The Road to Adulthood: Creating Your Own Medical Portfolio
My “Must Have” Papers

Community of Practice, Northeast Massachusetts 2011

There are some papers that everybody must have. Here are some tips about keeping and protecting your important personal records and information.

Get a Binder or Folder to Keep Important Documents – an “accordion folder” works really well

What to Keep in Your Wallet or Purse

- State ID or Driver’s License
- SNAP Card
- Health Insurance Card
- Important numbers
- Appointment Book / Calendar
- ATM Card (only if needed)
- Who to call in case of emergency
- List of medications & who doctor prescribes them.

What to Keep in Your Binder

- Education documents
- Medical Information
- Housing / Utilities information
- Work Information
- Financial Information
- Learn more about these on the other side of this paper

Essential Documents to Have

These documents can help you get the other information you may need. You only need 2 of these to get a job and fill out the necessary paperwork.

- Birth Certificate
- Social Security Card
- State ID or Drivers License
- Passport: This document can replace all of the essential documents listed above

If you need to get your birth certificate: Go to the Town Clerk or City Hall in the town/city you were born in and request it. If you were born further away you can contact the Town Clerk/City Hall (via internet or phone) and ask how to get it. Most often there is a fee (up to about $25). You may also ask a DCF/DMH/DYS worker if they either have a copy or can assist you.

If you need to get a License/ID/Permit: Go to the Registry of Motor Vehicles (RMV). You will need the required ID. Sometimes if you don’t have enough forms of ID (such as a birth certificate and social security card) a letter from DMY or DCF may be helpful explaining your situation. MASS.gov/RMV has more info about this.

To get a social security card: You, or your representative payee, will need to present your ID to the Social Security office and request a new card. (There is a limit to the number of cards you can request in your lifetime so it is important you keep it safe). Don’t keep your social security card in your wallet unless you are using it that day to apply for a job-store it somewhere safe. Try to memorize the number.

To get a passport: Go to your local post office or check with your state’s Passport Agency for details.

If you keep information such as a social security number or bank information in your phone be sure to password protect it in case you get a new phone, or your phone is lost or stolen.
After turning age 18:

- Doctors and other health care providers must:
  - Get informed consent from adult patients to carry out a medical procedure
  - Have the patient’s written permission to share health information with others

- BUT…. Patients can ask family members or friends to help answer questions and fill out forms
Adult patients should be able to:

- Name chronic medical conditions or allergies
- Know the correct names of medications, when to take them, and why
- Take medications independently
- Order medications when needed
- Call to make doctor appointments
- Know what to do in case of an emergency
- Know what to do to stay healthy, and do it without being reminded

If you can’t do these things, you need to learn!
Self-Advocacy Guides

Since You’re Not a Kid Anymore
It’s time to be more in charge of your health

Now that you’re in High School...
It’s time to be more in charge of your health

When You’re 18
You are in charge of your health

Health Care Transition Guide for Teens in Middle School
Health Care Transition Guide for Teens in High School
Health Care Transition Guide for Young Adults
10 Steps to Successful Health Care Transition

Success in the classroom, within the community and on the job requires that young people stay healthy. The best ways to stay healthy are to understand your health, participate in health care decision making, and receive age-appropriate care. Here are 10 ways to ensure a smooth transition from pediatric to adult health care for all teens and young adults, including those with disabilities or chronic health conditions.

1. Start early! Begin preparing for transition even when very young, like starting a health summary and talking about health needs.

2. Focus on responsibility for health care. Taking responsibility for health care should be based on age and abilities. Become more independent by learning the skills for managing health care, like scheduling appointments, arranging transportation, taking medication, filling prescriptions, and talking to doctors.

3. Create a health summary. Put important information about personal health in one place, including medications and plans for an emergency.

4. Create a health care transition plan. Work with your primary care provider to develop a written health care transition plan that includes future goals, services that will be needed, who will provide them, and how they will be paid for.

5. Maintain wellness. Support good habits that will continue into adulthood: Talk about risky behaviors such as alcohol use and smoking as well as sexuality and relationships. You can ask to speak to your physician alone!

6. If you have an Individualized Education Plan (IEP) or 504 Plan, include health care self-management activities in the plan. Consider self-determination and advocacy skills, understanding personal health conditions and needs, and knowing how to access health care services.

7. Know options for health insurance and public assistance programs in adulthood. If you’re unsure about eligibility, it’s always best to go ahead and apply.

8. Find adult providers. If still in the care of pediatric providers, ask them to help you identify and transfer to a primary care physician and specialists (including mental health professionals) who work with adults. Transfer of care typically occurs between ages 18 and 21.

9. Know about legal rights and responsibilities that start at age 18! Learn about community services and supports for adults.

10. Include health in other areas of transition. Ask your primary care physician to provide documentation of medical conditions and special health care needs for other programs or agencies, as needed.

Visit www.FloridaHATS.org to find resources and services.

June 2012
JA Transition Toolkit & Resource Library

JA Transition Toolkit

Your future is on its way.

Foundation Transition Toolkit is designed to help youth and their families develop the skills they need to successfully make the leap to independence. Take a brief health care skills assessment and create a customized Transition Toolkit that meets YOUR needs. Or check out the resource library to learn more about: Communicating with your doctors, organizing your health care, going to college with arthritis, managing stress, eating well, and much more!

Create your transition toolkit at www.JAtransition.org.

Meet Other Families

JA Conference
Camps
More...

What's Happening Near You?

Speak to someone in your local area about the latest JA programs and events.

Find Local Contact

KGAT News Updates
Get the quarterly JA e-newsletter

www.kidsgetarthritisalso.org/resources/transition-toolkit.php
Resource Library

Communicating with friends and families about your disease
Communicating with your Doctor and Scheduling Appointments
Depression and Anxiety
Finding an Adult Rheumatologist
Getting a Job
Getting Organized and Creating a Health Summary
Going to College
Health Insurance
Juvenile Dermatomyositis
Juvenile Idiopathic Arthritis
Juvenile Scleroderma
Lupus
Managing Stress
Medications
Mixed Connective Tissue Disease
Nutrition
Other Rheumatic Diseases
Preparing for Transition: Videos
Reproductive Health
Scholarships
Transition Overviews and Guides
Transition Tools and Checklists
Vasculitis
Teen Care Notebook

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

The Teen Care Notebook is a modified version of the Care Notebook for Parents, which only include the things a teen might need. It's a great way to stay on top of things and 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 Teen 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 Teen 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.

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### 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
## Getting to Know Me

<table>
<thead>
<tr>
<th>Name:</th>
<th>Nickname:</th>
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</thead>
<tbody>
<tr>
<td>Date of Birth:</td>
<td>Today's Date:</td>
</tr>
</tbody>
</table>

- Who am I? How would I describe myself?

- What are my strengths/interests?

- What is my life like in the community? (Things to consider: school, favorite places)

- How would I describe my family situation? (Things to consider: siblings, parents, other relatives, pets, where you call home)

- What is my diagnosis (diagnoses) and what that means for me? (Things to consider: doctor's explanation, my explanation)

- What are my challenges? (Things to consider: things that frustrate me about my illness, how people interact with me due to my illness)

- What do I think of my overall health? (Things to consider: limitations, things that bother me, things I can control)

- What are my prior surgeries, procedures, lab/diagnostic studies? Date: | Procedure: | Results: |

- What are my current medicines/doses?

- What are my allergies?

- What are things to avoid? (Things to consider: food, procedures, activities such as gym class, etc.)

- What Equipment/Assistive Technology do I need?
  - Braces/orthotics
  - Walker, wheelchair
  - Communication device
  - Home O₂
  - Insulin pump
  - Nebulizer
  - Suction
  - Other:

- What other things I'd like you to know about me and my condition:

- How do I want information? (Things to consider: tell me in writing, tell me alone, or tell me and my parents together)

- Things I want help with:

- Boundaries:

- My responses to my illness: (Things to consider: general responses, tired, excited, hungry)

- How I want to be treated:
  - It's OK to ask me if I need help.
  - It's not OK to ask me if I need help.
  - It's OK to ask me details about my condition.
  - It's not OK to ask me details about my condition.
# Medical Summary and Emergency Care Plan

**Six Core Elements of Health Care Transition 2.0**

This document should be shared with and carried by youth and families/caregivers.

<table>
<thead>
<tr>
<th>Date Completed:</th>
<th>Date Revised:</th>
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</thead>
</table>

**Contact Information**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Nickname:</th>
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<tbody>
<tr>
<td>D.O.B.</td>
<td>Preferred Language:</td>
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<tr>
<td>Parent (Caregiver):</td>
<td>Relationship:</td>
</tr>
<tr>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Cell #:</td>
<td>Home #:</td>
</tr>
<tr>
<td>E-Mail:</td>
<td>Best Way to Reach:</td>
</tr>
<tr>
<td>Health Insurance/Plan:</td>
<td>Group and ID #:</td>
</tr>
<tr>
<td>Emergency Care Plan:</td>
<td>Relationship:</td>
</tr>
<tr>
<td>Emergency Contact:</td>
<td>Phone:</td>
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</tbody>
</table>

**Preferred Emergency Care Location:**

**Common Emergent Presenting Problems** | Suggested Tests | Treatment Considerations
--- | --- | ---

**Special Concerns for Disaster:**

**Allergies and Procedures to be Avoided**

<table>
<thead>
<tr>
<th>Allergies:</th>
<th>Reactions</th>
</tr>
</thead>
<tbody>
<tr>
<td>To be avoided:</td>
<td>Why?</td>
</tr>
<tr>
<td>Medical Procedures:</td>
<td></td>
</tr>
<tr>
<td>Medications:</td>
<td></td>
</tr>
</tbody>
</table>

**Diagnoses and Current Problems**

**Problem** | Details and Recommendations
--- | ---

- Secondary Diagnosis
- Behavioral
- Communication
- Feed & Swallowing
- Hearing/Vision
- Learning
- Orthopedic/Musculoskeletal
- Physical Anomalies
- Respiratory
- Sensory
- Stamina/Fatigue
- Other

**Medications**

<table>
<thead>
<tr>
<th>Medications</th>
<th>Date</th>
<th>Frequency</th>
<th>Medications</th>
<th>Date</th>
<th>Frequency</th>
</tr>
</thead>
</table>

**Health Care Providers**

<table>
<thead>
<tr>
<th>Provider</th>
<th>Primary and Specialty</th>
<th>Clinic or Hospital</th>
<th>Phone</th>
<th>Fax</th>
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</table>

**Prior Surgeries, Procedures, and Hospitalizations**

<table>
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<tr>
<th>Date</th>
<th>Date</th>
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<th>Date</th>
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**Baseline Vital Signs:**

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<tr>
<th>HT</th>
<th>WT</th>
<th>RR</th>
<th>HR</th>
<th>BP</th>
</tr>
</thead>
</table>

**Baseline Neurological Status:**

**Most Recent Labs and Radiology**

<table>
<thead>
<tr>
<th>Test</th>
<th>Date</th>
<th>Result</th>
</tr>
</thead>
</table>

**EEG**

**EMG**

**X-Ray**

**C-Scan**

**MRI/AI**

**Other**

**Equipment, Appliances, and Assistive Technology**

- Wheelchair
- Communication Device
- Orthotics
- Other

- Other

- Other

**Other**

- Other

- Other

- Other

- Other
Your Family Medical History Questionnaire

Even if you’re healthy now, knowing your family health history will provide important clues to your future health and the future health of your family. Do certain diseases and health conditions run in your family? If you’re unsure, begin collecting your family health history today by using this easy to follow questionnaire and checklist.

You may feel uncomfortable asking for personal health information from some family members, but it’s important to try. Pick a time when you’re less likely to get interrupted so your discussion can be more relaxed. And, remember, older relatives (and even younger relatives) may not use the same health terms as you do, so be aware to listen for clues about how they might describe a relative’s behavior or health history. For example, “Grandmother always spent a week in bed in the dark each month,” could indicate that she suffered from menstrual migraines.

The information you gather will help you and your health care provider determine what health problems you may be at increased risk for in the future so that you can take action today to lower those risks. At HealthyWomen, we want you to live the longest, healthiest life possible. This Family Medical History Questionnaire can help you do just that.

ALL ABOUT YOU

<table>
<thead>
<tr>
<th>Your name:</th>
<th>List any questions or concerns you may have about your medical history:</th>
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<tr>
<td>Date of birth:</td>
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<td>Blood type:</td>
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<td>Ethnic origin:</td>
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Known health problems:           Onset age:                   List any lifestyle or environmental factors related to your health and wellness:

- Alcohol and/or drug abuse
- Allergies
- Asthma
- Cancer If yes, what kind? __________
- Depression
- Diabetes
- Heart disease
- High blood pressure
- High cholesterol
- Mental illness
- Stroke
- Other __________________________
- Other __________________________

Do you smoke? ☐ Yes ☐ No
If yes, cigarettes smoked per day: __________________________
If yes, total years as a smoker: __________________________

How often do you experience stress: __________________________

Do you get regular physical activity? ☐ Yes ☐ No
If yes, how often: __________________________

Is your diet healthy and balanced? ☐ Yes ☐ No

Do you take risks with your health, such as abuse drugs and alcohol, drive over the speed limit, not wear a seat belt or have multiple sexual partners or unprotected sex? ☐ Yes ☐ No If yes, please describe:
## Appointment Log

<table>
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<tr>
<th>DATE</th>
<th>PROVIDER</th>
<th>REASON FOR APPOINTMENT / CARE PROVIDED</th>
<th>NEXT APPOINTMENT</th>
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Electronic Resource List
for Health Care Accessibility and Self-Management

1. **www.kidsgetathritis2oo.org/resources/transition-toolkit.php**: The JA Transition Toolkit offers an interactive self-assessment and creates a customized kit for YOUR transition needs. The resource library provides information about communicating with your doctors, organizing your health care, going to college with arthritis, managing stress, eating well, etc.


3. **www.gotransition.org/youthandfamilies**: Got Transition, the national Center for Health Care Transition Improvement, offers best practices and resources that include youth and family transition stories, radio episodes and webinars/videos.

4. **www.floridahats.org**: Florida Health and Transition Services provides a state clearinghouse of information for accessing adult-oriented health care and acquiring self-management skills.

5. **http://life.col.ufl.edu/jaxhats**: This website for JaxHATS, a medical home for medically complex teens and young adults in Jacksonville, FL, provides many tools and resources for health care management, including self-care instructional videos.

6. **http://flfcic.fwli.ufl.edu**: Florida Center for Inclusive Communities at USF. Click on Health Resources tab for Health Series Factsheets, My Health Passport, and other materials for individuals with intellectual or developmental disabilities.

7. **www.healthytransitionsny.org**: Teaches skills and provides tools for care coordination, keeping a health summary, and setting priorities during the transition process. It features video vignettes that demonstrate health transition skills and interactive tools.

8. **www.ahrq.gov/legacy/questions/ob**: An interactive website that allows you to electronically create a list of questions to take to medical appointments.


10. **www.aclspocketcard.org.uk/7-Millar.pdf**: Simple photo and video apps to support communication, by Sally Millar.

11. **www.santeacher.org**: Create and print AAC cards/sheets from templates.

12. **http://disabilities.temple.edu/aavocabulary/edall.shtml**: Vocabulary that individuals who use augmentative and alternative communication (AAC) and their families need to participate in socially-valued adult roles.

13. **www.freedomscientific.com/jaws-hq.asp**: Jaws for Windows is a powerful accessibility solution that reads information on your screen using synthesized speech.

14. **www.DeafMD.org**: Uses ASL to promote wellness of the Deaf and Hard of Hearing communities; provides explanations of medical tests, diseases, where to find a doctor.

15. **www.apple.com/accessibility**: Information about the many accessible features built into Apple’s products; click on “Special Education” for specifics.

16. **www.rjcooper.com**: Site devoted to adaptations and modifications of special software and hardware products.
