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Helping Your Teenager Make The Transition From Pediatric To Adult Care

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Adolescence is a period of growing independence and change and most teenagers don't have any difficulty asserting their independence when it comes to choosing clothes, music and friends, expressing their opinions about family rules and values and learning how to drive. However, when it comes to taking responsibility for their own health care, their enthusiasm dwindles and they seem quite content to let their parents do all the work when it comes to setting appointments, asking questions in the doctor's office and even making decisions about treatment.

"So what?" you may ask, "Doesn't it make sense for the parent, who has lots of practice interacting with health care professionals and has spent years learning all the medical jargon, to simply continue advocating for the teen patient until he or she is ready to be discharged from pediatric care?"

The answer is no, for two reasons:

- There are major differences between the Pediatric Care System and the Adult Care System, differences teens need to get used to in steps.
- Even in the pediatric care setting, such as the Hospital for Sick Children, there is no longer a minimum age for consent to treatment, which means that we expect older children (and certainly adolescents) to be able to understand their treatment choices and participate in their treatment decisions.

Let's first talk about the differences between pediatric and adult health care:

In a pediatric hospital, the child is seen with one or both parents and the latter usually do most of the talking and listening in the doctor's office, as well as taking responsibility for explaining what the doctor said either during or after the appointment. In an adult hospital, the patient is seen alone. Family members are usually not invited to medical appointments and the patient is expected to book appointments, show up on time and with adequate preparation for medical procedures, come prepared with questions for the consulting doctor and make decisions about treatment all by themselves.

Furthermore patients should not expect a "Team Approach", as they are used to in the children's hospital: there probably won't be a social worker, psychiatrist or psychologist working directly with the plastic surgeon and, where such psychosocial supports are available, it's usually on request and only when there is a problem with discharge planning (the social worker), psychiatric complications of treatment (such as hallucinations in Intensive Care) or a specific research question being asked (in the case of the psychologist). In other words, there's no "hand-holding", you're on your own when it comes to managing your health care, expressing your needs and wishes and asking for counseling if you need it.

It takes time to learn everything you need to know to make the best treatment choices and this brings us to the next topic: what is "Informed Consent" and who can give it. Up until a few years ago, children under the age of 16 had very few rights when it came to making decisions about treatment: parents signed the consents for admission, tests and surgery and children were expected to trust their parents and doctors to make the best treatment decisions for them and to go along with these, even they weren't too sure they wanted these treatments.

All this changed a few years ago when the minimum age for consent to treatment disappeared: now a patient of any age is expected to be capable of agreeing with (or refusing) treatment. The only situation in which a parent (or other relative or "substitute decision maker") would be asked to make a decision against a child's wishes would be if the patient cannot understand what the treatment is for and what



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happens if this treatment is cancelled. In practical terms this means teenagers are now expected to be active partners in their own health care, even in a pediatric hospital such as Sick Kids.

What do you need to make smart choices? You need a lot of information about your body and how it works, about your particular medical condition and about treatment options for this condition. This is complicated information with many technical or medical terms, which take time to understand, digest and memorize.

Here is an overview of Tips for Teenagers about transition from pediatric to adult care:

- a) Learning about your own condition: Hopefully you have been talking about your facial difference at home since you were little and you know whether you were born with it or whether it happened later on in your life as a result of an injury, burn or tumour. But maybe you're not sure what exact syndrome it's called or how to spell it? Ask your parent to write it down for you before you start high school and ask your doctor, nurse or team coordinator for any pamphlets, booklets, web pages or even medical articles which describe it. It's very, very important for you to know exactly what it's called and how to spell it if you want your classmates, friends and teachers to consider you an "expert" on the subject.
- b) Understand what special health needs might come with your particular condition, if any: For instance, individuals with a Cleft Lip and Palate often have middle-ear infections and require tubes in their ears, they may also have some speech articulation problems and need speech therapy. Individuals with a purple Sturge-Webber discoloration on their face may have neurological problems such as seizures but a person born with a single Hemangioma may not have any associated health problem.
- c) Get familiar with the types of specialists you will need to manage your medical needs (Ears, Nose and Throat Specialist, Speech therapist, Orthodontist, Plastic Surgeon) in general, and the names of the specialists on your team, especially. Keep an address book (paper or digital organizer) with all their names, phone numbers, addresses and emails, if available).
- d) Ask your parents if they have kept a file with past medical reports about you and go through it with them. Don't be afraid to ask lots of questions if you don't understand some terms. If your parents aren't too sure what some medical terms mean, look them up on or ask your doctor or team coordinator, next time you have an appointment.
- e) Learn to keep track of your appointments and test results. A simple list in a day-planner will do, however a typed up summary you update yourself after each appointment is even better! Next time you come to the hospital, all you have to do is print out a copy of your summary and you'll have all the information you need to answer questions about your past history at your fingertips!
- f) Whenever a new test or treatment is offered, ask about advantages and possible risks associated with each one. If the treatment is surgery, ask the plastic surgeon if you can see pictures of other patients, before and after surgery. Don't be afraid to ask for time to do some research (in the library or on the Internet) before making a decision: plan a follow-up appointment, which will give you time to prepare any additional list of questions.
- g) Talking with other patients who have the same condition and/or have gone through a similar treatment to what you are being offered is probably the best way to really understand what the future holds for you: don't hesitate to ask the team coordinator or your doctors/dentists if they can facilitate such networking and, of course, call AboutFace, the experts in networking and advocacy about facial differences!



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- h) A really good way of finding out if you really have covered everything you need to know about your medical condition and its treatment is to give a presentation about it to your classmates, using either a science project or speech contest as an excuse to use them as an audience: not only will you probably wow them with your knowledge of medical terms, but their questions might bring up ideas you had not thought of (for instance a teen patient of mine gave her grade 9 class a talk about her burns and she was surprised when a classmate asked her if she'd ever heard of Vitamin E cream for scars, she had not, but was able to do some research online and bring questions about this to her next appointment with her doctor).
- i) If you are planning to have surgery, ask to visit the ward or ICU where you will be recovering before hand. Find out how long you can expect to recover at home, after discharge, and whether or not you will need to be on a special diet (for instance after jaw surgery) and whether you will need to buy or borrow a blender, a water-pik or other equipment. Ask about swelling, pain medication, stitches etc. and, once again, don't be afraid to request to speak to another patient who has already been through similar surgery.
- j) If you need to miss time off school or work, you will want to get a doctors' letters explaining why, well ahead of your return to work. If your friends are expecting to throw a welcome home party on the evening of your discharge home, you'll need to find out if you'll be in any shape to participate in it or should wait a few days.
- k) Last, but not least, start (well ahead of your 18th birthday) talking to the team asking about the specialists who treat adults with your condition in the adult care hospitals. Although we are fortunate in not having a rigid 18th-birthday-transfer-date for our Craniofacial and Cleft Palate patients, there's no reason why you can't, or shouldn't start finding out who is available where, well ahead of your 18th birthday, perhaps even asking to be connected with an adult patient 'mentor' who might be willing to take you along on a tour of the adult plastic surgery centre they attend.

I hope I haven't overwhelmed you with the length of the list of suggestions above: nobody expects you to follow all of these steps religiously and there's no quiz at the end and no pass or fail mark! Use this list as 'tips' rather than 'instructions', start wherever you want and improvise, add to it, make it your own: the most important thing is starting on the road to independence in your health care and wanting to make as many informed decisions about your own body and what happens to it as possible.

AboutFace is a national charitable organization dedicated to helping individuals with facial differences and their families. We support individuals whose differences are present at birth or acquired as a result of disease or trauma. If you or someone you know has a facial difference and would like more information, contact AboutFace at 1-800- 665-FACE or www.aboutface.ca.

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