, who is involved in their care (parent or guardian, group home or agency, etc.)? Have their respective roles and responsibilities been clearly defined?

Planning for emergencies

- ❑ Are there special considerations if my young adult needs emergency care?
- ❑ What information will care teams need to best treat and support my young adult in an emergency? How will this information be conveyed (medical bracelet, wallet card, smartphone, etc.)?
- ❑ Is it best they be taken to a specific place? What records should they have in advance? Will they take records in advance? How do I arrange this?

Understand healthcare privacy laws

Beginning at age 13, youth gain rights with respect to consent and confidentiality for certain kinds of care. Talk to your teen's care team to learn more about what this means for you and your teen.

Resources

Tools to share with your current providers:

- A plan can be developed with you, your child and their current provider to set priorities that integrate their health and personal goals. Examples include the "Transition Plan for Teens" from cshcn.org/teens or "Plan of Care" from gottransition.org

Free Interpreter Services

- In the hospital, ask your child's nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

- The "Transfer of Care" letter, "Medical Summary" and "Emergency Care Plan" forms from gottransition.org can be filled out by your pediatric providers and shared with future medical and other care providers.

Assessing you and your child's readiness for transition:

- Health Management Skills Assessment for Youth- Center for Children with Special Needs at cschn.org
- Transition Readiness Assessment for youth – gottransition.org
- Readiness Assessment for parents and caregivers – gottransition.org

Medication management

MyMedSchedule.com allows users to create their own printable medication chart with pictures of their pills and set up text or email refill reminders. Could be used with an adolescent learning to manage their medications.

For youth with intellectual and developmental disabilities

Available at www.arcofkingcounty.org:

- Transition from School to Adulthood (covers SSI, SSDI, DDA services, employment supports, legal information, school-to-work, medical coverage, care, respite and housing)
- Transition Planning Checklist for Life After High School
- Guardianship Information Packet
- Special Needs Trusts & Wills Information Packet

Available at www.informingfamilies.org:

- Supported Decision Making: Alternatives to Guardianship

Spanish resources

- Planificación Para la Vida Después de la Escuela de www.informingfamilies.org
- Información para jóvenes y familias de gottransition.org/youthfamilies/indexES.cfm

Available at www.floridahealth.gov/AlternateSites/CMS-Kids/kids_teens/teens/transitions:

- Ahora que Ud. está en la Escuela Secundaria: Es Tiempo de Tomar mas Responsibilidad de Salud
- 10 Pasos para una Transición Exitosa de Atención de la Salud

Seattle Children's offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children's will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

This handout has been reviewed by clinical staff at Seattle Children's. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's healthcare provider.

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