Transitions

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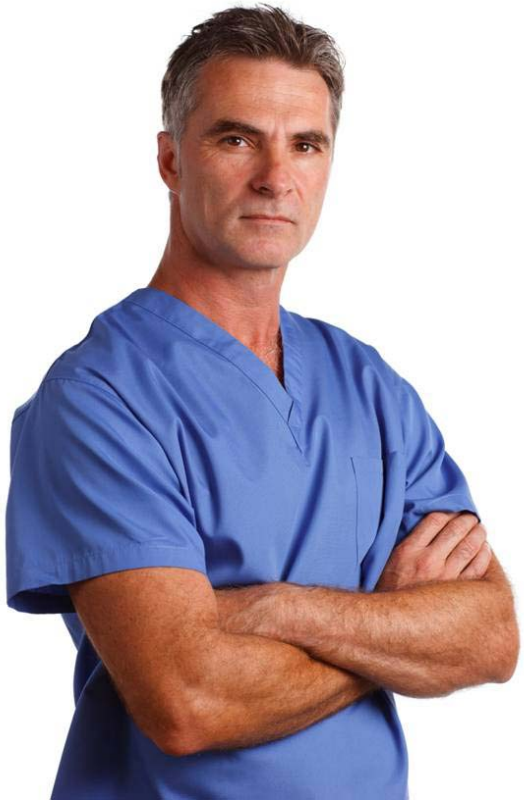
Katie Needs an Adult Doctor

Katie is a 19-year-old girl with several chronic medical conditions. She has diabetes, a seizure disorder, and developmental delays. Katie gets her specialty care at the children's hospital. At a check-up, her pediatrician told Katie and her mom that soon they would need to find Katie a new doctor. Because she is getting older it is time to change to an adult primary care doctor.

Katie and her mom felt unprepared because they had not thought about what would happen when Katie became an adult. Katie's doctor had taken care of her since she was a baby. They did not want to change and worried about how to find a new doctor. They didn't know where to start.

After the appointment, Katie's mom talked to the nurse about needing a new doctor. The nurse said Katie could still go to the pediatrician until she was 21 years old. In the meantime, the nurse said that she would help find an adult primary care doctor for Katie. The nurse started by giving them a list of doctors who care for young adults with chronic conditions. Katie and her mom felt better knowing that they had time and support to go through this transition process.



- How could Katie's family have started planning for adult care?
- What does Katie's mom need to do in the transition process?
- How can Katie's mom find resources to help with this transition?

What's It All About

Change is a normal part of life. A transition is the process or journey of going through those changes. Transitions do not happen all at once. The goal is to smoothly adjust to something new. Because children with long-term health conditions have many needs, they tend to experience more transitions. Some examples of transitions are:

- Going from hospital to home or from home to hospital.
- Starting school or an early intervention program like Birth-to-3.
- Changing schools, such as from middle school to high school.
- Graduating from high school and beginning work or college.
- Moving to a new city.
- Switching from pediatric to adult health care.
- Moving from living at home with parents to living alone or with a group.

Transitions affect your entire family's emotions, health, and social life. A transition is also a chance to learn new information and skills. Learning and using resources helps keep life as normal as possible. Each transition experience prepares you for future life changes.

Your involvement is key to the success of each transition. Knowing your child's likely transition points gives you time to plan. Including your child in planning and decision making helps them to be as independent as possible in managing transitions.

Talking with your child's care team helps you figure out needed resources. Resources may be people with special knowledge about the transition, organizations, resource centers, schools, or families who have been through the same transition.

Working with the team requires keeping the lines of communication open. You may need to use problem solving skills to make sure your child's transition goes smoothly. Remember that the main focus of any transition is for your child to be as happy and independent as possible.

Steps to Learning

1. List likely future transition points.
2. Make a plan for future transitions.
3. Put the transition plan into action.

Take Action

Talk with your health care provider.

List likely future transitions points.

All children experience transitions. These changes can be exciting. Transitions are a time to learn and experience new things. Even good changes can be hard and challenging.

Children with long-term health conditions may experience more transitions. Transitions may be more complicated because of your child's health condition. Some transitions you know are coming, while others may occur with little or no warning. It is important to plan ahead. Knowing what is involved in a transition can help you continue your family's routines and prevent problems.

The goals of a successful transition are to keep your child safe and avoid interrupting care and services.

During a transition your child moves from one care team to another. Not all the team members will change during a transition. You will need to work with both the old team and the new team your child is transitioning to. You and your child are members of both teams.

Tips for going through transitions

- Accept that change is a normal part of life.
- Focus on the positive.
- Don't take on new commitments.
- Keep daily routine the same as much as possible.
- Don't rush, know it takes time to adjust.
- Don't assume, verify your options and what has been done.
- Be aware of possible challenges.

Take Action

Talk with your health care provider.

This table shows examples of major transitions children may go through. Check the Resources and More Information page for materials to help with each kind of transition.

From	To	Things to think about
NICU (Neonatal Intensive Care Unit)	Home	Appointments, medicines, treatments, home care
Home, Daycare	Birth to 3 Early Intervention	Therapies and IFSP (Individual Family Service Plan) are centered around the family and often has care at home
Birth to 3 Early Intervention	Early Childhood, Preschool, Head Start	Therapy and services at school are focused on the child's learning needs, change IFSP to IEP (Individual Education Plan)
Early Childhood, Preschool, Head Start	Kindergarten Elementary school	May need new testing to qualify for special services, longer school day, bigger school, less caregiver involvement
Elementary school	Middle school High school	Planning for life skills, jobs, future education, by age 14-16 the school must involve your child in formal transition plan.
High school	Adult life New housing Vocational school or college Employment	Loss of control for caregiver, safety of young adult, guardianship, housing options, health benefits, expenses, need for social support system and resources, recreation activities, estate planning, accommodations needed for work or school
One city or state	New city or state	New school, health care, community resources, benefits
Home	Hospital, rehabilitation program, residential care (long term care)	Loss of control for caregiver, need to stay involved in care and decision making, new caregivers, change in routine, impact on family, expenses
Hospital, rehabilitation program, residential care (long term care)	Home	Adjusting to routines, possible new problems, medicines, treatments, or home care needs, return to school
Pediatric health care	Adult health care	New health care providers, changes in caregiver's role and rights, changes in benefits and services

Take Action

Talk with your health care provider.

Make a plan for future transitions.

A transition plan helps everyone understand what will happen. One of the most important things is to focus on the goal. Involve your child as much as possible. Consider your child's hopes, dreams, and specific needs. Make sure that your child stays safe and services are not interrupted.

Plan process involves:

- Think ahead about future transitions.
- Decide on the goal of each transition.
- Talk with others who have experienced similar transitions.
- Talk with providers.
- Decide what resources will be needed.
- Find out what new skills you need to learn.
- Find out what records and information the new team will need.

Make a plan in writing. A plan can help everyone understand what to expect and what to do. Make sure the plan clearly states the transition goals, what you and others will do, when it will be done, and what resources are needed. You can use Form 12.1, Transition Worksheet, to keep track of transition planning. Write down things to do, your questions and answers, and resources.

Put the transition plan into action.

Once you know the transition goals and have a written plan you can put the transition plan into action. It is best to put the plan into action as early as possible. This way you will have enough time to practice new skills, learn new information, and find out about resources.

Communicate with the team.

- Know who is on the team. There are usually many people involved in a transition.
- Make sure your child is part of the team.
- Be honest. Say what you think your child needs. Tell the team what you can't do or are uncomfortable doing.
- Ask questions and let the team know when you do not understand or do not know how to do something.

Take Action

Talk with your health care provider.

Use community resources.
- Think about what is needed and be creative to find resources.
- Make contact with resources.
- Gather information.
- Do what is needed to get and use the resource.

Take one step at a time.
- Break the transition into small steps or goals.
- Figure out the timeline for when things need to be done.
- Give yourself and others enough time.
- Use a checklist such as the Hospital to Home Transition Plan (Form 12.2).
- See the Resources and More Information page for where to find checklists for other transitions.

Learn new skills.
- Tell the team how you learn best.
- Ask questions until you understand.
- Practice the skills whenever possible.
- Show the new skill to a provider to check that you're doing it right.
- Ask a family member or friend to learn the new skills too.

Make informed decisions.
- Know what your choices are.
- Get information about each choice.
- List the pros and cons for each choice.
- Consider your child's goals and strengths.
- Think about what matters to your family.

Tips for working with transition teams

- Include team members who know your child such as teachers, therapists, social workers, and providers.
- Include members of the new team.
- Keep in contact with all team members throughout the process.
- Schedule a transition meeting such as a care conference or a school meeting.
- Prepare for meetings by gathering information and your questions.
- Include your child or get their input when possible.
- Have a contact person on the current and the new team.
- Remember that you all share a common goal.

Check Yourself

- ❑ I have listed likely future transitions points.
  - ❑ Between hospital and home
  - ❑ School programs
  - ❑ Pediatric to adult care and services
- ❑ I have made a plan for future transitions.
  - ❑ Decided on transition goals
  - ❑ Asked questions
  - ❑ Found resources
  - ❑ Involved my child
- ❑ I have put the transition plan into action.
  - ❑ Worked with transition team
  - ❑ Made informed decisions
  - ❑ Learned new information and skills
  - ❑ Used resources

More Information and Resources

School Transitions

- **Early Childhood Transition: What happens when my child turns 3?:** 25-minute video training to help prepare families and children for transition from Early Intervention. It includes a family story, strategies that help, notes, and a glossary and links to other resources: http://www.vermontfamilynetwork.org/wp-content/trainingvideos/early-childhood-transition/player.htm
- **Making the Education Transition To Elementary, Middle, and High School**: Article from Exceptional Parent Magazine: http://www.eparent.com/main_channels_education/School_Transitions.asp
- **NICHY Transition Guides:** National Dissemination Center for Children with Disabilities information about school transitions to adulthood: http://nichcy.org/schoolage/transitionadult#anchor6
- **Making the Transition from High School to College for Students with Disabilities**: Download information and checklist for students getting ready for college: http://www.ncld.org/images/stories/Publications/Forms-Checklists-Flyers-Handouts/checklist-transitioningfromhs-college.pdf
- **If I knew then what I know now**: Download a booklet with advice from parents and kids about school transitions: http://www.iidc.indiana.edu/styles/iidc/defiles/cell/transition%20planning_Patterson_Havill.pdf
- **Moving from Elementary to Middle School**: Download an article about school transitions for students with disabilities: http://www.familiestogetherinc.org/PDF%20FILES/VOL37NO3JanFeb2005_TEC_Carter37-3.pdf

Health Transitions

- **Balancing Academics and Serious Illness**: Written information and an audio clip about balancing illness and school while your child is in the hospital: http://kidshealth.org/parent/positive/family/academics_illness.html

More Information and Resources

Transition to Adulthood

- **This is Health Care Transition**: Web video series to help youth and young adults with chronic health conditions and their families be better prepared to move from pediatric to adult health care.
  - **What does transition mean to me**: YouTube Video (Part 1): http://www.youtube.com/watch?v=b2Go8eziUQk
  - **Taking control of the decision making process**: YouTube Video (Part 2): http://www.youtube.com/watch?v=cfEt8ih3u8s
  - **Learning about your health care needs, participate in your health care decision, and becoming responsible for all your health care**: YouTube Video (Part 3): http://www.youtube.com/watch?v=-FwNQ2qVjwQ
  - **Taking charge of all decision related to your health care needs as an adult**: YouTube Video (Part 4): http://www.youtube.com/watch?v=jgqeVcFkdC8
- **JAN (Job Accommodation Network):** Free, expert, and confidential help about workplace accommodations and disability employment issues. JAN offers one-on-one guidance to employees and employers over the phone and online: askjan.org
- **Healthy & Ready to Work:** National Resource Center with information, downloadable files, and links to other resources related to services, youth involvement, health care access and funding, education, employment, recreation, and independence: www.hrtw.org

Other Transitions

- **Moving to a new location**: Q&A and checklist for planning a move: http://nichcy.org/families-community/moving
- **Transition Developmental Checklist**: Download a checklist of skills needed to support health and independence, listed by age starting at 2 years: http://chfs.ky.gov/NR/rdonlyres/8C5EEDBE-14FC-4488-8C85-1BAC1EDE0516/0/Checklist.pdf

Transitions Forms

Form	How it can be used
Transition Worksheet 12.1	Use this form to keep track of transition planning. Write down things to do, your questions and answers, and resources.
Hospital to Home Transition Plan 12.2	Use this form to start planning for the transition home as soon as your child is admitted to the hospital. Review with your child's care team.

Transition Worksheet

Use this form to keep track of things to do, your questions and answers, and resources.

Transition Information			
Transition from:	Transition to:		
Contact name: Phone:	Contact name: Phone:		
To do	**Who is responsible**	**Due Date**	**Done**
			☐
			☐
			☐
			☐
			☐
			☐
			☐
			☐
			☐
Questions	**Answers**		
Transition Resources			

Hospital to Home Transition Plan

Use this form to start planning for the transition home as soon as your child is admitted to the hospital. Review with your child's care team.

Admission Information	
Date of Admission:	
Reason for Admission:	
Insurance contacted ☐ Date:	Primary care doctor contacted ☐ Date:
Main doctor:	
Other doctors:	
I have information about the health condition ☐	
I need information about:	

Tests	**Describe results or List when/how to get results**
	Yes ☐ No ☐
	Yes ☐ No ☐
	Yes ☐ No ☐
	Yes ☐ No ☐

Surgery or Procedure	**Reason**

Treatments (medicine, diet, equipment)	**Date and Reason**

Plans for going home	
Expected discharge date:	Person helping plan:
What needs to happen before discharge:	
Where we plan to go: Home ☐ Someone else's home ☐ Hotel ☐ Other ☐	
Are home changes needed, such as a ramp? List changes:	
How we will leave: Car ☐ Taxi ☐ Public Transportation ☐ Ambulance/van ☐	

Skill to learn	**Skill was taught**	**I learned the skill**	**Questions**
	Yes ☐ Date:	Yes ☐ Date:	
	Yes ☐ Date:	Yes ☐ Date:	
	Yes ☐ Date:	Yes ☐ Date:	

Equipment/Supply	**Provider**	**Ordered, Date**	**Delivery date/time**
		Yes ☐ Date:	
		Yes ☐ Date:	
		Yes ☐ Date:	

Hospital to Home Transition Plan

Treatments (medicine, diet, equipment)	
☐ Have up-to-date written list of medicines. Include those stopped, started, or changed.	
☐ Have prescriptions ready on or before day of discharge.	
☐ Pharmacy contacted. Medicine will be ready by day of discharge.	
☐ Have a way to get to pharmacy.	☐ Need help paying for medicine
☐ Have written medicine schedule.	☐ Time of last dose or time next dose is due:
☐ Special diet (tube or IV feeding, special food, special food preparation)	☐ Ordered or bought what is needed for diet. Date: Provider:
☐ Need help paying for special diet	☐ Have a way to pick up from provider
Emergency Planning	
☐ Have a written emergency plan. It is ☐ New ☐ Updated	
Responders who come if I dial 9-1-1:	
☐ Responders know about my child's needs.	
☐ Public utilities called.	☐ Child is on a priority list. Date:
Home Care Services	
Services needed: ☐ Home nursing ☐ Home health aide ☐ PT ☐ OT ☐ Speech ☐ Respiratory care	
☐ Have a home care agency? Date agency contacted: Provider name: Contact info:	

Follow Up Care				
Appointment Provider Name	Where	Date/Time	Why?	Instructions, notes, etc.
Test Name	Where	Date/Time	Why?	Instructions, notes, etc.

Activity level (return to school, need homebound, partial or full schedule):
☐ School contacted:
Resources (support groups, mental health support, public health benefits, public programs, etc.)
☐ I know what insurance will pay for:
Discharge
☐ I have written discharge instructions.
☐ I know the warning signs. They are:
☐ I know WHEN to call for help:
☐ I know WHO to call for help:
☐ I know what to do:
☐ I reviewed the plan with the doctor. Date: