

Transition From Pediatric to Adult Medical Care

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Defining Transition

A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems.



It is a process, not a single point in time.

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Objectives

- Preparing to become an adult in the medical setting
 - Health behaviors
 - Health care behaviors
 - Logistics
- Working with your pediatric providers
- Determining who needs to be on your adult medical team
- Finding providers
- Initiating contact with a new provider/practice
 - Troubleshooting challenging situations

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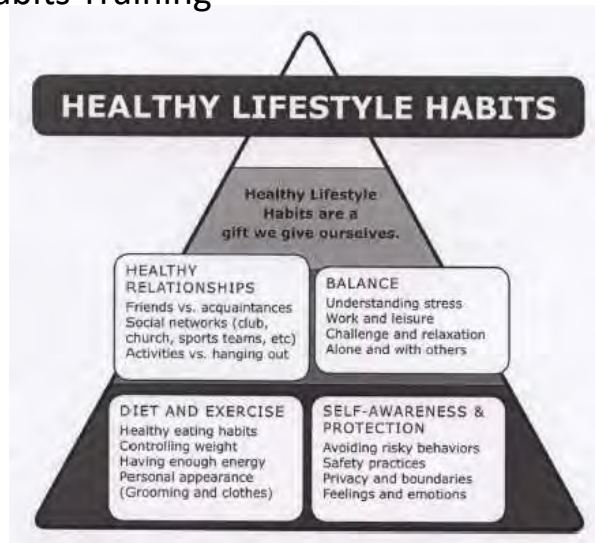
Becoming an Adult in the Medical Setting – Health Behaviors

- Set expectations for healthy habits early
- “An ounce of prevention is worth a pound of cure.”



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Health Habits Training



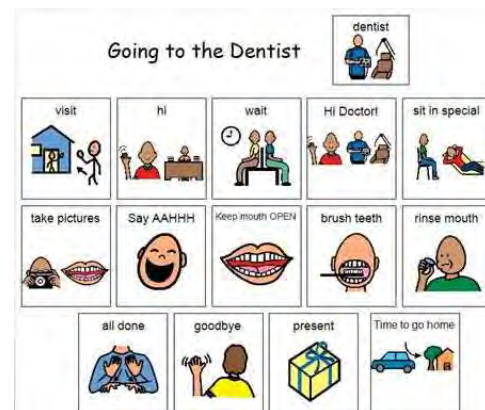
From Journey to Adulthood: A Transition Travel Guide
 Developed by: Shriners Hospital for Children, Lexington

<https://chfs.ky.gov/agencies/ccshcn/Documents/TransitionBookDecember122011Final100pages.pdf>

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Becoming an Adult in the Medical Setting – Health Care Behaviors

- What does your child need to prepare for a visit?
 - Pictorial schedule
 - 2 hours/days/weeks notice
 - Something to help transition from typical daily activity that has been interrupted



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Becoming an Adult in the Medical Setting – Health Care Behaviors

- What does your child need to prepare for a visit? (continued)
 - Is there a planned procedure or lab draw that requires premedication?
 - Please don't make promises you can't keep
 - Identify, with your child what the goals of your visit are, make a list and bring it



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Becoming an Adult in the Medical Setting – Health Care Behaviors

- What do you (the parent or caregiver) need to prepare for a visit?
 - Arrange a specific time to minimize wait-room time if needed
 - Anything else that may be needed should be packed, depending on your and your child's needs
 - Medical information: current medication list, any changes to medical history, information about any new providers or ER visits.
 - Bring your written list of goals and topics you want to cover.
 - Depending on the length of the list, be prepared that you may not cover all the things on your list



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Becoming an Adult in the Medical Setting – Health Care Behaviors

- What does your child need to wait for the visit?
 - Do you need to request AHEAD of time that the office staff attempt to minimize waiting room time or waiting in the exam room.
 - Usually the first appointment of the morning or afternoon is the easiest way to accomplish this
 - Bring entertainment
 - Tablets and phones are fine
 - Please be prepared to have your child shut them off (and preferably turn your own off!) during the visit with your provider- this is your time to accomplish your visit goals



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Becoming an Adult in the Medical Setting – Health Care Behaviors

- During the Visit
 - Please encourage your provider to directly address and interact with your child at their level of understanding and ability
 - Please allow your child to be directly addressed and respond at their level of ability
 - This will allow them to develop trust and bond with the health care provider, and express any fears or concerns they may have
 - Your healthcare provider may wish to speak to your child alone, dependent on their ability to communicate



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Becoming an Adult in the Medical Setting – Health Care Behaviors

During the Visit (continued)

- Give tips and tricks to the health care provider to help them optimally examine your child
 - Do you know they always want to have their ears checked first? Do you know tricks that have been used in the past that have worked well?

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Becoming an Adult in the Medical Setting – Health Care Behaviors

• During the Visit (continued)

- If your child needs shots or labs drawn:
 - Please do not present it as a punishment or a negative thing (this is part of keeping you healthy)
 - Please share tips for staff attempting to do these things- specific language to use, interventions and distractions that have worked in the past
 - Be open to needing to desensitize your child - they may need to be introduced to the environment and sit in the lab chair then come back next week to have labs drawn

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Becoming an Adult in the Medical Setting - Changing roles during Transition

	Age and Time		
	Early	Increasing Age	Increasing Age
Provider	Major Responsibility	Support Parent/Family and Young Person	Consultant
Parent	Provides Care	Manager	Supervisor
Young Person	Receives Care	Participant	Manager

Adapted from <http://www.sickkids.ca/good2go/>

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Becoming an Adult in the Medical Setting – Logistics

- **Medical Decision Making**
 - Please be clear on who can and cannot make decisions for your child
 - Bring up to date documentation and offer to share it with office staff
 - Make sure the appropriate person is signing the consent forms
 - If your child is their own guardian and you are not a durable power of attorney, but they wish for you to be able to receive information from the doctor's office, please ask that your child sign a release of information for you
 - This is good for 12 months after signing, but can be revoked at any time by the person signing it

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Becoming an Adult in the Medical Setting – Logistics

- Insurance
 - Bring your insurance card to every medical visit and pharmacy visit
 - Or have your child carry their card
 - Your child can stay on your private insurance (such as employer provided insurance) until the age of 26 years
 - Speak to your HR representative about whether you can continue to keep a dependent adult child on your insurance beyond age 26 years
 - Having Medicaid as a secondary (if you have private insurance) may help pick up co-pays and other costs not covered by your primary (private) insurance.

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Working with Pediatric Providers

- Early Adolescence
 - Encourage your child to be as independent as possible- asking the provider questions and allowing time to speak to them by themselves
 - Ask your provider(s) about what their transition policy
- Mid-adolescence
 - Confirm transition policy
 - Start a transition plan which should include what providers are needed for your child's medical neighborhood, timing of different transitions and discussions about decision making support needs
 - Consider asking your own primary care doctor (parent/caregiver's PMD) if they are willing to see your child when they become an adult, discuss timing

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Working with Pediatric Providers

- Late adolescence-early adulthood
 - Ask your peds provider if there are adult providers that they recommend and can assist in connecting you to.
 - Follow up on unmet needs in your transition plan
 - Ask your pediatric provider their policy and process for transfer of medical records
 - Ask do they prepare a portable medical summary
- Make clear plan for timing of transfer so you are not scrambling to get medications refilled, or a form completed for work/school

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Determining who needs to be on your adult medical team

- Who are your pediatric providers?
 - Not all pediatric providers have a parallel adult provider
 - For example, developmental pediatrics
- Discuss with your child's PCP and specialists what their ongoing medical needs will likely be
 - If your child already has an adult PCP, this is the perfect person to talk to!
- Discuss whether there are specialties they will not continue to need in adulthood
 - For example, adult PCPs may be more comfortable managing certain chronic medical conditions without specialist support or with less specialist support

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Determining who needs to be on your adult medical team

- Identify conditions and problems your adult PCP or specialty provider may not be comfortable managing
 - Discuss with your pediatric provider how to proceed
 - Do you need to find another provider to manage a specific problem?
 - For example, for behavioral medications, your developmental pediatrician may recommend you follow with psychiatry



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Finding providers

- Ask your pediatric provider who they recommend
 - Ask friends, other parents and family members
 - Ask your (the parent's) primary care provider
 - Go to your insurance company website and do a provider search based on your preferred criteria
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- <https://illinoisap.org/wp-content/uploads/2020/01/Finding-Adult-Providers.pdf>
 - <https://chfs.ky.gov/agencies/ccshcn/Documents/FindingAdultCa>

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Finding Providers

- Think about your child's physical needs
 - Handicap accessible buildings (okay to drive by before calling to see what you think)
 - Wheelchair accessible scales
 - Exam table that lowers so your child can easily get on it for a visit and examination
- Think about your child's emotional needs
 - Do they have processes in place to immediately bring your child to the examination room when you arrive for a visit - or willing to develop one?
 - Do they have staff willing to move slowly through giving a shot or drawing blood if needed, or to help desensitize your child

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Initiating Contact with a New Provider or Practice

- Be friendly to staff that answers the phone!
 - You catch more flies with honey than with vinegar...
- If you are your child's guardian, you can call and tell them you would like to schedule a new visit, explaining that you are the adult's legal guardian
- If your child is their own guardian, have them call and you can support them if they get stuck
- When you call to schedule the first time, if you have private insurance, give the name of that insurance to the receptionist FIRST, then when they ask if there is secondary insurance you can give them the Medicaid information

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Initiating Contact with a New Provider or Practice

- Know that it may take a few months to get in as a new patient at a new practice
 - Start the process early so you can still go back to your pediatric provider if new or urgent issues arise
 - Make a plan with your pediatric provider around what to do if it takes longer than expected
 - Request your pediatric provider send a portable medical summary or transfer summary letter to your new provider or practice prior to your first visit

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Initiating Contact with a New Provider or Practice

- Important first visit questions:
 - Get information about how best to communicate with your new provider
 - Secure electronic messaging, phone call, etc.
 - Learn the process for after hours calls/concerns
 - Ask about how long it usually takes to process refills and paperwork
 - So if you have either need in the near future you can plan ahead
 - Is there an additional cost for paperwork?
 - What is their late and no-show policy?
 - What happens if your provider is ill or out of the office?
 - Does another provider see your child or answer your question?

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Initiating Contact with a New Provider or Practice

- Important first visit things to do:
 - Bring and review a complete medication list
 - Bring and review your child's medical history, surgical history and chronic medical problems
 - Discuss with your new provider which medications and orders you hope they will be responsible for
 - You may see here a difference between the way the pediatric and adult systems are modeled. You may be surprised by how much your adult PCP is comfortable managing!
 - Bring a list of your child's other medical providers or team members that may need to be able to communicate with your primary care doctor/specialty provider
 - Sign releases of information if necessary

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Initiating Contact with a New Provider or Practice

- The dating analogy.

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Completing Transfer to a New Provider or Practice

- Once you have established with a new provider, inform your prior provider, home care agency and pharmacy
 - Wait to do this until after you have transferred your care (ie don't "fire" a provider until you have another to manage your child's needs)
 - New providers will not complete paperwork or give refills unless you have already established care

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Troubleshooting Challenging Situations

- With preparation and planning, most challenging situations can be prevented
 - Emergency care planning
 - Running out of medications or supplies
 - Denial of refills/paperwork because you are overdue for follow up

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Troubleshooting Challenging Situations

- “Behaviors”
 - They might happen, people know that
 - If they are interfering with your ability to get your child to a visit, call the office to let them know you are having difficulty and ask if you can reschedule or come late
 - In the office, if there is something that could be done to help (like get back into an exam room quickly), then ask!
 - The worst that will happen is they will say no.

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Troubleshooting Challenging Situations

- Not able to reach the doctor on call
- They want to talk to your child about what?
 - Mood, sexuality and substance use
- Issues around consent.
- Lapse in insurance.

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Troubleshooting Challenging Situations

- Audience Examples

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Clinical Resources

- UCHealth Transition Clinic
 - for patients with developmental disabilities and/or pediatric onset medical complexity looking to transition to adult primary care and assistance connecting with adult speciality services (when needed)
 - Phone 513-585-9009
 - Lauren Wang, MD, Abigail Nye, MD, Tim Freeman, MD

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Clinical Resources

- DDBP Transition Clinic (Division of Developmental Behavioral Pediatrics), Cincinnati Children's
 - For current DDBP patients
 - Adolescents and young adults (age >14) with intellectual and developmental disabilities - Transition consultation
 - Phone 513-636-4611
 - Katie Thoman, CNP, Jason Woodward, MD
- Transition Medicine Clinic (Division of Adolescent and Transition Medicine)
 - Adolescents and young adults w/ chronic conditions (age >13), transition consultations, primary care bridge
 - Phone 513-803-4348
 - Jason Woodward, MD, Anne Marraccini, RN, MSW

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Online Transition Resources

- www.gottransition.org
- www.aucd.org
- Portable medical/health summary
 - <http://www.gottransition.org/resourceGet.C1111:10=222/>
 - <https://www.sickkids.ca/myhealthpassport/>
- Specific condition websites (Autism Society, Down Syndrome Association, United Cerebral Palsy Foundation, Spina Bifida Association)



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Resources and Support

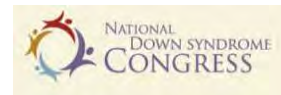
Autism Society of America
www.autism-society.org



United Cerebral Palsy Association
www.ucp.org



National Down Syndrome
 Congress
www.ndscenter.org



Spina Bifida Association
www.sbaa.org



Children and Adults with ADHD
www.chadd.org



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Resources

- Nutrition
 - www.choosemyplate.gov
- Physical activity
 - Special Olympics: <http://www.specialolympics-hc.org/>
 - National Center on Health, Physical Activity and Disability:
<http://www.nchpad.org>
- Sleep
 - <http://sleepeducation.org/essentials-in-sleep/healthy-sleep-habits>
 - https://www.cdc.gov/sleep/about_sleep/sleep_hygiene.html

