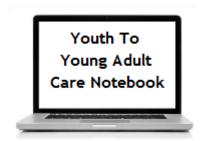


Office for Genetics and People with Special Health Care Needs

iTransition-Health: Maryland Health Care Transition Program "Youth Transition to Adulthood"

http://phpa.dhmh.maryland.gov/genetics/SitePages/Health Care Transition.aspx



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STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

201 W. Preston Street • Baltimore, Maryland 21201

Martin O'Malley, Governor - Anthony G. Brown, Lt. Governor - Joshua M. Sharfstein, M.D., Secretary

Dear Family,

This "Youth2YoungAdult" Care Notebook has been adapted from The Center for Children with Special Health Care Needs for youth and their families. This resource is designed to help youth and young adults to learn how to take charge of and manage their own health. It is helpful to have all the information you need in one place and organized so that you can find it easily. This notebook is a start, but you can certainly "customize" it any way you would like.

The Office for Genetics and People with Special Health Care Needs (OGPSHCN) is also a resource for information you may need about services for children and youth with special health care needs. Please feel free to contact us at the numbers below, especially our Children's Resource Line:

The Office for Genetics and People with Special Health Care Needs (OGPSHCN) is also a resource for information you may need about services for children and youth. Please feel free to contact us at the numbers below, especially our Children's Resource Line:

Birth Defects Reporting & Information System	410-767-6625	
Children's Health Resource Line	410-767-1063 or	1-800-638-8864
Children's Medical Services	410-767-5164	
Infant Hearing Services	410-767-6432 or	1-800-633-1316
Sickle Cell Disease Services	410-767-6737	
Specialty Care Services Health Care Transition Services	410-767-5592	
Health Care Transition Services	410-767-5602	

Our resource database on the web at http://specialneeds.dhmh.maryland.gov/ provides a searchable database of resources for children and youth with special health care needs across Maryland, and includes a section on Youth Transition. We hope you find these resources helpful.

Sincerely,

Sound of Harris

Donna X. Harris

Director

Office for Genetics and People with Special Health Care Needs

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
Hospital Information List
Medical/Dental Care Providers List
Home Care Providers List
Therapists List
Pharmacy List
Special Transportation List
Teen Family Information List
Insurance/Funding Sources List
Keep Track of Appointments and Care
Care Schedule
Appointment Log
Medical/Surgical Highlights
Lab Work/Tests/Procedures List
Equipment and Supplies List
Medications List
Diet Tracking Form
Hospital Stay Tracking Form
Medical Bill Tracking
Make a Calendar
Notes
Document Your Care Plan
Getting to Know Me
What's the Plan?
Emergency Information Card
iTransition-Health: Online Resources
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

Family Information

Your Name:		_ Nickname:		
Date of Birth:				
Diagnosis:				
Blood Type:				
Legal Guardian:				
Address:				
Phone:				
Family Members				
Mother's Name:				
Address:				
Daytime Phone:	Evening Pl	hone:	Cell:	
• Father's Name:				_
Address:				
Daytime Phone:	Evening Pl	hone:	Cell: _	
Sibling's Name:	Age:	Name:		_ Age:
Name:	Age:	Name:		Age:
Other Household Member	·S:			
 Important Family Informat 	ion:			
 Language Spoken at Hom 	ne:			
Other Language(s):				
Interpreter Needed? Yes:	: No: 🗌			
Interpreter:			Phone:	
Emorgonou Contact				
Emergency Contact				
Name:				
Address:				
Daytime Phone:	Evening Pi	none:	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"

AGES 15 – 17 "Practicing Independence"

AGES 18 & UP "Taking Charge

		Iransition Checklist
Transition Checklist	Transition Checklist (Check the items that are true for you.)	I can tell someone the effects that getting older may have on my disability or health condition.
(Check the items that are true for you.)	I keep a personal health notebook or	or health condition.
I can describe how my disability or health condition affects my daily life.	medical journal. I reorder my medications when my	I can tell someone about medications that I should not take because they might interact with the medications I take.
I can name my medications (using their proper names), and the amount and	supply is low and call my doctor when I need a new prescription.	I am alone with the doctor(s) or choose who is with me during health care visits.
times I take them.	I answer many of the questions during a health care visit.	I answer all the questions during a health care visit.
I answer at least one question 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	I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
I have talked with my doctors or nurses about going to different doctors when	with the medicines and treatments they suggest.	I manage all of my regular medical tasks outside the home (school, work).
I am an adult. I manage my regular medical tasks	I know if my doctors do not take care of patients who are older than a certain age (for example, 21).	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).
at school. I can call my primary care doctor's or specialist's office to make or change an appointment.	I regularly do chores at home. I can tell someone the difference between a primary care doctor and a specialist.	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							

Medical / Dental **Community Health Care Providers**

Office Nurse:			
		Email:	
Website:			
Community Hospital	l:		
Medical Record Nur	nber:		
Address:			
Phone:	Fax:	Email:	
Website:			
Community Specialt	y Care Provider:		
Address:			
Phone:	Fax:	Email:	
Website:			
Community Specialt	y Care Provider:		
Community Specialt	y Care Provider:	Email:	
Community Specialt Address: Phone:	y Care Provider: Fax:		
Community Specialt Address: Phone: Website:	ty Care Provider: Fax:	Email:	
Community Specialt Address: Phone: Website: Dentist / Orthodontis	ty Care Provider: Fax: st:	Email:	
Community Specialt Address: Phone: Website: Dentist / Orthodontis Address:	ty Care Provider: Fax: st:	Email:	

Pharmacy

Community Health Care / Service Providers

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

Therapists

Community Health Care / Service Providers

Therapists:			
 Occupational Ther 	apist (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:	

Appointment Log

DATE	PROVIDER	REASON FOR APPOINTMENT / CARE PROVIDED	NEXT APPOINTMENT

Insurance/Funding Sources

Insurance Company			
		Email:	
website.			
Insurance Company: _	_		
Phone:	Fax:	Email:	
Website:			
Insurance Company: _			
		Email:	
Website:			
Supplemental Security	y Income (SSI):		
Contact Person / Title	:		
			_
		Email:	
Wehsite:			

(continued)

Insurance/Funding Sources

Oller			
Contact Person/Title	:		
Address:			
		Email:	
Website:			
Other:			
Phone:	Fax:	Email:	
Website:			

......

Medical Bill Tracking Form

DATE	PROVIDER	COST	INSURANCE PAID	DATE PAID	FAMILY OWES	DATE PAID

Home Care

Community Health Care / Service Providers

Home Nursing Agency:	
Start Date:	
	Email:
Home Nursing Agency:	
	Email:
Website:	
Home Nursing Agency:	
Contact Person:	
	Email:
Website:	

Medications

A 11		•	
ΔΠ	ı⊵r∩	ies:	
<i>~</i> 11	ici y	IICS.	

Pharmacy: Phone:

MEDICATION	DATE STARTED	DATE STOPPED	DOSE / ROUTE (with or without food?)	TIME GIVEN	PRESCRIBED BY

Special Transportation Community Health Care / Service Providers

Transportation (to and f	rom medical / therapy a	opointments)	
Contact Person:			
Agency:			
Address:			
		Email:	
Website:			
 Transportation (to and f Contact Person: 	rom medical / therapy ap	,	
o ,			
		Email:	
Wehsite:			

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:		

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



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:		
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:

.....

Hospital Stay Tracking Form

DATE	HOSPITAL	REASON	NOTES

Lab Work / **Tests / Procedures**

DATE	TEST	RESULTS	COMMENTS

Medical / Surgical **Procedures**

DATE	PROCEDURE	RESULTS	COMMENTS
	_	_	

"MAKE-A-CALENDAR"

Month

Year

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Notes

(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

<u>http://kidshealth.org/teen/index.jsp?tracking=T_Home</u> 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

<u>http://www.mymedschedule.com/</u> - 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

<u>http://www.mdtransition.org/</u> - This site has transition planning resources for employment, education, health care and transportation for Maryland youth and young adults.

(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

<u>http://fha.dhmh.maryland.gov/genetics/SitePages/care_notebook.aspx</u> - 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

<u>http://www.mdtransition.org/</u> - 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/EmergencyPreparednessTheTakendGoEmergencyBook.pdf

-This resource is a quick source of information during disasters if families are separated.

(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.pd

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.

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(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)

 <u>http://www.mdtransition.org/</u> 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.