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# SNOHOMISH COUNTY CHILD HEALTH NOTES

Promoting early identification and partnerships between families, primary health care providers & the community.

Distributed by: Children with Special Health Care Needs Program and the Infant Toddler Early Intervention Program  
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“Parents get programmed to complete paperwork themselves and to be advocates and be assertive, but leave out the youth. By sitting down and completing the Health History Summary with my son, I saw how little he knew about his condition and how difficult it was for him to explain his condition so that it’s understood. I told him, ‘You need to learn this; I won’t always be there to help you with this.’”

*Parent of a teen with special health care needs*

## Health History Summary A Tool for Youth Transition to Adult Health Care

Available at:

<http://depts.washington.edu/healthtr/healthhistory/default.html>

*The Health History Summary* is a tool for teens with special health care needs and their parents to complete together. The summary takes 30 to 45 minutes to complete. It covers:

- Health history
- Medications
- Health care providers
- Family health history
- Significant details about medication effects, surgeries and other health events

As teens with special health care needs approach adulthood, they often find it difficult to change from pediatric to adult-oriented health care. It is hard to give up a relationship with a trusted pediatric provider. Even if continuing on with their family medicine physician, youth and families may feel overwhelmed by new responsibilities in medical decision-making and self-advocacy.

**A critical first step is to** optimize the youth’s understanding and management of his/her health condition. (2001 Consensus Conference on improving transition). Participants in a focus group study of Washington state teens and young adults with chronic health conditions (*Family Community Health*, 1999) indicated planning for transition was seldom occurring. These youth stated lack of involvement in health care decisions, difficulty with medical jargon, and the lack of a clear medical summary as barriers to their successful transition to adult health care. The Health History Summary can help overcome these barriers.

### Transitioning youth should be able to describe (as developmentally appropriate):

- Current condition(s) and treatment
- Roles of primary care and subspecialty physicians
- Signs and symptoms requiring urgent attention
- Source of emergency services
- Long-term complications of health condition
- Effects of condition on reproduction and sexuality
- Awareness of support organizations
- Covering health care costs/insurance

### What youth say about the completing Health History Summary:

- I feel more confident assuming responsibility for my health care
- I am more likely to initiate contact with my health care providers
- I am better prepared to take responsibility for managing my medications and health care

### What parents say about the completing Health History Summary:

- We have a better understanding of what our teen knows and how she explains her condition
- It helped our teen ask us questions and got us talking about health care management
- Using the Health History Summary helped our family place a priority on preparing for the transition to adult health care.

### How Families Successfully Use the Health History Summary:

- Begin in the early teen years to complete the Health History Summary at least annually
- Update the Summary when there is a major health event or a change in medication type or dosage
- Complete the Summary as a parent-youth team, moving more responsibility to the teen as possible
- Have teen help obtain additional health information by asking their provider, researching at a library, and/or using reliable web resources
- Take the Summary to the visits with health care providers

### What You Might Consider in Your Office Practice:

- Give a copy of the Health History Summary to the youth and family by middle school years
- Offer yourself as a resource and support to the family as they begin preparation for transitioning to adult-focused health care management
- Remind youth and families each year to update their Health History Summary

### INFORMATION AND RESOURCES:

- **WA State** Adolescent Health Transition Project <http://depts.washington.edu/healthtr/>
- **National** Healthy and Ready to Work National Center [www.hrtw.org](http://www.hrtw.org)

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