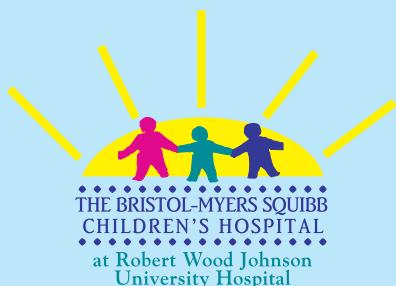




BMSCH Transition Guide A Toolkit for Providers

732-828-3000



ROBERT WOOD JOHNSON
UNIVERSITY HOSPITAL



This toolkit is provided to you as a guide to assist in your efforts to transition adolescent and young adult patients to adult care. It will provide you with guidelines, models, and patient/family education to support your transition activities for all adolescent/young adult patients and their families – regardless of diagnosis or acuity.

Provider Resources

“Got Transition” is a collaboration between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. The goal is to improve the transition from pediatric to adult health care. Links to their model for health care transition are listed below. Click on the area(s) of interest to you for access to the materials as needed.

Pediatric Providers:

- “Got Transition” www.gottransition.org
- o Core Elements of Health Care Transition www.gottransition.org/providers/leaving.cfm
- o Transition Policy www.gottransition.org/providers/leaving-1.cfm
- o Transition Flow Sheet & Registry www.gottransition.org/providers/leaving-2.cfm
- o Transition Readiness Assessments for Youth & Parent/Caregiver
www.gottransition.org/providers/leaving-3.cfm
- o Transition Planning www.gottransition.org/providers/leaving-4.cfm
- o Transfer of Care www.gottransition.org/providers/leaving-5.cfm
- o Transfer Completion www.gottransition.org/providers/leaving-6.cfm
- o Transition Measures www.gottransition.org/providers/leaving-measure.cfm
- Insurance & Payment www.gottransition.org/resourceGet.cfm?id=353

Adult Providers:

- “Got Transition” www.gottransition.org/providers/index.cfm
- o Core Elements of Health Care Transition www.gottransition.org/providers/integrating.cfm
- o Transition Policy www.gottransition.org/providers/integrating-1.cfm
- o Tracking & Monitoring www.gottransition.org/providers/integrating-2.cfm
- o Transition Readiness www.gottransition.org/providers/integrating-3.cfm
- o Transition Planning www.gottransition.org/providers/integrating-4.cfm
- o Transfer of Care www.gottransition.org/providers/integrating-5.cfm
- o Transfer Completion www.gottransition.org/providers/integrating-6.cfm
- o Measuring Transition www.gottransition.org/providers/integrating-measure.cfm
- Integrating Young Adults with Developmental Disabilities into Practice
www.gottransition.org/resourceGet.cfm?id=367

BMSCH Adolescent/Young Adult *Transition Guidelines*

Consider the following transition activities for each stage of Adolescence:

Early Adolescence (ages 11-14):

- o Discuss office transition policy (expected age of transfer, patient, family & provider's responsibilities in preparing for transition)
- o Identify those at risk for more complicated transition due to special medical, developmental, social or environmental needs
- o Create a transition registry to keep track of individual needs and progress toward transition
- o At 14 year visit, conduct a readiness assessment to develop a formal transition plan with patient/family collaboration
- o Identify multidisciplinary team members (Physician, Nurses, Dietary, NP, Social Work) available for questions/help
- o Consider identifying a "patient navigator" for consistency of practice

Middle Adolescence (ages 15-17):

- o Conduct patient transition readiness assessments annually or as needed
- o Set realistic readiness goals and identify new skills needed by the patient to meet those goals
- o See patients without parents for part of clinic visit
- o Identify multidisciplinary team members (Physician, Nurses, Dietary, NP, Social Work) available for questions/help
- o Consider identifying a "patient navigator" for consistency of practice

Late Adolescence – Transition Time (18-21+):

- o Pediatric and Adult care teams schedule "transition clinics" as needed to provide an opportunity for both care teams to meet with the patient prior to transfer. Consider scheduling "transition clinics" at set times during the year so providers, patients and their families can plan in advance.
- Both care teams are encouraged to meet before first transition visit to review patient's history, current status and active issues. The patient and their family are encouraged to participate in the process and provide their own summary of important health events for any new care providers.
- **First Transition Visit:** The pediatric team leads the visit, with the patient being introduced to the adult care team and what to expect. Patients are encouraged to tour hospital if desired to ensure comfort and safety within the new clinical environment.
- **Second Transition Visit:** This visit is led by the adult team with input from the pediatric team as necessary. After this visit, if practicable, care will be transferred to the adult care team. For the patient's first hospitalization on the adult side, please consider coordinating with a social worker to assist as a patient care navigator to ensure a smooth process has occurred.



Patient/Family Education

“Got Transition” guidelines encourage providers to start the transition conversation in the early adolescent years. The following patient/family tools can help you begin the conversation, as well as help them prepare for other kinds of transitions in their lives – such as going off to college or making plans for guardianship and decision-making for those patients who do not have the ability to do it for themselves.

Taking Care of You

Tips for Youth ages 11-13

1. Understand your health needs and medical history:
 - Know your diagnosis
 - Know what makes your health better or worse
 - Keep track of what treatment(s) are you getting
2. Get to know the members of your healthcare team:
 - Know the name of your primary doctor
 - Know the names of other doctors or specialists and which health issues they treat
 - Know how to contact your doctors
3. Keep track of any medicine you are taking:
 - Know what, why, how much, and how often to take your medicine
 - Be aware of any side effects
 - Identify any allergies you have to medicines
4. If you have allergies to medicine, food, contact items or other things:
 - Know how to avoid them and how to speak up to prevent contact
 - Be aware of the signs of an allergic reaction
 - Know what treatment you may need
5. If you use medical equipment:
 - Know what it does
 - Know how to use it
 - Know who to call if it needs to be fixed
6. Be prepared for emergencies:
 - Know the signs that you need help right away
 - Know who to call and what to do
 - Carry an emergency card that lists your important health information
7. Take an active role during doctor's visits:
 - Make a list of questions before your visit
 - Ask questions to make sure you understand the care plan
 - Write down what you need to do and why
8. Help maintain your health:
 - If you have a special diet, follow it
 - Learn to call and make your own appointments
 - Ask about special programs or camps to learn more about your medical needs

Taking Care of You

Tips for Youth ages 14-17

1. Understand your health needs and medical history:
 - Know your diagnosis
 - Know what makes your health better or worse
 - Keep track of what treatment(s) are you getting
2. Get to know the members of your healthcare team:
 - Know the name of your primary doctor
 - Know the names of other doctors or specialists and which health issues they treat
 - Know how to contact your doctors
3. Keep track of any medicine you are taking:
 - Know what, why, how much, and how often to take your medicine
 - Be aware of any side effects or allergies you have to medicines
 - Drinking alcohol or taking street drugs can affect how your medicine works.

Be honest when talking to your healthcare team.
4. Be in charge of taking your own medicine:
 - Use an alarm or chart to remind you to take your medicine.
 - Read all labels on medicine bottles and pamphlets.
 - Call the pharmacy or doctor's office for refills before they run out
 - Changing or skipping doses can make you very sick. Do not share your medicine or take someone else's medicine.
5. If you have allergies to medicine, food, contact items or other things:
 - Know how to avoid them and how to speak up to prevent contact
 - Be aware of the signs of an allergic reaction
 - Know what treatment you may need
6. If you use medical equipment:
 - Know what it does
 - Know how to use it
 - Know who to call if it needs to be fixed
7. Be prepared for emergencies:
 - Know the signs that you need help right away
 - Know who to call and what to do
 - Carry an emergency card that lists your important health information
 - Add emergency contact number to your phone (In Case of Emergency or I.C.E contact)



8. Take an active role during doctor's visits:

- Make a list of questions before your visit
- Share how you are feeling, ask questions to make sure you understand the care plan
- Write down what you need to do and why
- Work toward speaking up so that you are doing most of the talking

9. Help maintain your health:

- If you have a special diet, follow it
- Learn to call and make your own appointments
- Think about your future. Talk to your doctor about life changes that may affect your health. (Driving, college, alcohol/drug use, getting a job, etc.)



Patient/Family Education Resources

- “Got Transition”

www.gottransition.org/youthfamilies/index.cfm

A website listing helpful steps to transition and offers ways patients and families can start preparing now.

- Guardianship & Alternative Decision Making

www.gottransition.org/resourceGet.cfm?id=17

A short guide that explains different support options available to families of youth or young adults with intellectual disabilities who are unable to make decisions about their own health on their own.

- Sharing Health Information with Family & Friends

www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/sharing-family-friends.pdf

Information on how HIPAA or the Health Insurance Portability and Accountability Act effects who can look at or receive your medical information – including family and friends.

- Family Perspective: “Three Documents Every College Student Needs”

http://support.jvsdet.org/site/DocServer/3_Documents_Every_College_Student_Needs.pdf?docID=2802

One mother’s perspective on the three things patients and their families should consider talking about before leaving home.