

TRANSITION EXPERIENCE AND ADVICE OF ONE YOUNG ADULT

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WHAT WENT WELL...



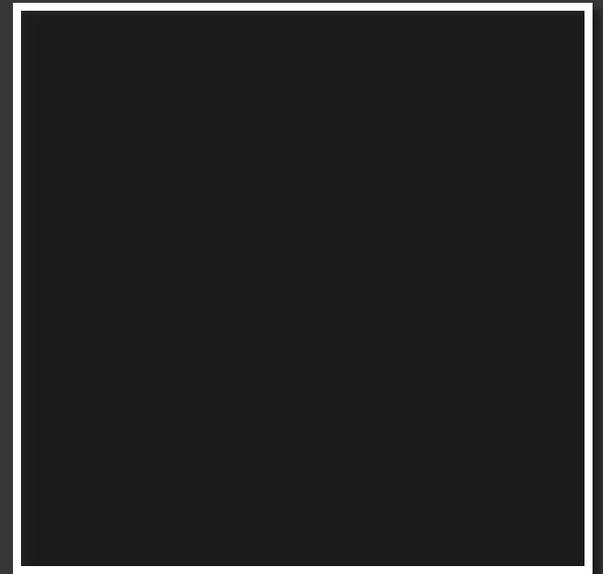
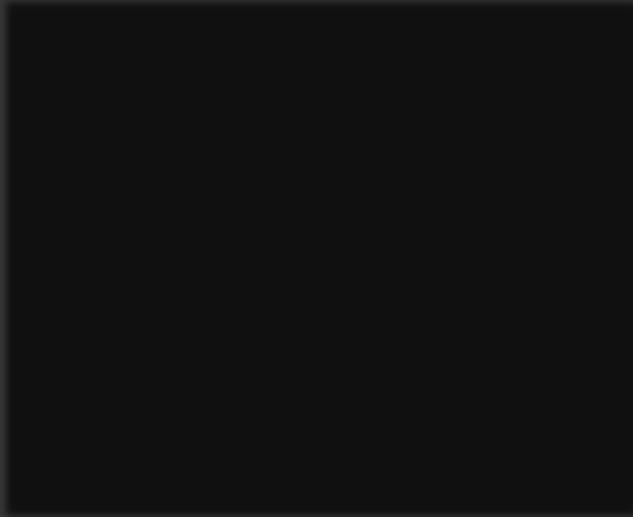
- I had one existing specialist who agreed to keep seeing me until he retires. They know me well in his clinic.
- I have another doctor who is at Children's who said that he will keep me until Children's makes him get rid of me. I am 24.
- Had some advice on what to look for in an adult provider (Med Peds)
- I had a specialist from Children's who emailed my mom a couple years later with the name of a Med Peds Doctor because she knew I was looking for a doctor.

WHAT COULD HAVE GONE BETTER...

- We should have had a doctor in place before the age of 21. We tried to find one when I was around 18 or 19 years old, But there aren't many Med Peds around.
- The pediatrician had to leave abruptly with a six week warning. For somebody who has a complicated history six weeks isn't a long time.
- We did not have a lot of help finding adult providers. We had to research and try to find a Med Peds and Specialists on our own.
- I would have liked to have known about the Med Peds Doctor sooner.
- My first adult doctor knew stuff when it came to healthcare but was unprofessional at times and then left the practice.

I learned to be independent in managing my health care...

- My mom and I butted heads a lot at first
- It helped to get some advice and learn how to manage my needs
- I got a structured plan that I follow and that helps a lot
- I've grown a lot in my skills since I started following the plan



How it feels to transition to new providers

- It was difficult because it wasn't a smooth transition.
- I felt surprised because it happened so quickly and without time to prepare.
- It probably bothered my mom more than me. I was naïve and just figured we would easily find new doctors.
- I try to go into new experiences with a positive attitude and see how it goes.

Now I can see some of the differences from Pediatric to Adult Health Care providers.

In the pediatric world, the doctors listen to the parent and patient and address their concerns.

In the adult world, you really have to advocate for yourself. If the doctor doesn't listen to you when you have concerns about your health, you will need to seek a second opinion.

You're the one in charge of your health, not your doctor.



Transition Advice for Parents

- Try to help your kid be as independent as possible within limits. Be prepared to have a doctor make you step back and have your child try to take their meds and other cares on their own without the parent saying anything even if you know your child didn't take their meds or do their cares.
- Have them take their meds on their own, but make sure they did take them. I realized that I needed help and then me and my mom started working together with my meds and now I have no issues taking my meds. I also had to step up with my personal cares as well and I have.
- Step back in certain situations and see how they do, and if they need help then help them. See if that will make them grow.
- If they make a mistake when scheduling an appointment, and don't have transportation available, then have them call back and ask to reschedule for a different day and/or time.

Transition Advice for Providers

For doctors who are transitioning patients OUT

- Make sure that they have an idea of what way they're going to go and show them some different providers that might match what they need. Each patient is different, so if you can give different options that fit their personality or situation that would be good.
- It's good to spend time alone with the patient (without their parents) in order to help them learn that their healthcare is their responsibility – maybe at 13 years old.

Transition Advice for Providers

For doctors on the adult side who are receiving new patients

- Don't let your ego get in the way. Even if you think you can take on the patient with their exceptional health care needs, you have to be able to admit if you don't have enough information or experience in that certain area and consider referring the patient to a colleague who might be equipped to help someone like that.
- Or, you could educate yourself more and see if you can handle it. Be willing to learn from the patient or parent or other physicians about the patient's experiences.

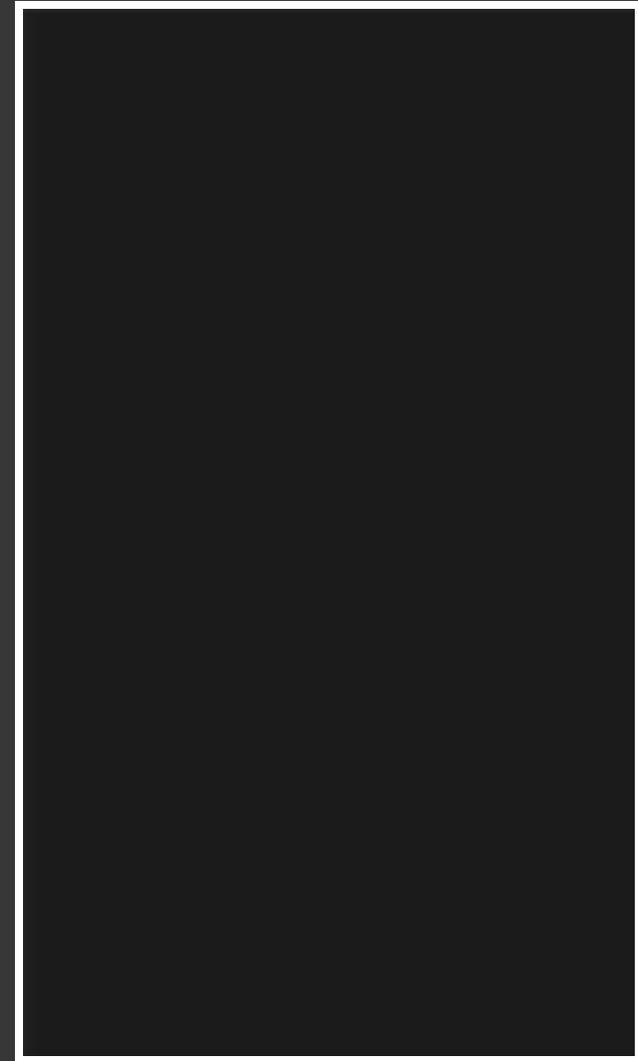
Transition Advice for Youth

- You have to be your own advocate, if you think something is wrong tell your doctor to look at it more thoroughly. If he doesn't think it's that serious, then you need to see another professional and get another opinion.
- There are some good doctors out there but you have to put in the hard work to find one.

Listen UP!

Transition Advice for Youth

- Youth need to start asking their own questions, be their own advocate and start to take charge.
- When you're 16, talk to your parents and ask if you can have more of a role or ask some questions in the doctor's office.
- Ask how often to take a med, when to take it, make sure you get the right directions about whether to take with food or not. Make sure that you're responsible and use the medications as you should. Know what the names are and what the interactions might be. I don't drink alcohol at all because of the interactions.



My Life Goals

My goals in life include

- College
- A career in which I can be proud of and make a decent living
- Have a family get married.

“I don’t have to make \$100,000 but if I have a career I enjoy and a roof over my head I’m happy.”

At work

