

An Adolescent's Guide



to Being a Patient



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. We have a lot of experience visiting doctors and being in the hospital.

This booklet is written by TALC teens for any 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 treatment, and advice on how to plan ahead and prepare for your future.

Going to the doctor or hospital is never high on our to-do list. But if you have to be here, the information in this booklet may help you to get the most out of the experience.

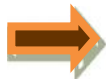
Top 10 Things to Expect

- 1** **The hospital is large and can be confusing.**
It helps to know the name of the provider you are seeing and the location of their office.
- 2** **You will most likely have to wait to see a provider.**
This can be a good time to catch up on homework, or you should bring something to distract yourself.
- 3** **Once you're in an exam room, you may be asked to change into hospital clothes.**
If you get cold easily, bring a sweater!
- 4** **Lots of people are going to come to talk to you in the room.**
There are usually many members of your health care team, including medical students who are learning, and all will need to hear what you have to say.
- 5** **To be asked many questions.**
Try to be patient if different people seem to be asking the same questions.
- 6** **The visit should be an exchange of information.**
This means that you should be an active part of your care.
- 7** **Don't forget to ask your questions.**
It's all about you, so speak up!
- 8** **Part of the visit will be one-on-one with you and the provider.**
This time without your family in the room will give you a chance to talk about anything you don't want to say in front of others.
- 9** **It is possible that tests, like blood draws or x-rays, may be ordered.**
Try to be flexible, there is always a reason they are ordered.
- 10** **Always Tell the Truth.**
Your providers cannot help you if they don't know what is actually going on.

Trust and Respect

- ✦ Respect your own body and take care of yourself.
- ✦ Have respect for your providers.
- ✦ Tell your provider if you feel uncomfortable.
- ✦ Respect your provider's time.
- ✦ Answer your provider's questions HONESTLY.

These are some of the things that we think are important for trust and respect. What is important to you? Feel free to write down your ideas/questions and bring them to your next appointment.



Confidentiality

- ✦ Know when something is important enough to tell your parents.
- ✦ If you want your parents in the room, don't be afraid to ask to have them there.
- ✦ If you're not comfortable with your parents in the room, you can request that they leave for part of the visit.
- ✦ Make sure to ask your provider if they can keep what you are discussing private.
- ✦ Understand that there may be times your provider has to tell your parents, due to laws.

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 you express any thoughts of harming yourself or others, your provider is required to share this information to get you appropriate supports.

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

Communication

- ✦ Speak up - it's all about you and you have a say.
- ✦ Notify your provider or parents if you think something is wrong or if something changes.
- ✦ Tell your provider what sort of things you like doing, so they can help you keep doing those things.
- ✦ Be nice - you'll get a better response.
- ✦ Be prepared to ask questions when you see your provider. It helps to write them down before your visit.

*Not sure what kind of questions to ask?
Here are a few we suggest to get started!*

- ➔ What should I know?
- ➔ What should I be doing?
- ➔ What are my treatment options?
- ➔ What are possible side effects of treatments?
- ➔ Are there any 'warning signs' I should look for?

Treatment and Medication

- ✦ If something about a treatment stresses you out, try to distract yourself with music, games, or something that makes you happy.
- ✦ Negotiate a realistic medical schedule that works for your lifestyle (medication and treatments).
- ✦ Be responsible for taking your medications (on time and the right dose).
- ✦ Know your side effects and what to do if they happen.
- ✦ If something about your treatment plan isn't working, speak up!

Some important things to think about when negotiating a treatment plan.

- What is your normal schedule like?
- What activities are important for you to be involved in?
- Will the plan work within normal school rules or will you need to get special accommodations (IEP or 504 plan)?
- Is it clear who will be doing what for your plan (you versus your parents)?
- Do you feel like you are able to stick to the plan?
- If no, what parts of the plan will be hardest?
- What parts do you think will be easiest?

Sexuality

- ✦ Talking about sexually related questions in front of parents can be awkward - it's ok to have part of your visit without your parents in the room.
- ✦ Your provider is happy to talk to you about safe sex.
- ✦ No one will judge you if you ask about sexually related issues (like pregnancy, STDs, sexual orientation).
- ✦ It's ok to ask your provider for LGBTQ resources if you would like them.
- ✦ Tell your doctor if you feel uncomfortable during an exam.

What are some things you want to know more about? If you're too embarrassed to ask out loud, you can show this to your doctor.



Transition

- ✦ As you get older, you won't have as much help as you used to - but that can be a good thing.
- ✦ Know your medical facts - like your diagnosis, medications, and doses.
- ✦ To get practice, fill out forms on your own at visits - it's not a test, so you can bring the information with you to help (on your phone, print-outs, etc.)
- ✦ It helps to communicate with adults who have been involved in your care - especially your parents.


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. Here is a checklist to help you get started. Don't worry if you don't know any now – the idea is to learn them 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.

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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