

A Provider's Guide



to Treating Adolescent Patients



Hasbro Children's Hospital

The Pediatric Division of Rhode Island Hospital

A Lifespan Partner

All for one.



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The Adolescent Leadership Council (TALC) of Hasbro Children's Hospital is a group of teenagers who live with chronic medical illnesses.

The Adolescent Leadership Council (TALC) of Hasbro Children's Hospital compiled the content for this booklet to help bridge the gap between providers and their adolescent patients. They have also created a booklet for their peers about how to be a patient. The parents created a companion booklet for parents of adolescents receiving medical care. These are available as resources to distribute to your patients if you would like to do so.

In addition to suggestions from the TALC teens, we also provide some refreshers on adolescent development, confidentiality laws, current policy recommendations, and other information that is pertinent to the topic. These refreshers can be found on the boxes at the bottom of the following pages.

Top 10 Tips for Practice with Adolescent Patients

- 1 Be calm.**
If you're nervous, it makes us nervous.
- 2 Include us in the conversation.**
If you only talk to our parents, it makes us feel like we are kids.
- 3 Keep your word.**
We would rather you tell us no than break a promise.
- 4 Have private time with us during our visits.**
There may be things we aren't comfortable telling you in front of our parents.
- 5 Treat us based on our age.**
It may not always seem like it, but we want to be a part of our care team.
- 6 Ask first before you do anything**
Even if we are nervous or scared, we'll take it better if you ask.
- 7 Take your time in appointments.**
We want enough time to ask and understand what you're saying.
- 8 Be kind and gentle.**
We know we aren't always the best at listening, but it's hard for us to respond well if things get stressful in the room.
- 9 Follow-up in a timely manner.**
We get impatient sometimes and think the worst, so if you can give us a time-frame, that is really helpful.
- 10 If you don't know, just ask!**
Even though we don't always seem interested, we are willing to answer questions.

Trust and Respect

- ✦ Respect our bodies.
- ✦ Trust our knowledge of our illness.
- ✦ Treat us like people, not a disease.
- ✦ Stay true to your word.
- ✦ Ask before inviting medical students or other staff into the room.

The Principles of Patient and Family Centered Care are important to consider when working with adolescents

- **Dignity and Respect** - The healthcare team listens to and honors patient and family perspectives and choices. Patients and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing** - The health care team communicates and shares complete and unbiased information with patients and families in ways that are useful and affirming.
- **Participation** - Patients and families are supported and encouraged in participating in care and decision-making at the level they choose.
- **Collaboration** - Patients, families, health care practitioners and hospital leaders collaborate in policy and program development, implementation, and evaluation. They also participate in facility design, professional education, as well as the delivery of care.

www.ipfcc.org

Confidentiality

- ✦ If we don't want our parent to know something, don't tell them.
 - ✦ If telling our parents is required, please let us know first.
- ✦ Before discussing important personal matters, ask us if we want our parents to step out.
- ✦ Find out if the patient wants to relinquish confidentiality in the event of an emergency.
- ✦ If we disclose our sexuality or gender identity, please respect our wishes on how we want that shared.
- ✦ As we get closer to turning 18, please explain to us how confidentiality will change.

A Couple Points About Confidentiality and Medical Decision Making Rules

- Generally, whoever has the right to make a health care decisions has the right to maintain confidentiality of the information associated with that decision.
- In general, in non-emergency situations, parents have the right to make medical decisions for children under the age of 18.
- Anyone age 16 or older may make decisions about “routine emergency medical or surgical care.”
- Parents can allow their children under 18 to make some decisions, on their own, in non-emergencies.
- Individuals 18 or older can generally make their own medical decisions.
- If your patient expresses any thoughts of harming himself/herself or others, you are required to share this information to get your patient appropriate supports.

R.I. Gen. Laws §§ 23-4.6-1, 23-8-1.1, 23-6.3-4

Communication

- ✦ Before you enter the room, please be sure you have enough time to be with us.
- ✦ When you enter the room, please introduce yourself and your role in our care.
- ✦ Talk with us, not at us - even though we may seem uninterested, we really want to be included in our care.
- ✦ Please give us a chance to answer questions before you ask our parents - you'll be surprised at what we know.
- ✦ We have a hard time when we don't know what is going on, so please explain what you're going to do before it happens.

Why is it so hard to work with teens? A few helpful reminders about adolescent development.

- Emotional responses are heightened during adolescent development.
- The brain is evolving in its ability to organize, regulate impulses, and weigh risks and rewards.
- Males find it more difficult to talk to people, but are better at providing accurate details.
- Females are better at talking to people, but have a hard time focusing on and remembering/recalling facts.

US Dept. of Health and Human Services (2013) *Overview of Adolescent Brain Development* (OAP Self-Directed Modules). Retrieved from www.hhs.gov/opa/familylife/tech_assistance/etraining/adolescent_brain/Overview

Treatment and Medication

- ✦ We get anxious about taking medication, so please explain what they do, why we need to take them, and what side effects to be aware of.
- ✦ Creating a medication plan with us, that respects our schedules, will make it easier for us to follow.
- ✦ Listen to us about what does and doesn't work.
- ✦ Even though we aren't always the best at following our treatment plans, we still want to be treated with respect. We will respond better too.
- ✦ We love a good joke or distraction - especially when things are scary or stressful.

Why don't teen patients follow treatment plans?

- The parts of the brain responsible for controlling impulse and planning ahead (the frontal cortex) are the last to mature.
- Adolescents are *more* likely than adults to:
 - Act on impulse.
 - Misread or misinterpret social cues and emotions.
- Adolescents are *less* likely than adults to:
 - Think before they act.
 - Pause to consider the potential consequences of their actions.
 - Modify their dangerous or inappropriate behaviors.

AACAP (2012) *The Teen Brain: Behavior, Problem Solving, and Decision Making* (AACAP Facts for Families No. 95). Washington, DC: www.aacap.org

Sexuality

- ✦ Keep it PG in front of our parents.
- ✦ When our parents aren't in the room, ask about sexual activity - we are probably embarrassed to bring it up, but we will answer you.
- ✦ If there is a reason to see a 'private' body part, please ask us first.
- ✦ Please explain why you are asking a sexually related question so we'll know why you are asking.
- ✦ Be an advocate for LGBTQ patients and provide community resources for support.

Here are a few sexual health/sexuality related resources, in case your patients want more information.

- The Trevor project - LGBTQ resources and suicide prevention site
<http://www.thetrevorproject.org/>
- Young Women's Health - Resources specific about young women
<http://www.youngwomenshealth.org/>
- KidsHealth Teen site - Various topics that include sexuality, jobs, drugs, alcohol, diseases, fitness, and mind/body balance
<http://kidshealth.org/teen/>

Transition

- ✦ Start talking more to your patients (instead of their parents) as they get older.
- ✦ Give your patients an opportunity to ask questions.
- ✦ Give your patients the option to meet one-on-one for part of the appointment.
- ✦ Encourage your patients to fill out their own medical forms.
- ✦ As they get older and closer to transition, give your patients a summary of their medical history.
- ✦ Help your patients identify possible adult providers - and if you can't, explain why.


Transition Recommendations

- After the age of 12, patients should have at least part of a visit one-on-one with their doctor.
- Start the conversation early (age 12-14). At some point, all patients will transfer to an adult provider. Discussing changing health care needs will help decide when is the best time.
- Family members and health care providers should foster personal and medical independence in teens.
- Planning for the future regarding insurance coverage, adult providers, equipment, and skills necessary to navigate the adult health care system should begin during early adolescence.

Reiss, J. and Gibson, R. (2002) Health Care Transition: Destinations Unknown. *Pediatrics* 110 (6) p 1307-1314.

Health Related Skills

There are a lot of skills we will need to be completely independent, but sometimes we don't know what they are. Here is a checklist of skills we would like you or our parents to help us learn, over time, so it's not so overwhelming.

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- Make a doctors appointment.
 - Ask questions of your doctor.
 - Give an accurate health history.
 - Name your diagnosis and explain what it means.
 - Carry the numbers of your doctors with you.
 - Know all your medications, doses, and what you take them for.
 - Fill a prescription.
 - Take medication on your own.
 - Arrange travel to appointments.
 - Arrange payment (insurance, co-pays, etc) for appointments.

Hasbro Children's Hospital embraces a model of patient and family centered care, putting patients and families at the center of all that we do. TALC is the Youth Advisory Council, and in partnership with the Patient and Family Centered Care Steering Committee and Family Advisory Council, participants identified and implemented the project of creating booklets to support patients, parents and providers in their care.

The Adolescent Leadership Council (TALC) provides year-round programming for kids, teens, and parents.

- Teens (age 13-18) with a chronic medical illness
 - Join TALC by attending our 6-session, every other week Transition Program, focusing on how to live with illness.
 - Three times a year to join. Sessions start in September, January, or April.
 - Opportunity to meet college mentors and peers.
 - After completion participants are eligible to join the TALC monthly Leadership Council.
 - Focus on skill-building and leadership projects.
 - Multiple art-related event, social events.
 - Annual overnight summer leadership camp.
- Kids (age 8-12) with a chronic medical illness
 - TALC Jr meets every other month during the school year.
 - Annual TALC Jr. Day Camp.
- Parents
 - Concurrent parent groups offered for the TALC Transition Program, the TALC Leadership Council, and for TALC Jr.

For more information about TALC programming, please visit our website www.TALCProgram.org, call our Program Director at 401-444-7563, or email us at TALCProgram@gmail.com.

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