10 STEPS to Taking Charge of Your Health Care

Using the GLADD Approach
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Agenda

- After Your 18th Birthday
- 10 Steps Using GLADD
- State and Local Programs
  - My Health Care
  - FloridaHATS Regional Coalitions
- Conclusion
YOU are in Charge of Your Health Care
Success in school, at work, & in the community requires that you stay healthy!

- The best ways to stay healthy are to
  - understand your own health
  - receive age-appropriate health services
  - 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

- Name chronic medical conditions or allergies you have
- Know the correct names of medications you take, when you take them, and why
- Take your medications when you are supposed to
- Order medications when you need more
- Call to make appointments with your doctors
- Know what to do in case of an emergency
- Know what to do to stay healthy, and do them without someone reminding you

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:
  › **G**ive information
  › **L**isten and learn
  › **A**sk questions
  › **D**ecide on a plan
  › **D**o your part

› Take charge by following 10 important steps!
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  NO HURT
2  Hurts Little Bit
4  Hurts Little More
6  Hurts Even More
8  Hurts Whole Lot
10  Hurts Worst

No Pain  Mild  Moderate  Severe  Worst Pain Imaginable
Tools to Assist

Picture Communication Aid

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

I will point to where I hurt.
GLADD

Listen and Learn
#2 Practice good listening skills

- Listening includes UNDERSTANDING
- Pay attention to body language

**SLANT**

- **S**it up
- **L**ean in
- **A**sk questions
- **N**od
- **T**rack 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
- 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
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

AHRQ Question Builder

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?

Good Questions for Your Good Health
Tools to Assist

ASK THEM 3!

All teens and their families should ask their pediatric doctors these 3 questions:

1. When should I/my child transfer to adult primary and specialty care physicians?
2. Who should I/my child go to for adult primary and specialty care?
3. Will you help with the transfer of care by communicating my/my child’s needs and providing a transfer summary?
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
Tools to Assist

For Youth & Families

FloridaHATS Information Guides

- FloridaHATS Brochure (English) (Spanish) (Haitian Creole)
- 10 Steps to Successful Health Care Transition (English/Spanish) (English/Haitian Creole)
- Algorithm for YSHCN in Florida (decision-making tree for preparation for transition to an adult model of care)

From the Institute for Child Health Policy at the University of Florida:

- Since You’re Not a Kid Anymore (English) (Spanish)
- Now That You’re in High School (English) (Spanish)
- When You’re 18 (English) (Spanish)
- Envisioning My Future (English) (Spanish)

Transition Toolkit

An easy-to-use, interactive Transition Toolkit for physicians, families and youth, case managers, and teachers. Through a series of questions, the toolkit helps you determine which resources may be most useful (depending on your role) to support the transition process. Developed by the JacksonvilleHATS Coalition, the Toolkit incorporates instruments and resources that have been adapted for Floridians but can be used by anyone. Get started here!

Transition 2 Go

A series of informational briefs with transition-related tips and resources for consumers and health care providers in Florida:

- T2G: Health Insurance (English) (Spanish) (Haitian Creole)
- T2G: Employment (English) (Spanish) (Haitian Creole)
- T2G: Medicaid Waiver Programs (English) (Spanish) (Haitian Creole)
- T2G: Guardianship (English) (Spanish) (Haitian Creole)

Skill-Building Curricula and Videos

- Health Care Self-Management videos from JacksonvilleHATS and Healthy Transitions (short vignettes with step-by-step instructions for scheduling medical appointments, arranging for transportation, managing medications and more)
Service Directory

Health Services Directory for Young Adults

Use the form below to search for health care programs and providers in your area that serve young adults, including those with disabilities or chronic health conditions.

Please help us keep the directory up-to-date! We encourage both consumers and providers to let us know about resources you think should be included. For instructions on how to add a service, update an existing entry, or recommend a program, please visit our Submission Instructions page.

Disclaimer: A listing in this directory does not imply an endorsement from FloridaHATS, Children's Medical Services, or Florida Department of Health. The information is solely for your convenience in locating services from those available in your area. Individuals should perform their own research of any organization they choose. If the service is covered on an insurance plan, first check the plan’s provider network. However, if you believe a particular listing in this directory does not meet our criteria of serving young adults with chronic health conditions or disabilities, please contact us here.

Search By: Categories AND/OR Keyword(s)

City, State, County: -- Any City --
County: -- Any County --
Health Category: Behavioral and Mental Health
Search by Keyword(s):

Submit Query Reset
Plan for change in insurance coverage

- Medicaid
- Parents’ plan
- Employer-based
- Marketplace plans
#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
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

My Health Passport

If you are a health care professional that will be helping me, PLEASE READ THIS before you try help me with my care or treatment.

My full name is: ________________________________
I like to be called: ________________________________
Date of birth: ______/____/____
My primary care physician: ________________________________
Physician's phone number: ________________________________

This passport has important information so you can better support me when I visit/stay in your hospital or clinic.
Please keep this with my other notes, and where it may be easily referenced.

My signature: ________________________________ Date completed: ______/____/____
You can talk to this person about my health: ________________________________ Phone number: ________________________________ Relationship: ________________________________

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)

Attach your picture here!

My current medications are:

When I take my medications, I prefer to take it: (e.g. with water, with food)

My medical history:
(e.g. asthma, diabetes, cancer, other conditions)

How I cope with medical procedures: (e.g. how I usually react to injections, IVs, physical examinations, x-rays, oxygen therapy—also note procedures I have never experienced before or in recent years)

If I am in pain, I show it through: (e.g. tears, First Aid, etc.)

If I have a bowel movement, I tell the following:

My mobility needs are:
(e.g. whether I can walk, use a wheelchair, use stairs)

My favorite foods and drinks are:

When drinking, you may assist me by:

I am very sensitive to: (e.g. lights, noise, smells, food)

Things I like to do that will help pass the time:

How to make future/follow-up appointments easier for me:

I do not like to eat or drink the following:

My 5 favorite activities:

USF HealthCare

Treat Me Right

My favorite foods and drinks are:

When drinking, you may assist me by:

I am very sensitive to: (e.g. lights, noise, smells, food)

Things I like to do that will help pass the time:

How to make future/follow-up appointments easier for me:

I do not like to eat or drink the following:

My 5 favorite activities:
#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
#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

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
Resources

- FloridaHATS, www.floridahats.org
- Health Care Transitions, http://hctransitions.ichp.ufl.edu
- JaxHATS Clinic,  http://hscj.ufl.edu/jaxhats
- Healthy Transitions, www.healthytransitionsny.org
- AHRQ Question Builder, www.ahrq.gov/legacy/questions/qb
- My Health Passport, http://flfcic.fmhi.usf.edu/program-areas/health.html
- FDDC, www.fddc.org
State and Local Programs
My Health Care

- A health literacy and communications training program sponsored by FDDC

- 22-hour curriculum
  - Designed for classroom of learners
  - PPT presentations with imbedded videos
  - Interactive role play, modeling, games
  - Implement in 2-3 hours/week over 9 weeks
  - Step-by-step Instructor’s Guide and accompanying instructor training video

- Available to everyone in 2015
Instructors said *My Health Care* “made a huge difference” with participants. Learners said:

- After the health care class last year, I started having more say of say so at my doctor’s appointments and asking more questions – Michael
- I learned it is important to take my medicine everyday – Becky
- It impacted me by possibly going to the doctors without my parents or my guardians – Oliver
- I learned it is important to ask questions and use eye contact – Vera
- I have learned to always ask questions and make my appointment – Shawn
- The best thing I’ve learned about what to do and what not to do when talking with your doctor is what questions to ask and to take notes on those questions so that you understand what the doctor is saying – Hayley
- I have learned to be at the doctor on time and who, what, where, when, and how – Paul
- I remembered to do my part and ask questions – Jana
FloridaHATS Regional Coalitions

- Providers, youth and families working together to improve transition from pediatric to adult health care:
  - Tampa/Hillsborough
  - Northeast Florida (Jacksonville)
  - Panhandle area
  - South Florida (Miami/Ft. Lauderdale)

- Local action plan to improve transition
  - Outreach, education and advocacy

- Quarterly meetings

- Visit www.floridahats.org, go to Regional Coalitions
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 (books, websites)
#5 Prepare questions ahead of time (Ask Me 3)
#6 Participate in developing a plan of care  (FloridaHATS materials)
#7 Practice negotiating skills  (self-advocacy guides)
#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)