How to Help Your Child Transition to Managing Their Care

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Goals

• Explain reasons that a gradual transition is best for your child
• Identify ways that you can help your child be involved in their care at any age
• Discuss tools to help with the transition process
What we know...

• Knowledge about medications, prior medical history, and impact of lifestyle behaviors on health (e.g., drugs, smoking) → essential for successful transfer

YET

• At the time of transfer, only a small proportion of young adults can function independently for specific aspects of their care
What we know...

• At time of transfer, patients are unable to:
  • Schedule appointments
  • Take medication independently
  • Call in prescription refills
  • Summarize medical history and health needs
  • Understand insurance coverage
  • Make healthy lifestyle choices
  • Manage daily health care needs
  
  AND MUCH MORE…
Why does this happen?

• Risk Factors:
  • Caregivers maintain primary responsibility for all disease-management tasks
  • Poor communication between patient and caregivers about who is responsible for specific aspects of the treatment regimen
  • Youth are granted few opportunities to become involved in their health care
  • Youth aren’t provided needed education, preparation, and support to become involved in their health
Preparation is key...

Transfer to Adult Care = period of greatest health risk!

- Increased non-adherence to treatment regimens
- Increased variability in self-management
- Increased health care costs
  - Proportion of patients admitted via the emergency department nearly doubled at the time of transfer to adult care
- Delays in receiving appropriate medical care
Preparation is key...

• Loss to follow-up
  • \( \frac{1}{4} - \frac{1}{3} \) have no follow-up appointment with adult provider

• Increased risk of negative health outcomes

• Significant declines in patient/parent quality of life

• Reluctance from receiving adult provider to assume primary care
Transition: a gradual process...

TRANSITION = Disease and treatment-related responsibilities gradually change between the adolescent and caregiver; responsibility for managing health care tasks shifts from caregiver to young adult.

Caregiver shifts from primary health managers to supportive role that encourages independent decision-making and self-care by the youth.

Adolescent takes on greater responsibility for self-care and medical needs (e.g., taking medications, calling in prescription refills, scheduling visits).
Transition: Starting at an Early Age Birth to 3 Years Old

- Set routines and rules for your child
- Expect your child to participate in self-care activities
- Be honest when explaining a procedure to your child, even the ones that will hurt
- Talk with your child about clinic visits ahead of time and bring a favorite toy for comfort
- Use play activities and books to talk with your child about his/her medical care
Transition: It Can Happen at Any Age
4 to 7 Years Old

• Give your child choices so he/she can learn and practice decision making
• Encourage involvement in school and community activities
• Teach your child skills related to his/her medical condition
• Make sure your child knows the name of his/her condition
• Help prepare your child for medical appointments by talking about it beforehand
Transition: It Can Happen at Any Age
8 to 11 Years Old

• Encourage your child to express his/her needs and wants
• Coach your child on how to talk to friends about his/her condition
• Involve your child in taking his/her own medications
• Explain your child’s medical condition to them in simple terms
• Work with your child to make a list of questions before medical appointments
Transition: It Can Happen at Any Age
12 to 14 Years Old

As the parent, encourage your child to:

• Ask questions, talk about his/her needs and how he/she feels about their condition
• Get involved in school community groups/activities
• Set up his/her own routine
• Keep track of prescriptions and test results with help from you and the medical team
• Increase his/her knowledge of their condition and understand reason for tests, procedures and medications.
Transition: It Can Happen at Any Age 15 to 17 Years Old

As the parent, encourage your child to:

- Look for young adult support groups
- Take charge of preparing and taking medications
- Plan ahead to fit your daily care into your schedule
- Keep track of appointments
- Take part in healthcare discussions with the medical team
Transition: It Can Happen at Any Age
18 and Up

As the parent, encourage your child to:

• Know your medications and what they do
• Write down questions you have before any medical appointments
• Be responsible for calling and scheduling appointments
• Understand your medical condition and be able to explain it to others
• Know when you need to seek help immediately, have a plan for how to handle emergencies and who to contact
Building Confidence | The Center for Children with Special Needs
Tips & Tricks to Support Growing Independence

• Recognize and honor how roles need to change over time
• Start where you are. It’s never too early or too late to begin sharing management
• Create opportunities to build confidence and a sense of mastery
• Keep lines of communication open with doctors/nurses
• Develop collaborative relationships with your child’s medical team
Tips & Tricks to Support Growing Independence

• Include your child in medical decision-making
• Bring your child to one of your appointments
• Parents are **KEY** agents of change – model healthy lifestyle behaviors
• Talk openly about worries, fears, barriers to transition and transfer
• Find healthcare related transition resources to help you
Transitioning Care...

• Choose one health management task to gradually shift responsibility: Focus on one task at a time
  • **Step 1**: parent completes the task, child observes
  • **Step 2**: parent AND child complete the task together
  • **Step 3**: child completes the task, parent supervises
  • **Step 4**: INDEPENDENCE 😊
Sharing Management

Shared Management | The Center for Children with Special Needs
Different Way to Look at Transition…

• Approach transition and transfer as exciting milestones!
  • Graduation into adulthood
  • Greater independence/control over decision-making
  • Greater awareness of important health-related issues
  • Empowerment: treated as mature adult and trusted with increased responsibility
  • Increased comfort discussing intimate topics (e.g., drugs, alcohol, sexual activity) in absence of parents
  • Decreased worries, fears regarding entering adulthood
MyHealth Passport

Welcome to MyHealth Passport, a project of the SickKids Good 2 Go Transition Program. MyHealth Passport is a customized, wallet-size card that gives you instant access to your pediatric medical information. It can be used when you go to a new doctor, visit an emergency room or are entering your first school, and want the names of your medications for your health care.

Start by filling out the information below:

CREATE PASSPORT

Passport

Submit

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https://www.sickkids.ca/myhealthpassport/
Three Sentence Summary

How do I use it?

• Sentence 1: My age, diagnosis and brief medical history
• Sentence 2: My treatment plan
• Sentence 3: My question/concern to talk about during this visit

• Practice with the health-care providers you see the most
• Ask if your 3-Sentence Summary is correct and includes all the important information
Hi, my name is Josh Williams.

1) I am 16 and have polycystic kidney disease. I have been hospitalized twice, but not in the last 5 years.

2) I have been taking enalapril for my blood pressure and tramadol for pain.

3) I am here today for a routine check of my labs and blood pressure.
# Medication Tracking Log

|       | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | Mid-Morn | Dinner | Bedtime | Breakfast | Mid-Morn | Lunch | 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# Other Tracking Tools

## Appointment Log

<table>
<thead>
<tr>
<th>DATE</th>
<th>PROVIDER</th>
<th>REASON FOR APPOINTMENT / CARE PROVIDED</th>
<th>NEXT APPOINTMENT</th>
</tr>
</thead>
<tbody>
<tr>
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**Insurance/Funding Sources**

- Insurance Company: ____________________________
  - Policy Number: ____________________________
  - Contact Person / Title: ____________________
  - Address: ____________________________
  - Phone: __________________ Fax: __________ Email: __________
  - Website: __________

**Medications**

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>DATE STARTED</th>
<th>DATE STOPPED</th>
<th>DOSE / DOSE (with or without food?)</th>
<th>TIME GIVEN</th>
<th>PRESCRIBED BY</th>
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- Supplemental Security Income (SSI): __________
  - Contact Person / Title: ____________________
  - Address: ____________________________
  - Phone: __________________ Fax: __________ Email: __________
  - Website: __________

http://cshcn.org/download-documents
Other Medication Tools

- www.ontimerx.com
- www.mymedschedule.com
  - Weekly checklists
  - Wallet-size checklist
Health Care Transition Resources

Got Transition: developed by The National Health Care Transition Center. The website offers 30-minute “radio shows” on relevant transition topics. Episodes are co-led by a young adult with special health care needs and a parent.  
http://www.gottransition.org/

Health Care Transition Initiative: developed by University of Florida’s Institute for Child Health Policy. The website offers a wide range of useful websites, videos and print materials.  
http://hctransitions.ichp.ufl.edu/
Resources Continued...

Sick Kids: Good 2 Go Transition: developed by The Hospital for Sick Children in Toronto, Canada. It is designed to help children and youth with chronic health conditions acquire skills while in the pediatric system.  [http://www.sickkids.ca/good2go/](http://www.sickkids.ca/good2go/)

The Center for Children with Special Needs: is through Seattle Children’s Hospital. The website has information on diagnoses, ways to organize medical information, help to create a plan of care, find support through others with similar experiences.  [http://cshcn.org/](http://cshcn.org/)
Thank You!