Operation independence: becoming more responsible for your health

Adolescent Transition

Adolescent Transition Education Package | Fact Sheet 11a

An information sheet for patients transitioning from paediatric to adult health services

Part of being a teenager is getting a stronger sense of self-identity and beginning to establish your independence. You may already be starting to negotiate your independence with your parents/carers as well as teachers, friends and extended family. It is important for you to gain independence in your healthcare too. This will be an advantage when you get older and are expected to make your own decisions and choices about taking care of your health. It is a good idea to begin practicing these skills now, while your parents or carers and other trusted adults are still really available to help you out if things get complicated.

Negotiating independence if you have a medical condition

Some young people find that living with a health condition or disability and trying to gain their independence can be frustrating.

A great first step is to demonstrate that you are responsible and capable. This will help those around you feel comfortable about you making your own healthcare decisions.

All decisions you make in life will have positive and negative parts to weigh up, but it is particularly important that you are aware of the potential risks to your health when your decisions involve risky behaviours. Read the *Risk Taking & Choices* fact sheet for more details on how to make informed choices.

Negotiating independence with your parents/carers

It may be a challenge to negotiate with your parents/carers about gaining some independence in your life. This is because they care about you and want to see the best outcomes for you. Parents and carers also want to protect you, and can find it hard to stop making all the decisions for you because they want to help you stay as healthy as possible. You may find this hard to accept, especially when things don't always go the way you want them to at this stage in your life.

During adolescence you may find that your opinion differs greatly from your parents/carers and this can result in a lot of conflict. You will find it easier to work with (and not against) your parents/carers about making decisions if you state how you feel in a clear, rational and open way. You may feel that your parents/carers are overprotective or worry about you too much, but remember that they do this because they love and care for you. Here are a few tips for negotiating your independence.

Operation Independence Intervention!

- 1. **Choose the right time to talk** with your parent/carers about independence. Make sure you all have enough time to give one another your full attention.
- 2. Always aim to be **open and honest** with your parents/ carers as well as your doctor and medical team. If you wish to tell your doctor something without your parents/ carers being present it is ok to ask for some time alone with your doctor. As a young person you are entitled to increasing amounts of confidential time with your doctor. See our *Know your rights, including confidentiality* fact sheet for more information on this.
- 3. **Be clear** about what you want and why you want it. Write down the key points you want to make. This will help you to remember everything when you start to discuss things face to face.
- 4. **Set small goals** for you and your parents/carers to achieve together in relation to managing your health. You can also set some individual goals and discuss these with your parents/ carers. See our Goal setting fact sheet for more information.

Operation independence: becoming more responsible for your health

Adolescent Transition Education Package | Fact Sheet 11a

- 5. **Be calm and don't get angry** if the discussion isn't going your way. If you can't find a happy medium then hit the 'pause' button instead of getting into an argument and reassess the issue with your parents/carers at a later time. Use a phrase like "I need to discuss this with you later" and then calmly walk away. You could also try and find an impartial person to help facilitate and guide the conversation next time – this could be any member of your healthcare team, a family friend or a teacher
- 6. **Discuss how you are feeling with your parents/carers.** How they think you feel and how you actually feel may be different. Also discuss how your parents are feeling as well, because what you think they are feeling or worried about and what is really on their mind might be different.
- 7. **Discuss how you are feeling with your doctor** and medical staff and come up with a plan that gives you more involvement in your healthcare, for example attending part of your appointment on your own.
- 8. Demonstrate that you're capable and ready to act responsibly. Showing initiative before you are asked to do something and doing what is asked of you before anyone feels they have to nag you, is a good way to show your parents/carers that you are capable of listening to instructions, making good decisions and acting in your own best interests.
- 9. **Don't push too hard.** Small steps will eventually achieve big changes. You may push your parents/carers too far which could result in taking a few steps back. Be gentle in your approach and remember it can be hard for them to let you go. Try to tell your parents/carers what they are doing well and how they can continue to help support you.

Gaining independence in all parts of life, including healthcare, may require a different approach for each individual. Some young people may already be living away from home or attending solo appointments. Other young people may enjoy not having to make big decisions in their lives and prefer to leave certain decisions to their parents/carers. Each person is different.

Don't worry if you feel like your friends or siblings are more independent, eventually you will be too. Remember that it is important to continue to work on establishing more independence in all areas of your life.

Independence – the experience of one of our young people

I was a patient at The Royal Children's Hospital until I was 20. I was an adult in a children's setting. I remember how unpleasant it would feel being an adult sitting in amongst the screaming children in pathology.

I didn't even think about transition until my mum brought it up in one of my appointments when I was 19. Now looking back I can really see the benefits of an early transition that is planned; there are no shocks and no feeling of being out of place. Being prepared and being able to see a doctor in a hospital that I am not too old to be admitted to, would have been rather handy back then.

Probably the worst thing was the lack of independence and control over my own healthcare. I only started going to my appointments on my own when I was 21. Up until then my Mum came with me, booked my appointments, paid, drove, parked, waited and did most of the talking while I pretended to listen with the occasional nod of agreement thrown in. My doctor did have a really nice view from his window, a highlight of my appointments.

I felt pretty silly still being dependent during hospital visits when I had already moved out of home and was looking after myself.

A few months before I turned 21 I had my first ever solo appointment with my new doctor. I was so nervous beforehand, I tried to convince my Mum to come in with me, but she was adamant on sitting in the waiting room. "I only came to drop you off", she said. Then during my appointment my doctor congratulated me on not bringing my Mum and said that she doesn't let parents come in with her adult patients. I told her Mum was with me but just dropping me off, thank goodness I didn't convince her to come in. Now I am quite competent at having appointments by myself, I can express what I am feeling well and pay and book my next one with the receptionist at the end.

I feel pretty happy about where I am at now. I don't feel like the oldest anymore, in fact I am usually the youngest in the waiting room, a welcome change. I also feel a great sense of independence and self-management in my own care. Sometimes I still have to rush to the chemist to pick up a script as I've run out of pills that morning, but slowly and surely I am getting there.

