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# My Health, My Future: Encouraging Self-Determination in Healthcare Transitions

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# UIC-DSCC- Who We Are

Care coordination programs for families of children and youth with special healthcare needs. Connecting families to the services and resources they need.

- **Core/Connect Care programs-** for those with an eligible health condition. May also include financial assistance for items insurance doesn't cover.
- **Home Care Program-** for those with complex medical needs requiring in home skilled shift nursing.
- **Interim Relief Program-** For children and youth with an eligible mental health or behavioral disorder where there is a need for Psychiatric Residential Treatment Facility level of care.
- Learn more on our website at <https://dsc.uic.edu/>





# Agenda

- Introduction
- Understanding Your Health
- Learning How to Take Care of Your Health
- Speaking Up About Your Health
- Preparing for Adult Healthcare
- Summary

# What is Healthcare Transition?

- Got Transition defines it as the “process of getting ready for healthcare as an adult.”
- This includes a shift from parent-directed care to youth/young adult-led care.
- Skill building on: understanding, asking questions, managing health



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# A Person-Centered Approach

- Self-management is possible with the right supports.
- When planning for health care transition, a **person-centered approach** understands that youth and young adults are not just receiving care.
- They know themselves best and can help decide what being healthy means to them and what they need to stay well.

*Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan*, edited by I. Leslie Rubin, et al., Springer International Publishing AG, 2016. *ProQuest Ebook Central*, <http://ebookcentral.proquest.com/lib/uic/detail.action?docID=4514222>.

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# Understanding Your Health

# Understanding your health condition or disability, helps with:

- Talking more easily with doctors, family, teachers, and others
- Speaking up for what you need
- Taking more responsibility and building independence
- Staying healthy and doing the things you enjoy
- Finding the supports or accommodations that help in daily life



# Learning About Your Health

## Self-management starts with understanding your health:

- Ask doctors to share information and pamphlets about the youth's condition and how it affects their daily life.
  - [Nemours Health Topics for Teens](#)
  - [DSCC's Knowing Your Healthcare Needs](#)
- Learn the warning signs that mean they need emergency medical help and know what to do in an emergency.
  - [DSCC's What to Do in a Medical Emergency](#)



# Learning About Your Health



**Understanding your health is key to making informed choices. Youth should learn to:**

- Take care of their daily health needs
  - [Special Olympics Health Promotion Tools](#)
- Keep clear, organized medical records. Know how to access their electronic record.
  - [DSCC's Portable Medical Summary](#)
  - [DSCC's "All About Me" pages](#)
  - [DSCC's Knowing Your Health Condition](#)
- Take a more active role in medical appointments
  - Practice explaining their health condition to others in their own words.
  - Use a form to fill out for reminders about what to ask the Doctor, to note any current symptoms/concerns, and things to remember after the appointment.
    - [My Health Care Visit](#)



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# Learning How to Take Care of Your Health

# Learning About Your Medicines and How to Take Them

## Teach youth to:

- Know why they take each medicine and for how long
- Know the possible side effects of their medicine
- Keep a medication list
  - [DSCC's Managing Medications Tip Sheet](#)
  - [LifeCourse Nexus Healthy Living Medication List](#)
- List what time they take each medication and how often they take it
- Take their medicine at the same time every day



# Remembering Medications

- Take at the same time as the young person does another daily routine
- Use pill organizers
- Use medication dispensers
- Set alarms on a phone or smart watch



# Making a Doctors Appointment

## Sample Script:

"Hello, my name is \_\_\_\_\_"  
*(Use your first and last name)*

"I need an appointment to see \_\_\_\_\_"

"Because \_\_\_\_\_"  
*(Example: "I need a checkup, I'm having headaches, I'm having ear pain.")*

"How soon can I get in? \_\_\_\_\_"  
*(Write date and time here)*

*If the date and time is okay, say, "Thank you, that will be fine." If not, say, "That won't work for me, can you look for something else?"*

"How long is the appointment? \_\_\_\_\_"  
*If you think you will need more time, say, "I think I will need more time."*

***If you will need extra help or equipment, be sure to say so:***

"I will need \_\_\_\_\_"  
*(Example: a lift to get onto the exam table)*

***Before you end the phone call, repeat the date and time of your appointment:***

"Okay, I will be there on \_\_\_\_\_ at \_\_\_\_\_"  
*(Date) (Time)*

Follow-up steps: \_\_\_\_\_

**Put the appointment on the calendar so you won't forget it.  
Prepare questions for your doctor. Bring a list of your medications.**

DSCC's Making Your Own Appointments



# Remembering Doctors and Appointments

- **Ways to keep track of doctors and appointments:**

- MyChart or a similar app
- Smart phone calendar
- Appointment book

- **Moving to Adult Health Care: Knowing About Your Health**

- [Medical Provider List](#)
- [Medical Provider List Tip Sheet](#)



# Practicing Healthy Habits

## Healthy Living Skills

- Get enough sleep to feel rested
- Eat balanced meals that support your health
- Stay active in ways that feel safe and enjoyable for your body
- Use healthy ways to manage stress

## Resources

- [321Go!](#)
- [Creative Healing for Youth in Pain](#)
- [ImaginAction](#)



# Self-Care Skills Assessment

- [DCCC's Self-Care Skills Assessment for Young Adults](#)
- [DSCC's Self-Care Skills Assessment for Young Adults in Spanish](#)
- [DSCC's Self-Care Assessment for Parents/Caregivers of Young Adults with Intellectual/Developmental Disabilities](#)
- [DSCC's Self-Care Assessment for Parents/Caregivers of Young Adults with Intellectual/Developmental Disabilities in Spanish](#)



# Heather's Health & Self-Management Checklist

## Taking Care of Her Health

- Knows the name of her medication and why she takes it
- Knows what to do if she misses a dose or has side effects

## Managing Her Health Condition

- Understands her health condition in simple terms
- Tracks symptoms or concerns (notes, app, journal)
- Knows when to manage things on her own and when to ask for help

## Healthy Living Skills

- Gets enough sleep to feel rested
- Eats balanced meals that support her health
- Stays active in ways that feel safe and enjoyable for her body



# Speaking Up About Your Health

(Goetsch Weisman et al. 2023; Nugent et al. 2018; Pin et al. 2016)

[SA]

# Learning About Your Rights

**Young adults have the right to:**

- Have a support person with them at doctors' visits
- Ask questions about their health until they understand what they need to know to make choices about their health
- Make choices about their care. That is saying yes or no to medical treatments
- Reasonable accommodations
- A copy of their medical information if they ask

A Self-Advocate's Guide to Patient Rights



# Being Involved in Healthcare Visits

## **Before the Visit, help the young person:**

- Know Why They Are Going
- Make a List
- Come with Questions
- Practice talking about their health
- Bring what they need
- Decide who comes with them



# Being Involved in Healthcare Visits

**During the visit, help the young person by:**

- Being their supporter
- Making sure the doctor speaks directly to the young person
- Taking notes to help them remember
- Asking the doctor to print out any instructions they give them
- Making sure they understand what they need and why

DSCC's Make Each Doctor's Appointment Work for You



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# Preparing for Adult Healthcare

# What Young People Can Do Now

- Use resources like the [Health Care Transition Timeline](#)
- Complete a healthcare readiness assessment every year
  - [Healthcare Transition Readiness Assessment for Youth](#)
  - [Healthcare Transition Readiness Assessment for Parents/Caregivers](#)
  - [Self-Care Skills Assessment for Young Adults](#)
  - [Self-Care Assessment for Parents/Caregivers of Young Adults with Intellectual/Developmental Disabilities](#)
- Set goals for skills that the young person would like to work on



# What Young People Can Do Now

- Practice skills at home and in real-life settings.
  - Young people and their parents/caregivers can use the tip sheets below.
    - [Finding Adult Providers](#)
    - [Getting a prescription and managing medication](#)
    - [Understanding health insurance](#)
    - [Responding to a medical emergency](#)
    - [Working with the doctor](#)
    - [Knowing about differences in care](#)
    - [Knowing healthcare needs](#)



# Pediatric and Adult Care Differences



## **Pediatric Doctor**

- Has known the young person for a long time.
- Parents stay with the young person during visits.
- Parents help answer questions from the doctor and make treatment decisions.

## **Adult Doctor**

- The young person may need to explain more about themselves and their conditions.
- The young person can decide if someone stays with them during visits.
- The young person will explain things about their treatment and condition on their own.



# Pediatric and Adult Care Differences



## **Pediatric Doctor**

- Parents help young people follow their treatment plan.
- The young persons' doctors focus on present and future possibilities.

## **Adult Doctor**

- The young person will need to decide about their treatment, follow up on tests, and take more responsibility for their treatment plan.
- Adult doctors might focus on what the young person can do in the present.



# Finding Adult Providers

- It is important to find your adult doctors early.
- Young people who see a pediatrician or a children's doctor will switch to an adult doctor between the ages of 18 to 22.
- If they see a family doctor, they might not need to change doctors. Instead, who makes the health decisions changes.

## Resources

- [DSCC's Finding an Adult Healthcare Provider Tip Sheet](#)
- [DSCC's Annual Health Visits for Teens Tip Sheet](#)



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# Conclusion



# Questions?

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