10 STEPS to Taking Charge of Your Health Care

USING THE GLADD APPROACH
YOU are in Charge of Your Health Care
Success on the job requires that you stay healthy!

- The best ways to stay healthy are to
  - understand your own health, and
  - participate in health care decision-making
After your 18th birthday

- Doctors and other health care providers must:
  - Get informed consent from you to carry out a medical procedure
  - Have your written permission to share information about you

BUT.... You can ask family members or friends to help you answer questions and fill out forms
Some things you should be able to do

• Health care
  o Name chronic medical conditions or allergies you have
  o Call to make appointments with your doctors
  o Know what to do in case of an emergency
  o Know what to do to stay healthy, and do them without someone reminding you

• Medication management
  o Know the correct names of medications you take, when you take them, and why
  o Order medications when you need more
  o Take your medications when you are supposed to

If you cannot already do these things, you need to learn!
What you can do

- Use the GLADD approach when talking to doctors or nurses and in managing your care:
  - Give information
  - Listen and learn
  - Ask questions
  - Decide on a plan
  - Do your part

- Take charge by following 10 important steps!
GLADD
Give Information
#1 Communicate how you are feeling

- Be HONEST in giving complete, detailed information
- Describe how your condition affects your everyday life
- Describe symptoms
  - Handy High 5: Who, what, when, where, why
  - Keep a medical diary
- Use visual aids if needed
  - Pain Scales
  - Health Pictures, Communication Boards
Tools to assist

PAIN MEASUREMENT SCALE

0  2  4  6  8  10
No Hurt  Hurts Little Bit  Hurts Little More  Hurts Even More  Hurts Whole Lot  Hurts Worst

No Pain  Mild  Moderate  Severe  Worst Pain Imaginable
## Tools to assist

### Picture Communication Aid

**Picture Communication Aid**

*Ask me questions if you need to, but please wait patiently for my replies.*

I will point to where I hurt.

<table>
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<tr>
<th>I'm fine</th>
<th>Hurt</th>
<th>Dull pain</th>
<th>Sharp pain</th>
</tr>
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<td><img src="image" alt="Dull pain" /></td>
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<table>
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<th>Sick</th>
<th>Leg</th>
<th>Arm</th>
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<td><img src="image" alt="Leg" /></td>
<td><img src="image" alt="Arm" /></td>
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</tbody>
</table>

<table>
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<th>Headache</th>
<th>Stomach ache</th>
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</thead>
<tbody>
<tr>
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<td><img src="image" alt="Homesick" /></td>
<td><img src="image" alt="Headache" /></td>
<td><img src="image" alt="Stomach ache" /></td>
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</tbody>
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<table>
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<th>No</th>
<th>Hurt feelings</th>
<th>Backache</th>
<th>Seizure</th>
</tr>
</thead>
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<tr>
<td><img src="image" alt="No" /></td>
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<td><img src="image" alt="Seizure" /></td>
</tr>
</tbody>
</table>
GLADD

Listen and Learn
#2 Practice good listening skills

- Listening includes UNDERSTANDING
- Pay attention to body language

**SLANT**

- Sit up
- Lean in
- Ask questions
- Nod
- Track the speaker
#3 Remember what is said

- Write down information
  - Take notes in your diary
- Use a voice recorder to enhance information recall and understanding
  - Free iphone recording apps
  - Always ask for permission before recording
  - Practice before you go to the doctor’s office

Doctor, what you say during our visit is very important to me. Recording this visit would be helpful with remembering what you tell me, and what to do. May I have your permission to record this session?
#4 Learn more about your condition

- Read books
- Explore the internet
  - Ask your doctor/nurse for recommended web sites
- Identify considerations for your job
  - Environment
  - Special dietary or medication needs
  - Accessibility
  - Stamina and strength issues
- Talk to people who have the same or a similar condition
GLADD
Ask Questions
#5 Prepare questions ahead of time

- Be prepared with questions and issues to discuss at office visits
  - Write questions on paper
  - Record them on a voice recorder
- If you don’t understand what you’re being told:
  - Let your doctor/nurse know
  - Ask them to explain in a different way
  - Ask for written instructions or materials to take home
  - Keep asking until you understand

There’s no such thing as a DUMB question!
Tools to assist

Ask Me 3

Ask Your Doctor, Nurse, or Pharmacist:

1. What is my main problem?

2. What do I need to do?

3. Why is it important for me to do this?

Ask Me3

Good Questions for Your Good Health

www.npsf.org/?page=askme3

AHRQ Question Builder

www.ahrq.gov/patients-consumers/question-builder.html
GLADD

**Decide on a Plan of Care**
#6 Participate in developing a plan of care

- With your doctor or nurse, decide:
  - What medical services will be needed
  - Who will provide them
  - How will they be paid for

- With your health care team and circle of support, set longer term goals for health, work and independent living

- Explore community resources that can help you reach your goals
  - Your doctor may need to provide documentation of medical condition/disability to meet program eligibility guidelines
#7 Practice negotiating skills

- It is important to provide feedback to the physician about your treatment plan
  - Can you follow the plan? If not, why not?
  - Are there alternative treatment options?

- Tips for negotiating
  - Know what you want and why
  - Plan what you will say
  - Be truthful
  - Be assertive
Self-advocacy guides

www.floridahats.org/?page_id=616
FloridaHATS service directory

Florida Health and Transition Services

Welcome to the FloridaHATS Web site. FloridaHATS is a program of Florida Department of Children's Medical Services. Our mission is to ensure successful transition from pediatric to adult health care for all youth and young adults in Florida, including those with disabilities, chronic health other special health care needs. To learn more about our program, visit About Us.

Tool Box

Our health care transition tool box contains documents and a variety of local, state and national resources. Materials for youth and professionals are organized in these categories:

- For Health Care Practitioners
- Independent Living
- For Youth & Families
- Decision-Making & Guardianship
- Education & Training for Professionals
- Service Delivery & Models of Care
- Health Insurance & Financing
- Advocacy
- Secondary & Post-Secondary Education
- Juvenile Justice

Search by Categories AND/OR Keyword(s)

Some Resources

Some Materials for Youth and Families

Some Tools for Providers

Need Training?

www.floridahats.org/service-directory/search-service-directory
GLADD
Do Your Part
#8 Carry a health summary with you

- Put personal health information in one place and keep it updated
  - Medical history and medications
  - Equipment and supply needs
  - Physician, hospital, emergency contacts
  - Health insurance
- Be able to access it easily
  - Paper copy
  - Thumb drive
  - Electronic Patient Portal
Tools to assist
#9 Learn how to schedule and navigate doctor’s visits

- Practice scheduling your doctor’s appointment
- Arrange for transportation
- Fill out paperwork at the doctor’s office
  - Medical history
  - Insurance
  - Consent to Treat
  - HIPAA Privacy form
- Ask questions if you don’t understand, and don’t be afraid to ask for help!
Tools to assist

Short Videos with step-by-step instructions

www.floridahats.org/?page_id=616
#10 Manage your medications

- Learn the correct names of your medicines, when you take them, and why
  - Be able to read prescription labels
  - Be able to refill your prescriptions
- Bring a list of your medications to doctor visits
- Keep a chart with times you need to take medicine and dosage
- If you take several medications, a pill organizer can help
Tools to assist

https://secure.medactionplan.com/mymedschedule/transplantexperience/

Using MyMedSchedule.com

This video will demonstrate how you can use MyMedSchedule.com, an electronic reminder tool that can help you manage your medication regimen.

View Video

http://hscj.ufl.edu/JaxHATS/Videos.aspx
Tools to assist

www.aucd.org/template/news.cfm?news_id=11188&id=17
Take charge now!

Give – Listen – Ask – Decide – Do

#1 Communicate how you are feeling (Handy High 5)
#2 Practice good listening skills (SLANT)
#3 Remember what your doctors/nurses say (use a voice recorder!)
#4 Learn more about your condition
#5 Prepare questions ahead of time (Ask Me 3)
#6 Participate in developing a plan of care
#7 Practice negotiating skills
#8 Carry a health summary with you (My Health Passport)
#9 Learn how to schedule and navigate doctor’s visits (watch videos and practice!)
#10 Manage your medications (MyMedSchedule.com)
Creating Your Own Medical Portfolio
“Must have” papers

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
- Social Security Card
- Health Insurance Card
- Important numbers
- Appointment Book & Calendar
- ATM Card (only if needed)
- Who to call in case of emergency
- List of medications & what doctor prescribed 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

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 farther 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/DDS 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 DMH 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 pays, 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.

What to Keep in your Binder

Education Documents
- A copy of transcript from all schools attended or GED Certificate
- Most recent IEP or 504 Plan
- Any other certifications (CPA/First Aide), Vocational, CNA, etc.
- College information; Financial aid information (including passwords), & transcript
- Print copies of any email confirmations you get & keep them too

Medical Information
- Copy of most recent physical & immunizations (important for school & jobs)
- List of doctors names & numbers (keep a copy in your binder & your wallet)
- List of medications, times, dosages, & who prescribes them (keep a copy in your binder & your wallet)

Work Information
- List of references – first & last names, their position, the company name, phone number, & dates worked
- Copy of letters of recommendation if you have them (don’t give your last one away)
- Dates of places you have worked or volunteered & what your responsibilities were
- Work Permit – if you need it (you must get this through your school or city hall)

Housing / Utilities Information
- Phone billing contracts & the most recent 2 bills
- Copy of your lease
- Keep a list with your previous & current landlord’s name, contact info, & the dates you lived there
- Most recent gas, electric, cable bills & contracts
- Any housing list / subsidy information, copies of places you have applied
- Start & end dates to where you previously lived, the landlord name, phone number & a written reference is even better

Financial Information
- A bank book or most recent statement
- Most recent Social Security award letter
- Keep all pay stubs
- Anything Social Security sends you
- All credit/debit card information
- Tax documents: Yearly W-2, tax documents

You can also make folder on your computer or email and keep a lot of this information there – like important emails or confirmations.

What information You SHOULD NOT Give Out?
- Do not give out passwords (computer, PIN for Bank, Financial Info, etc.)
- Keep passwords and logins in a safe place for your own personal use
- Social Security numbers (but sometimes it’s OK, like on a job or housing application or for a bank application)
- Bank account information (unlike for direct deposit of paychecks requested by employer)

Downloaded at: http://www.university.edu/transitionalTC/Resources/publications/10091013_and_10091014.html

Care notebook

http://cshcn.org/planning-record-keeping/teen-care-organizer/
### Emergency plan

**Medical Summary and Emergency Care Plan**

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

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

**Contact Information**

- **Name:**
- **DOB:**
- **Preferred Language:**
- **Parent (Caregiver):**
- **Relationship:**
- **Address:**
- **Cell #:**
- **Home #:**
- **Best Time to Reach:**
- **E-Mail:**
- **Health Insurance:**
- **Group and ID #:**

**Health Care Providers**

- **Provider:**
- **Primary and Specialty:**
- **Clinic or Hospital:**
- **Phone:**
- **Fax:**

**Prior Surgeries, Procedures, and Hospitalizations**

<table>
<thead>
<tr>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Baseline</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
<td></td>
<td><strong>Baseline</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td><strong>Vital Signs:</strong> Ht, Wt, RR, HR, BP</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td><strong>Neurological Status:</strong></td>
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</table>

**Most Recent Labs and Radiology**

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

**Diagnoses and Current Problems**

- **Problem:**
- **Details and Recommendations:**

**Emergency Contact:**

- **Relationship:**
- **Phone:**

**Emergency Care Plan:**

- **Preferred Emergency Care Location:**
- **Common Emergent Presenting Problems:**
- **Suggested Tests:**
- **Treatments Considerations:**

**Allergies and Procedures to be Avoided**

- **Allergies:**
- **Reactions:**

**To be Avoided:**

- **Medical Procedures:**
- **Medications:**

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Family health history

## Appointment Log

Use this form to keep track of your appointments and when to schedule future appointments.

<table>
<thead>
<tr>
<th>Date</th>
<th>Provider or clinic seen</th>
<th>Reason seen/care provided</th>
<th>Next appointment (or when to schedule next appointment)</th>
<th>Clinic phone #</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example 2/7/15</td>
<td>Neurology, Dr. Roza</td>
<td>EEG. Went over seizure and sleep tracking sheets</td>
<td>Call in May to schedule next appointment</td>
<td>206-987-2201</td>
</tr>
</tbody>
</table>

Tip: You can use a calendar or an app like Evernote™ to remind you when to make future appointments.

Resources

Electronic Resource List
for Health Care Accessibility and Self-Management

3. [www.coffeetoxing.org/yoathfamilies]: Get 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://usc.fiu.edu/latexi]: This website is for JaxHEAT, a medical home for medically complex teens and young adults in Jacksonvill e, FL, provides many tools and resources for health care management, including self-care instructional videos.
6. [http://ficfic.fmh.usf.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.healthylivingtransition.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.
9. [www.napa.org/patients-consumers/question-builder.html]: an interactive website that allows you to electronically create a list of questions to take to medical appointments.
10. [www.npaf.org/for-healthcare-professionals/program/ask-me-3]: “Ask Me 3” initiative of the National Patient Safety Foundation, with video.
11. [www.scincolland.org.uk?-Millar.pdf]: Simple photo and video apps to support communication, by Sally Millar.
12. [www.scentteacher.org]: Create and print AAC cards/sheets from templates.
13. [http://disability.templ edu/aac/vocabulary/child.shtml]: Vocabularies that individuals who use augmentative and alternative communication (AAC) and their families need to participate in socially-valued adult roles.
14. [www.freedomscientific.com/jaws-hq.asp]: Jaws for Windows is a powerful accessibility solution that reads information on your screen using synthesized speech.
15. [www.apple.com/accessibility]: Information about the many accessible features built into Apple’s products; click on “Special Education” for specifics.
16. [www.scicon.com]: Site devoted to adaptations and modifications of special software and hardware products.
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