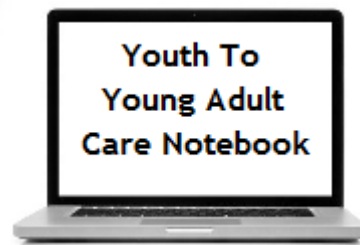




Office for Genetics and People with Special Health Care Needs

**iTransition-Health:
Maryland Health Care Transition Program
“Youth Transition to Adulthood”**

http://phpa.dhmh.maryland.gov/genetics/SitePages/Health_Care_Transition.aspx





STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

Larry Hogan, Governor - Boyd Rutherford, Lt. Governor - Van Mitchell, Secretary

Dear Parents and Caregivers,

This care notebook has been designed for you, the parents and caregivers of a child with special health care needs. You play an important role in your child's care and doctors and nurses rely on you to give them information about your child's health. It is helpful to have all your child's health care information organized and in one place so you can manage it easily. Please use this health care notebook to adapt it to fit your child's needs (see Creating Your Care Notebook on the next page).

The Office for Genetics and People with Special Health Care Needs is also a resource for locating information on services you may need for your child. Please call our Special Health Care Needs Resource Line on 410-767-1063 or 1-800-638-8864 for help. You can also log on to our Resource Locator website: <http://specialneeds.dhmh.maryland.gov/> to locate resources for children and youth with special needs.

If you have any questions, please contact our parent resource coordinator, Ms. Angela Sitter at the above number. She will be happy to assist you.

Regards,

Donna X. Harris
Director
Office for Genetics and People with Special Health Care Needs

Disclaimer

This Patient Care Notebook is intended to assist you in maintaining and organizing your child's medical record information. You should take the Notebook to your child's medical appointments and emergency visits to assist you in providing the necessary medical information to your child's medical provider and to update information from the current doctor visit. Please keep the Patient Care Notebook in a safe location. The State of Maryland will not be responsible for loss or misplaced Patient Care Notebooks.

The Youth2YoungAdult Care Notebook is adapted from the Teen Care Notebook created by Seattle Washington Hospital, Research, Foundation: The Center for Child with Special Needs © 2001 - 2013 Seattle Children's | All Rights Reserved.



Are you a young person with a health condition that is beginning to take a more active role in your own health?

The Youth2YoungAdult Care Notebook is a great way to organize information about your health condition and treatments in one place. You can also use it to share information with your parents, doctors, nurses, and other health care professionals.

You can use the Youth2YoungAdult Care Notebook to:

- Track changes in your medicines or treatments
- List phone numbers for health care providers and community organizations
- Prepare for appointments
- File information about your health history
- Share new information with your primary doctor, nurse, and others

To set up your Youth2YoungAdult Care Notebook:

- **Step 1: Gather your existing information:** Gather up any health information you and your parents already have. This may include reports from recent doctor's visits, immunization records, recent summary of a hospital stay, this year's school plan, test results, or informational pamphlets.
- **Step 2: Review the Care Notebook:** Which of these pages may help you keep track of information about your health or care? Choose the pages you like. You can either print copies of any that you think you will use and fill them out by hand, or download a copy and save it to your computer so that you can easily update the pages in the future.
- **Step 3: Choose what to keep in the Care Notebook:** Decide what information you look up most often and what information is needed by others. Store other information in a file drawer or box where you can find it if needed.
- **Step 4: Assemble your Care Notebook:** The key is to make it easy for *you* to find the information you need, quickly and easily. Some ideas in putting your Care Notebook together include using a 3-ring binder with tabbed dividers to create your own sections, pocket dividers to store reports, and/or plastic pages to store business cards and photographs. Or get an expandable folder if you are a "stuffer".

Youth2YoungAdult Care Notebook

Table of Contents

Keep Track of Your Contacts
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Health Care Transition Resources for Youth
Health Care Transition Resources for Parents, Families and Caregivers
Health Care Transition Resources for Providers
Health Care Transition Resources for Educators

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Family Information

- Your Name: _____ Nickname: _____
Date of Birth: _____
Diagnosis: _____
Blood Type: _____

Legal Guardian: _____
Address: _____
Phone: _____

Family Members

- Mother's Name: _____
Address: _____ Email: _____
Daytime Phone: _____ Evening Phone: _____ Cell: _____

- Father's Name: _____
Address: _____ Email: _____
Daytime Phone: _____ Evening Phone: _____ Cell: _____

- Sibling's Name: _____ Age: _____ Name: _____ Age: _____
Name: _____ Age: _____ Name: _____ Age: _____

- Other Household Members: _____

- Important Family Information: _____

- Language Spoken at Home: _____
Other Language(s): _____
Interpreter Needed? Yes: No:
Interpreter: _____ Phone: _____

Emergency Contact

- Name: _____
Address: _____ Email: _____
Daytime Phone: _____ Evening Phone: _____ Cell: _____

iTransition-Health: Resources for Youth and Young Adults

Check Your Skills

(Maryland Department of Health and Mental Hygiene, Prevention and Health Promotion Administration, Office for Genetics and People with Special Health Care Needs.
For more information visit: <http://phpa.dhmh.maryland.gov/genetics/SitePages/home.aspx>

AGES 12 – 14 “New Responsibilities”

Transition Checklist
(Check the items that are true for you.)

- I can describe how my disability or health condition affects my daily life.
- I can name my medications (using their proper names), and the amount and times I take them.
- I answer at least one question during a health care visit.
- I have talked with my doctors or nurses about going to different doctors when I am an adult.
- I manage my regular medical tasks at school.
- I can call my primary care doctor's or specialist's office to make or change an appointment.

AGES 15 – 17 “Practicing Independence”

Transition Checklist
(Check the items that are true for you.)

- I keep a personal health notebook or medical journal.
- I reorder my medications when my supply is low and call my doctor when I need a new prescription.
- I answer many of the questions during a health care visit.
- I spend most of the time alone with the doctor(s) during health care visits.
- I tell my doctors I understand and agree with the medicines and treatments they suggest.
- I know if my doctors do not take care of patients who are older than a certain age (for example, 21).
- I regularly do chores at home.
- I can tell someone the difference between a primary care doctor and a specialist.

AGES 18 & UP “Taking Charge

Transition Checklist

- I can tell someone the effects that getting older may have on my disability or health condition.
- I can tell someone about medications that I should not take because they might interact with the medications I take.
- I am alone with the doctor(s) or choose who is with me during health care visits.
- I answer all the questions during a health care visit.
- I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
- I manage all of my regular medical tasks outside the home (school, work).
- I can tell someone what new legal rights and responsibilities I gained when I turned 18 years old (sign medical consent forms, make medical decisions by myself).
- I can tell someone how long I can be covered under my parent's health insurance plan and what I need to do to maintain coverage (such as be a full-time student).

Source: *Envisioning My Future: A Young Person's Guide to Health Care Transition* from Children's Medical Services, Florida Department of Health. Available at: http://hctransitions.ichp.ufl.edu/pdfs/envisioning_my_future.pdf



Care Schedule

TIME	CARE
Morning	
Afternoon	

.....

Care Schedule

TIME	CARE
Evening	
Night	

.....

Diet Tracking Form

DATE	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

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Medical / Dental Community Health Care Providers

• Primary / Community Care Provider: _____
Office Nurse: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Community Hospital: _____
Medical Record Number: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Community Specialty Care Provider: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Community Specialty Care Provider: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Dentist / Orthodontist: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

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Pharmacy

Community Health Care / Service Providers

• Pharmacy: _____ Hours/Days of Operation: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Pharmacy: _____ Hours/Days of Operation: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Pharmacy: _____ Hours/Days of Operation: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

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Therapists

Community Health Care / Service Providers

Therapists:

- Occupational Therapist (OT) _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

- Physical Therapist (PT): _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

- Speech-Language Pathologist: _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

.....

Insurance/Funding Sources

• Insurance Company: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Insurance Company: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Insurance Company: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Supplemental Security Income (SSI): _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

(continued)



Insurance/Funding Sources

• Other: _____
Contact Person/Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Other: _____
Contact Person/Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

.....

Home Care

Community Health Care / Service Providers

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

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Special Transportation Community Health Care / Service Providers

- Transportation (to and from medical / therapy appointments)

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

- Transportation (to and from medical / therapy appointments)

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

.....

Equipment / Supplies

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____
Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____
Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____
Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____
Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

The Center for Children with Special Needs

Care Plans for Teens

What is a care plan?

A care plan is written information about how to best care for your own health needs. It is a way for you to know about, understand, and participate in your care. It is something you and your parents or doctor can make together.



A care plan may include:

- What medicines you take and when
- What foods you should avoid
- How often you get physical therapy
- What others should do if you have an emergency

How can a care plan help me?

Care plans can help you be active in your own care. They help you get information about your condition and understand your health history. They also help you prepare for spending time away from home or for emergency situations.

A teen with diabetes explains:

“Managing my health condition can be complicated. There are so many parts to keep track of and I can get overwhelmed. Creating and filling out a care plan really helps me focus on what questions I need to be asking and what things I need to be thinking about. It allows me to take on more responsibility for my own health. I print out copies of my care plan and make a list of people I should share it with. It makes talking to them much easier and I don't forget anything. My swim coach, friends, and teachers really appreciate it!”

Sound like something you might find useful?

[View sample care plans or create your own](#) ^[1].

Source URL: <http://cshcn.org/planning-record-keeping/care-plans-teens>

Links:

[1] <http://cshcn.org/care-plans-teens/teens-create-your-own-care-plan>

.....

Hospital Name

Address: _____

City, State, Zip Code: _____ Website: _____

Phone Numbers:

Main Number: _____ Emergency Room: _____

Medical Record Number: _____

• Clinic: _____ Hours/Days of Operation: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____ Email: _____

• Clinic: _____ Hours/Days of Operation: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____ Email: _____

• Clinic: _____ Hours/Days of Operation: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____ Email: _____



‘MAKE-A-CALENDAR’

Month

Year

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY



Notes



iTransition-Health: Resources for Youth and Young Adults

Websites and Online Resources

(Maryland Department of Health and Mental Hygiene, Prevention and Health Promotion Administration, Office for Genetics and People with Special Health Care Needs. For more information visit:

<http://phpa.dhmh.maryland.gov/genetics/SitePages/home.aspx>

Health Care Transition Resources for Youth

- **Youth2YoungAdult Care Notebook**
<http://cshcn.org/planning-record-keeping/teen-care-notebook> This resource help youth and young adults manage aspects of their own health care. It contains pre-made, fillable forms.
- **KidsHealth**
http://kidshealth.org/teen/index.jsp?tracking=T_Home This site educates youth on health basis, diseases and conditions.
- **The Youthhood**
<http://www.youthhood.org> – This site helps you start thinking about what you want to do with the rest of your life and plan for your future. Click on “[The Health Clinic](#)” for resources to help with health issues like doctor visits and health insurance.
- **Got Transition?**
<http://www.gottransition.org/youth-information> - This is the National Health Care Transition Center’s website and it has resources for youth (mostly links to other websites.) They also have a Facebook page and the “[Got Transition Radio Show](#)”. Click to listen to shows on topics like ‘Before a Dr’s visit: From Panic to Prepared’ and ‘Healthcare Transition & College- It Doesn’t Have to be Learned the Hard Way!’
- **Healthy Transitions**
http://healthytransitionsny.org/skills_media/tool_show - This is New York State’s website for moving from pediatric to adult health care. It has lots of fun and useful tools and ideas to help with health care transition. Some of the things are just for New York state residents, but a lot of the stuff is good for everyone, no matter where you live.
- **My Med Schedule**
<http://www.mymedschedule.com/> - This site helps you create and print medication schedules and to set up text or email reminders for yourself to take your meds and get refills.
- **Maryland Children and Youth with Special Health Care Needs Resource Locator**
<http://specialneeds.dhmh.maryland.gov>
This is an easy to use online database designed to help families of children with special health care needs, youth and providers find needed resources. It is accessible in over 50 languages, and offers user-friendly features including helpful search features, interactive maps and directions to each resource, and is 508-compliant for those with visual impairments.
- **Maryland Transitioning Youth**
<http://www.mdtransition.org/> - This site has transition planning resources for employment, education, health care and transportation for Maryland youth and young adults.

iTransition-Health: Resources for Youth and Young Adults

Websites and Online Resources

(Maryland Department of Health and Mental Hygiene, Prevention and Health Promotion Administration, Office for Genetics and People with Special Health Care Needs. For more information visit:

<http://phpa.dhmh.maryland.gov/genetics/SitePages/home.aspx>

Transition Resources for Parents, Families and Caregivers

- **My Health Care Notebook**
http://fha.dhmh.maryland.gov/genetics/SitePages/care_notebook.aspx - This resource helps parents manage aspects of their child and or youth's health care. It contains pre-made, fillable forms.
- **Maryland Children and Youth with Special Health Care Needs Resource Locator**
<http://specialneeds.dhmh.maryland.gov>
This is an easy to use online database designed to help families of children with special health care needs, youth and providers find needed resources. It is accessible in over 50 languages, and offers user-friendly features including helpful search features, interactive maps and directions to each resource, and is 508-compliant for those with visual impairments.
- **Got Transition**
<http://www.gottransition.org/family-information> - This part of the Got Transition website is for families to find and share transition information. Families will use this site to plan for health care transition; get ready to talk to their child's or young adult's pediatrician about health care transition; and learn about ways their young adult can help themselves as they go through a health care transition.
- **Maryland Transitioning Youth**
<http://www.mdtransition.org/> - This site has transition planning resources for employment, education, health care and transportation for Maryland youth and young adults.
- **Transition to Adult Health Care: A Training Guide in Two Parts**
<http://www.waisman.wisc.edu/wrc/pdf/pubs/TAHC.pdf> - This training resource "Transition to Adult Health Care: A Training Guide in Two Parts" helps young people with special health care needs and their parents prepare for transition to adult health care. Part One is aimed at parents of children with special needs. Part Two is aimed at the young people themselves.
- **Emergency Preparedness for People with Disabilities and their Families: The Take and Go Emergency Book -**
<http://new.dhh.louisiana.gov/assets/docs/OCDD/publications/EmergencyPreparednessTheTakeandGoEmergencyBook.pdf>
-This resource is a quick source of information during disasters if families are separated.

iTransition-Health: Resources for Youth and Young Adults

Websites and Online Resources

(Maryland Department of Health and Mental Hygiene, Prevention and Health Promotion Administration, Office for Genetics and People with Special Health Care Needs. For more information visit:

<http://phpa.dhmh.maryland.gov/genetics/SitePages/home.aspx>

Transition Resources for Providers

- **National Health Care Transition Center: Got Transition**
<http://www.gottransition.org/providers-best-practices> - This portion of the National Health Care Transition Center’s website: Got Transition supports health care professionals to implement transition best practices.
- **Maryland Children and Youth with Special Health Care Needs Resource Locator**
<http://specialneeds.dhmh.maryland.gov>
This is an easy to use online database designed to help families of children with special health care needs, youth and providers find needed resources. It is accessible in over 50 languages, and offers user-friendly features including helpful search features, interactive maps and directions to each resource, and is 508-compliant for those with visual impairments.
- **Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home**
<http://www.gottransition.org/UploadedFiles/Files/HCTClinicalReporteversion27June2011.pdf> -
This clinical report/resource represents expert opinion and consensus on the practice-based implementation of transition for all youth beginning in early adolescence. It provides a structure for training and continuing education to further understanding of the nature of adolescent transition and how best to support it. Primary care physicians, nurse practitioners, and physician assistants, as well as medical subspecialists, are encouraged to adopt these materials and make this process specific to their settings and populations.

Transition Resources for Educators

- “Health in the Individualized Education Plan (IEP)” -
(<http://depts.washington.edu/healthtr/documents/iep.pdf>) -These Washington State resource provides details on the parts of the IEP and how measurable health goals can be included.
- Adolescent Health Transition Project - (<http://depts.washington.edu/healthtr/school/iep.html>)
- This is a resource involving teens with SHCN, schools, and providers in transition.
- “Transition Planning for Special Education Students: The Role of the School Nurse”
(<http://depts.washington.edu/healthtr/documents/importanceofhealth.pdf>) - This resource provides details steps the school nurses can use for health transition planning.
-

iTransition-Health: Resources for Youth and Young Adults

Websites and Online Resources

(Maryland Department of Health and Mental Hygiene, Prevention and Health Promotion Administration, Office for Genetics and People with Special Health Care Needs. For more information visit:

<http://phpa.dhmh.maryland.gov/genetics/SitePages/home.aspx>

- “Matrix for Including Health in the IEP and Transition IEP” (http://depts.washington.edu/healthtr/documents/matrix_iep.pdf) - This resource is a chart which includes both the parts of the IEP and the Transition IEP.
- Parent Brief: “Promoting Effective Parent Involvement in Secondary Education and Transition” (<http://www.ncset.org/publications/viewdesc.asp?id=2967>) - This resource is from the National Center on Secondary Education and Transition which provides source of information for youth with disabilities and support person.

Agencies to Support Health Care Transition

- **Maryland Department of Health and Mental Hygiene (DHMH) Office for Genetics and People with Special Health Care Needs (OGPSHCN)**
<http://fha.dhmh.maryland.gov/genetics> - This office provides services for children and youth with special health care needs.
- **Maryland Center for Developmental Disabilities (MCDD)**
<http://mcdd.kennedykrieger.org/> - This agency provides programs and resources to people with disabilities and their families.
- **Maryland Developmental Disability Council (DD Council)**
<http://www.md-council.org/> - This agency provides leadership to ensure independence, productivity, integration, and inclusion of individuals with disabilities in the community through promotion of systems change.
- **Maryland Department of Disabilities (MDoD) and Governor's Interagency Transition Council for Youth with Disabilities (IATC)**
<http://www.mdtransition.org/> - This agency and council advances the rights and interests of people with disabilities so they may fully participate in their communities.
- **Maryland Medical Care Programs**
<http://mmcp.dhmh.maryland.gov/SitePages/Home.aspx> - This agency provides patient care coverage and services.
- **Maryland State Department of Education (MSDE)**
<http://www.marylandpublicschools.org> – This agency prepares children with disabilities to move from school to the appropriate postsecondary outcomes.