

A Guide for Parents



of 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 parents council is composed of TALC parent's who have a lot of experience visiting doctors and their children being in the hospital.

This booklet is written by TALC parents for any parent of a teenager who is a patient, whether it is for routine care, a chronic condition, or an emergency situation. The booklet has information on what to expect, some helpful tips on how to get the most out of your child's treatment, and advice on how to plan ahead and prepare for your child's future.

Going to the doctor or hospital is never high on a teen's to-do list. But if they have to be here, we hope the information in this booklet will help you and your teen get the best experience out of your visit.

Top 10 Things to Expect

- 1 The more open you are with your child, the better chance they will come to you for help.**
Even when there are subjects we don't want to talk about with our kids, doing it shows them they can come to us.
- 2 Expect to wait.**
Whenever you come in you will have to wait, and sometimes it can take hours in the Emergency Department.
- 3 Be prepared for visits.**
Bring snacks and something to pass the time.
- 4 Prepare your child to be willing to communicate.**
Most likely your child will need to give specifics about how they are feeling, so it can help to prepare them for this.
- 5 Encourage your child to start taking on more responsibility in their care.**
This can include filling out forms, asking questions, etc.
- 6 Be willing to listen to providers.**
Even though its hard sometimes, give the providers a chance to finish explaining before you ask question.
- 7 Be willing to listen to your child.**
It can help to give your child a chance to explain before you ask them questions.
- 8 You have to give respect to get respect.**
This is hard when you are frustrated, but patience and respect usually get a better result than frustration.
- 9 Educate Yourself.**
Don't be afraid to ask "why" or for resources.
- 10 Don't forget to "care for the caregiver" (yourself)**
It doesn't help to beat yourself up about the past, and if you don't care for yourself, you can't care for your child as well.

Trust and Respect

- ✦ Trust your instincts - and know you have the right to speak up if something feels uncomfortable.
- ✦ Trust that your child knows their own body and what “normal” feels like to them.
- ✦ Most of the time your child has the capacity and the ability to tell you if something is wrong.
- ✦ Teaching hospitals often include trainees and medical students as part of the patient care team, but you have the ability to make the final decision about who is on your team.
- ✦ Respect your child’s privacy.
- ✦ Stay true to your word.

The Principles of Patient and Family Centered Care

- **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.

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Confidentiality

- ✦ Don't be offended if your child or the provider asks to have some one-on-one time in the room - it's actually recommended after the age of 12.
- ✦ Encourage your child to learn how to have a confidential relationship with their providers. It's both empowering and teaches your child how to self-advocate.
- ✦ There will be times you will need to share information about your child with other organizations (like schools), but use discretion about what you share.
- ✦ Make sure the information you share about your child is pertinent to the person or organization with whom you are sharing.

A Couple Points About Confidentiality and Medical Decision Making Rules

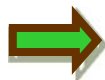
- Generally, whoever has the right to make a health care decision has the right to maintain confidentiality of the information associated with that decision.
- In general, in non-emergency situations, parents have the right to make medical decisions for children under the age of 18.
- Anyone age 16 or 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 child expresses any thoughts of harming himself/herself or others, your provider is required to share this information to get your child appropriate supports.

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

Communication

- ✦ Guide your child through education about their health history.
- ✦ Participate as you feel comfortable, which often includes giving your child a chance to answer first.
- ✦ Pay attention to changes in your child's behavior, activity, or mood - these changes sometimes indicate that something is going on in their life.
- ✦ Don't overload other potential caregivers with information - only what they need to know for their role in supporting your child.
- ✦ Don't be overwhelmed by providers - they are people too.

It can be helpful to providers if you come prepared with questions for the visit. Feel free to jot down a few questions here.



Treatment and Medication

- ✦ Be an advocate for your child and don't be afraid to ask as many questions as you need to.
- ✦ A teenager's choice not to follow a treatment plan may or may not be related to the treatment plan itself. The approach needed will depend on if the child is rebelling versus if there is a problem with the plan itself.
- ✦ Empower your child to take on responsibility for their treatment plan - but have a way to monitor that they are doing it.
- ✦ Help your child to understand the consequences of not following this plan - but understand that some teens may need to "fail" to understand how important it is.
- ✦ Sometimes medical illness can come with emotional issues, so please be open to additional supports.

Why don't teen patients follow treatment plans?

- The parts of the brain responsible for controlling impulse and planning ahead 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

We understand that sexually related topics are sensitive and that every family has their own approach to addressing these topics. It has been shown that preparing your child to be aware of sexually related issues does not increase the likelihood that they will become sexually active at a young age. However, you make the final decision regarding how much information is appropriate, and at what age.

- ✦ Encourage your child to speak up if they feel uncomfortable during an exam.
- ✦ Don't be afraid to ask the provider to bring up options for sexual health.
- ✦ Even though it may be uncomfortable, it's important to talk about reproductive issues with your child - especially if they are on medication or have a chronic illness.
- ✦ If you're uncomfortable talking to your child about safe sex, you can ask your child's provider to do it - and they will be happy to.

Facts on how puberty can affect your child.

- Puberty in girls usually starts between the ages of 10 to 12 and ends between the ages of 17 to 19.
- Puberty in boys usually starts between the ages of 12 to 14 and ends around age 20.
- The process of sexual maturation occurs over a period of several years.

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Transition

- ★ Have a medical summary and *bring it with you to appointments* (this helps with filling out the forms).
- ★ Keep your child's medical records organized and in one place.
- ★ As your child gets older, think about putting their health information on a USB stick for them to carry when you aren't together.
- ★ Transition skills have to be learned - it's your responsibility to let go and your child's responsibility to step up.
- ★ Transition isn't the end - your child will still need you, but in a different role.
- ★ Eventually your child will transfer to adult providers.

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 your child will need to be completely independent. Here is a checklist to help you and your child get started. Don't worry if your child doesn't know any now – the idea is to learn them over time so it's not so overwhelming. The goal is that your child can check each of these off.

- 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.

We would like to thank the Ocean State Charities Trust for their support of this project, which allowed for the initial printing of these booklets.



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593 Eddy Street

Providence, RI 02903

