Keeping a Health Summary

Moving from Pediatric to Adult Health Care

Continuing Education Module

healthy transitions

healthytransitionsny.org

✔ Learn ✔ See ✔ Do

Skills for Moving from Pediatric to Adult Health Care

- ☐ Scheduling an Appointment
- ☐ Getting Health Insurance
- ☐ Deciding About Guardianship
- ☐ Speaking up at the Doctor's Office
- ☐ Understanding Your Disability
- ☐ Managing Medications
- ☑ Keeping a Health Summary
- ☐ Looking into Service Coordination
- ☐ Setting Health Goals
- ☐ Finding Community Resources

Welcome!

This education module provides information that families and professionals can use to help youths who have developmental disabilities to keep a health summary.

Keeping a Health Summary:

Skill attainment for this topic is defined when the adolescent or young adult is able to:

✔ **State why a health summary is useful**

✔ **Describe information that is included in the Transition Information Form**

✔ **Bring a Transition Information Form to medical appointments**

✔ **Keep the Transition Information Form up to date by asking a doctor to review it**

✔ **Archive the Transition Information Form on a secure MY PLACE site at HealthyTransitionsNY.org**

This continuing education module is part of a 10-unit curriculum that was developed for families, health care providers, service coordinators and other professionals who would like to facilitate the transition from pediatric to adult health care for youths who have developmental disabilities. Adolescence and young adulthood is a time of tremendous change, not just physically, but also in terms of social and emotional development, and due to transitions in services, supports and health care providers. The Healthy Transitions curriculum provides a context for mutual understanding and collaboration during this complex time.

The curriculum is organized around 10 key skills that youths need to develop in order to transition to adult health care. The skills are not sequential. They can be developed over time, between the ages of 14-25 years. The Healthy Transitions checklist (see "script pad") can be used to track accomplishments. Each module provides strategies that families and professionals can use to help youths to develop a particular skill. The curriculum emphasizes self-determination and the active involvement of young adults who have developmental disabilities in their own health care.

The modules begin with a vignette that illustrates a transition "success story". This is followed by didactic information and a list of references and resources for skill development. A table with "tips for collaboration" lists concrete steps that youths, families, service coordinators, and health care providers can take in order to facilitate the transition process. A self-assessment quiz is included at the end of each module.

In addition to the Continuing Education Modules, the Healthy Transitions project offers Lessons Plans, Videos and a Moderator Guide for educators that can be used in group settings with young adults. Our website also features a secure network of personal health sites called **MY PLACE** that link youths to a personal transition team for care coordination, planning, and setting priorities during the transition to adulthood.

Please visit us at HealthyTransitionsNY.org to find out more. We welcome feedback!

William

William is an 18 year old man with spina bifida who is heading out of state to attend college. He has a complex past medical history that includes shunt placement for hydrocephalus and multiple bladder surgeries. William performs intermittent catheterization to empty his bladder via a surgical stoma, or opening, on his abdomen. This stoma allows William to be independent with his self-care. William's pediatrician is familiar with medical guidelines for the diagnosis and treatment of urinary tract infections in patients who have a bladder stoma. However, physicians at the health center at William's college do not routinely care for patients who have had this surgery. That is why William and his pediatrician have created a Transition Information Form. William's pediatrician uses this form to list specific treatment protocols for managing William's care when he has an acute illness, such as a urinary tract infection. In addition, the Transition Information Form summarizes William's medical history and provides contact information for William's surgeons, in case doctors at William's college have questions. The Transition Information Form also includes important information about William's health, such as his baseline physical exam, the type of shunt he has, and disability-specific recommendations for preventive health care. William's insurance information and "ICD-9" billing codes are also listed on the Transition Information Form. This is convenient for the physicians who will be taking over his care. The Transition Information Form is archived on William's MY PLACE site at HealthyTransitionsNY.org. It can be accessed, updated, and printed at any time.

Keeping a Health Summary
Learning Objectives:

1. Understand rationale for maintaining a personal health summary.

2. List the major components of a personal health summary.

3. Identify situations that warrant updating and/or review of a personal health summary.

4. Be familiar with FTC and HIPAA regulations for personal health records.

5. Name two billing codes that can be used to pay for health care encounters that focus on creation and/or review of a personal health summary.

Keeping a Health Summary

Introduction

Many young adults who have developmental disabilities have complex medical histories. It is important to convey this information accurately and concisely during the transition from pediatric to adult health care. If adult health care providers do not have access to this important information, delayed treatment, unnecessary tests, and even serious errors can occur. In addition, adult health care providers are better able to provide care if they are aware of the community supports and habilitation services that a young adult receives. Finally, it is essential that adult health care providers have access to condition-specific medical treatment guidelines when caring for adults with developmental disabilities. A personal health summary provides all this information, and more. The Transition Information Form is a personal health summary that was specifically designed for youths who have developmental disabilities. This module will outline how the Transition Information Form can facilitate the transition process.

What is a personal health summary?

A personal health summary (or personal health record) is a synopsis of an individual's health status. It includes a baseline physical exam, a concise medical history and list of previous surgeries, patient-specific recommendations for preventive care and emergency care, and contact information for the individual's health care provider(s). The personal health summary allows for efficient transfer of knowledge about an individual. It can provide valuable information in many situations and settings (for example, when seeing a new specialist or in an emergency). A personal health summary can help to avoid confusion regarding current medication use or allergic reactions. It can inform new doctors about events in the patient's health history which may otherwise be forgotten or overlooked. It can facilitate information sharing among medical providers and caregivers. Because a personal health summary is managed and controlled by the patient or individual, it is readily available across a variety of settings and can be easily updated. There are many other advantages to keeping a personal health summary. It is an excellent way for a young adult to better understand his/her own health and to become more actively involved in his/her own health care. When there is a communication barrier (linguistic, cultural, or disability-related), the personal health summary can be used to convey complex information that might not otherwise be relayed during a health care encounter.

The American Health Information Management Association provides useful tips and current information about laws and regulations regarding the personal health record at myPHR.com. It also provides a set-by-step guide for creating a personal health summary (see Table on page 5) .

Seven Steps
for Creating a
Personal Health Record

(adapted from American Health Information Management Association at myPHR.com)

STEP 1

Contact doctors' offices or the health information management or medical records staff at each facility where treatment is provided. Ask the physician or the health information manager to help determine which parts of the medical record you need.

STEP 2

Ask for an "authorization for the release of information" form. Complete the form and return it to the facility as directed. Most facilities charge for cost of copying (including supplies and labor), as well as postage if the copy is mailed. It can take up to 60 days to receive medical records.

STEP 3

Organize the paper copies chronologically in a file folder.

STEP 4

Transfer electronic information to a storage device or use an Internet-based service to store and retrieve personal health information (for example, the Transition Information Form on **MY PLACE at HealthyTransitionsNY.org**).

STEP 5

Bring the PHR to all health care visits. Entries can be made by a health care provider, the patient, or a family member but should be reviewed for accuracy and updated regularly during health care encounters.

STEP 6

Create and carry a card or medic alert tag that has vital information for emergencies — such as medication needs or allergies. The PHR does not replace these, and may not always be available in an emergency.

STEP 7

Remember that the PHR is private information, so protect it and maintain confidentiality.

Regulations for personal health records

HIPAA or the Health Insurance Portability & Accountability Act was passed by Congress in 1996. There are two components to HIPAA: Title I and Title II. Title I helps to protect health insurance coverage for families and workers when they change or lose their jobs. Title II is known as the Administrative Simplification or AS provision. Title II covers standards for electronic data, and also covers the privacy and security of health data and information. Under HIPAA the patient controls whether and how his/her personal health information can be used. HIPAA covers all formats of medical information including spoken, written or electronic records. Although the medical record belongs to the provider, the information within it belongs to the patient.

According to HIPAA, patients have the following rights:

- **Right to access, review, and copy health information.**
- **Right to revise or request corrections to health information.**
- **Right to request history of disclosures of health information—to learn who has received it.**

Because *personal* health records are not a part of the health care provider's medical record, they are not considered to be legal records. Therefore, they are not HIPAA covered entities.

However, in 2009 the FTC or Federal Trade Commission adopted the breach notification rule which applies to entities which are not covered by HIPAA, primarily vendors or suppliers of personal health records. The rule requires that the FTC and consumers must be notified when the security of identifiable health information has been breached. Notifications for consumers should include: a description of what occurred, what type of information was involved, necessary steps individuals should take for protection, a description of what is being done to address the breach, and contact information.

Transition Information Form

The Transition Information Form was created by the New York State Institute for Health Transition Training so that youths, parents, and physicians can work together to give adult health care providers the information they need to provide high quality care for their young adult patients who have developmental disabilities. The format is adapted from the American Academy of Pediatrics' Emergency Information Form for Children with Special Health Care Needs. The Transition Information Form was developed in 2004 with input from young adults who have developmental disabilities, parents, and a team of information specialists and health care providers. Because it includes text fields for listing pediatric providers alongside a corresponding list of adult health care providers, it can be used as a transition planner during the transition years (ages 14-25). It is available electronically as a PDF file or as a hard copy that can be downloaded from the "Tools" section of the HealthyTransitionsNY.org website. The Transition Information Form can also be archived electronically on a secure personal health site at HealthyTransitionsNY.org called **MY PLACE**.

Components of the Transition Information Form
(available at HealthyTransitionsNY.org)

Basic Information
- Name, Address and Phone number
- Date of birth
- Health care guardian – name and phone number
- Emergency contact – name and phone number
- Best method of communication

Insurance Data
- Insurer name
- Policy number
- ICD-9 billing codes

Provider List (includes health care providers as well as habilation service providers)
- Primary care
- Emergency care
- Tertiary care hospital
- Specialty care (e.g. audiologist, endocrinologist, neurologist, etc.)
- Dental care
- Other service providers (pharmacy, home health supplies, service coordination etc)

Informal Providers ("Circle of Support")
- Family members, friends, neighbors, etc. who support the young adult who has a developmental disability with day to day issues that are related to health care, such as taking medications, transportation, community participation, and self determination.

Medical History
- Synopsis of main medical issue(s)
- List of conditions
- List of past surgeries

Baseline Physical Exam and Ancillary Findings
- Height and weight
- Vital signs
- Physical findings including baseline neurological exam
- Results of Lab, x-ray, EKG, etc.

Emergency Management Data
- Patient-specific complications that are common or can be anticipated
- Patient specific diagnostic and treatment considerations
- Procedures to be avoided (and why)

Health Maintenance Data
- Allergies (symptoms)
- Medication list
- Immunizations
- Prostheses, Appliances, Implantable Devices
- Antibiotic Prophylaxis (and why)
- Dietary restrictions (and why)

and when applicable:

- Nursing care plan
- Behavior management plan
- Pain management plan
- Advanced care directive
- Condition specific recommendations for health supervision

MY PLACE: A Shared Personal Electronic Health Record

MY PLACE is a *shared* personal health record that was specifically designed for youths who have developmental disabilities. MY PLACE is similar to websites such as CaringBridge.com in that it links an individual to his/her "Circle of Support". Because a MY PLACE site focuses on health care and features a personal health record (*Transition Information Form*), it is a powerful tool for bringing health care providers into the "Circle of Support" for a young adult who has a developmental disability.

MY PLACE sites allow individuals to create, archive, update, and print the *Transition Information Form*. MY PLACE also offers the individual the option of sharing access to the *Transition Information Form* with a personal transition team ("Circle of Support"). The team receives email alerts when changes are made to the *Transition Information Form*.

Team members also share a calendar with an email reminder system and a goal-setting tool. The goal-setter tool fosters self-determination by prompting the youth to identify supports and set priorities during the transition process. A discussion area facilitates information sharing across systems of care (schools, day-habilitation programs, medical offices, family etc.). Team discussions are archived on the site and can searched by topic and date. Individuals can print discussion topics for review by a physician or nurse during health care encounters.

A sample My Place home page

Transition Planning

It is important to make sure the personal health summary is current. The Transition Information Form should be updated annually and when:

- **There are any changes in health status or health conditions.**
- **There are any changes in health care providers.**
- **There are any surgeries or procedures performed.**
- **There are any changes in personal information, such as address or phone number.**

Transition to adulthood is a key time for creating or updating a health summary since many of the changes listed above take place within this time frame. A dedicated health care visit to review the Transition Information Form at least once annually between the ages of 14-25 years is a great way to be pro-active about health care transition. It assures that transition takes place as a planned-out process, rather than as an abrupt and poorly coordinated event. The Transition Information Form thus is much more than a personal health summary. It also serves as a transition planner that can be used to identify adult health care providers, to assemble a transition team, and to prepare the adolescent for a more active role in understanding and managing his/her own health care.

Billing Information

A standard reimbursement system for physician review of a personal health record has yet to be developed. This is a controversial topic, with medico-legal implications. For physicians who are willing to review a personal health summary with their patients, billing code 99358 can be used for time spent reviewing medical records. Time-based billing is recommended when greater than 50% of a visit is spent counseling, as is often the case when transition planning.

In Summary

Personal health summaries can provide essential information in a variety of health care settings and situations. The Health Insurance Portability & Accountability Act (HIPAA) gives patients (and/or their guardians) the right to access, review and copy their health data. The Federal Trade Commission, rather than HIPAA, regulates privacy and security of personal health records. The Transition Information Form is a template for a personal health record that was specifically designed for youths who have developmental disabilities. It can be archived on a secure **MY PLACE** site at HealthyTransitionsNY.org.

MY PLACE also offers tools for transition planning and linking health care providers with the "Circle of Support" for young adult patients who have developmental disabilities.

Keeping a Health Summary
Tips for Collaboration

Adolescent/Young Adult

- Work with family member and/or the Medicaid service coordinator to create a personal health site and Transition Information Form on MY PLACE at https://HealthyTransitionsNY.org/healthy//my_dmsn/index
- Identify informal care providers for the "Circle of Support" section of the Transition Information Form.
- Invite members of your "Circle of Support" to become transition team members on your MY PLACE site.

Family

- Collect copies of medical reports.
- Keep a timeline of surgeries and medical procedures.
- Compile and update a list of health care providers and their contact information.
- Use tools such as the Transition Information Form to compile and summarize health information.
- Work with youth and/or Medicaid service coordinator to create a personal health site and Transition Information Form on MY PLACE at HealthyTransitionsNY.org.

Health Care Providers

- Help families to identify and obtain key medical documents relevant to the personal health summary.
- Provide a list of ICD-9 codes that are commonly used for health care encounters so that families can add these to the Transition Information Form.
- Review the Transition Information Form once annually between the ages of 14-25 years with patients who have developmental disabilities.
- Consider joining the transition team on a MY PLACE site if youth/family members invite you to participate.

Service Coordinators

- Introduce youths and families to MY PLACE personal health sites by downloading the MY PLACE handbook, privacy policy, and Terms of Use from https://healthytransitionsny.org/healthy//my_dmsn/index
- Work with youth and/or family to create a personal health site and Transition Information Form on MY PLACE at HealthyTransitionsNY.org.
- Use information that has already been collected for the Individual Service Plan to fill in the "Provider list" and "Circle of Support" sections on the Transition Information Form.
- List goals from the Individualized Service Plan in the "Goal Setter" on MY PLACE. Use this tool to email transition team about progress and to celebrate goal attainment.

References and Resources

Health Information Security
Federal Trade Commission. Health Breach Notification Rule, Final Rule. Federal Register, Aug. 25, 2009.
http://edocket.access.gpo.gov/2009/pdf/E9-20142.pdf

Heubusch, Kevin. *FTC releases breach notification rule.* Journal of AHIMA, Aug. 25, 2009.
http://journal.ahima.org/category/personal-health-records/

Health Insurance Portability & Accountability Act (HIPAA)
American Health Information Management Association (AHIMA).
Your Privacy Rights.
http://www.myphr.com/index.php/privacy_and_phrs/your_privacy_rights/

U.S. Department of Health & Human Services, Centers for Medicaid and Medicare Services.
Overview and General Information on HIPAA.
https://www.cms.gov/hipaageninfo/

U.S. Department of Health & Human Services, Office for Civil Rights.
Health Information Privacy for Consumers and Guidance Materials for Consumers.
http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html

Personal Health Records
AHIMA *Quick Guide to Creating a PHR.*
http://www.myphr.com/index.php/quick_guide_to_creating_a_phr/

Bourgeois, F.C., Taylor, P.T., Emans, S.J., Nigrin, D.J. Mandl, K.D. (2008) Whose Personal Control?
Creating private, personally controlled health records for pediatric and adolescent patients.
Journal of the American Medical Informatics Association
15(6):737-743.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2585529/?tool=pubmed

Emergency Information Form for Children with Special Health Care Needs
American Academy of Pediatrics and American College of Emergency Physicians
http://www.aap.org/advocacy/emergprep.htm

Health Care Notebook
Parent to Parent of New York State.
Health Care Information & Education Center, Record Keeping.
http://www.parenttoparentnys.org/Family2Family/Record%20Keeping/Notebook/notebook.htm

Transition Information Form
New York State Institute for Health Transition Training.
http://healthytransitionsny.com/data/3490_2009TransitionInformationForm.pdf

*MY PLACE personal health sites at **HealthyTransitionsNY.org***
New York State Institute for Health Transition Training.
https://healthytransitionsny.org/healthy//my_dmsn/index

Quiz

1. **Which of the following basic components should be included in a personal health summary?**

   a. Insurer's name

   b. Medical history

   c. Emergency care plans

   d. Baseline physical exam

   e. All of the above

2. **Are personal health records HIPAA covered entities?**

   a. Yes

   b. No

3. **A personal health summary should be updated and reviewed when**

   a. There are any changes in health status or health conditions.

   b. There are any changes in health care providers.

   c. There are any surgeries or procedures performed.

   d. There are any changes in personal information, such as address or phone number.

   e. All of the above.

4. **Under the Federal Trade Commission's breach notification rule, both the FTC and consumers must be notified when the security of identifiable health information has been breached. Notifications for consumers should include all of the following, EXCEPT:**

   a. Description of what occurred

   b. What type of information was involved

   c. Necessary steps individuals should take for protection

   d. Description of what is being done to address the breach

   e. Contact information

   f. Names of all parties affected by the security breach

5. **A secure MY PLACE site at HealthyTransitionsNY.org includes all of the following, EXCEPT:**

   a. Goal setting tool

   b. Shared calendar with email reminder system

   c. Contact information for a transition team

   d. Discussion area

   e. Transition Information Form

   f. Automated upload of laboratory reports from a designated health care facility

Answer key: 1(e); 2(b); 3(e); 4(f); 5(f)

Acknowledgements

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