

Being a Healthy Adult: How to Advocate for Your Health and Health Care

The following excerpts are used with permission from a booklet by Kathy Roberson at the Elizabeth M. Boggs Center on Developmental Disabilities in New Brunswick, NJ. This booklet is a very user-friendly guide to health transition for young adults. We recommend you download the entire booklet from the following website if you like the parts of it we have included below:

<http://rwjms.umdj.edu/boggscenter/products/documents/TransitiontoAdultHealthcare-EN-complete.pdf>

What does the word “health” mean?

“Health” has to do with taking care of our physical, mental, and emotional well-being. People with disabilities share the same basic health needs as other people their same age, but may also have additional medical needs because of their disability. All people, including people who have health needs because of their disability, can work towards increasing their health and wellbeing.

What does “health care” mean?

“Health care” usually refers to the services that help us get better when we’re sick or hurt, or help to keep us well. Health care includes things like visits to doctors, dentists, and hospitals. Health care also includes diagnostic tests, like x-rays and blood work, which help health care providers figure out how best to treat health-related problems. Health care also includes taking responsibility for our own well-being, and making good choices about things like the foods we eat and how much we exercise. Our health affects us in many ways, and the decisions we make about such things as medical treatments and lifestyle can have a big impact on our overall happiness and on our ability to reach our life goals.

Does having a disability affect my health?

It depends. Some people think that having a disability automatically means that the person is not healthy, but that’s not true. Having a disability is not the same thing as being sick. While some disabilities do present health challenges that go beyond the health needs that everyone shares, many do not. Part of what you will learn to do in this workbook is find out what, if any, health issues may be related to your specific disability.

It’s true, however, that some young adults have been dealing with health problems for many years, and for them, this time of transition may be even more complicated. They may feel like they’re tired of dealing with health issues, and would rather just think of other things, like going out with friends or finding a summer job. They may be nervous about leaving doctors they’re familiar with and getting to know new ones. Sometimes people with disabilities have a hard time finding appropriate health care. They may live in an area where there aren’t doctors that can treat their health needs, or they may have trouble finding or being able to afford health insurance. This workbook was written to help young adults become better self-advocates so that they can find the supports they need for their health and health care whatever their challenges.

What is “transition?”

Transition is when we move from one thing to another. The transition we are going to be talking about in this workbook has to do with moving from being a child to being an adult. While 18 or 21 years old are often the ages when people are thought to officially become an “adult,” growing up doesn’t happen on a single birthday. It is a process that happens over time. You have been learning skills that will help you to be a successful adult since you were a young child. You will also continue to learn and grow and change in lots of different ways throughout your life. The transition to adulthood involves many different parts of your life, including: moving from high school to work, or to college or another kind of school; deciding where you are going to live; and making new friends as well as finding ways to stay in touch with your old friends. In this workbook, we’re going to focus on your health, and moving from the health care you have gotten as a child to the health care you will need as an adult.

Does having a disability affect the transition to adulthood?

In many ways it doesn't. Leaving school and creating an adult life presents new opportunities and new challenges for everyone, and how people respond to those opportunities and challenges depends on many things. Your strengths and needs, your likes and dislikes, your family's expectations of what adult life should look like, and where you live, are all things that will help shape the choices you make. Having a disability is just one factor of many that can have an impact on someone's transition to adulthood.

There are ways, however, that having a disability can create unique challenges when someone is in the process of transitioning to adult life. For example, depending on the specifics of the disability, some young adults have had little experience doing things alone. Or, because they have needed specialized supports for many years, they wonder if that means they will never really be "grown up."

One thing to always keep in mind is that no one is completely "independent." The idea that adulthood means that people are able to do everything on their own is a myth! **All** people, regardless of whether or not they have a disability, need help to reach their goals. Ask people you know and admire, and they will tell you they didn't achieve their successes without some help along the way. (Have you ever watched the Oscars? Or seen athletes getting big sports awards? Almost always, they spend time thanking those people who have helped them get to where they are.)

What does it mean to have a "healthy lifestyle?"

In general, when people talk about having a healthy lifestyle, they mean you're making choices that are good for your body and mind. Here are some choices that will help keep you healthy:

1. Using proper hygiene prevents you from getting sick or getting an infection. It can also make you feel good about yourself.
 - a. Wash hands before you eat
 - b. Wash hands before you prepare food for cooking and eating
 - c. Wash hands after going to the toilet
 - d. Take a bath or shower everyday
 - e. Change underwear and clothes
 - f. Brush teeth in the morning and before bed
2. Don't smoke!
3. Get regular exercise.
4. Eat a healthy diet.
5. Use seat belts every time you ride in a car.
6. Don't drink alcohol and drive a car.
7. Don't drink alcohol and take medication at the same time.
8. Don't use illegal drugs.
9. Practice "safe sex" so you don't get sexually transmitted diseases or get pregnant.
10. Make your home safe so you won't have accidents.
11. Get a smoke alarm, hang it up in your house.
12. Make sure your house or apartment has a fire extinguisher.
13. Use sunscreen when you are out in the sun.
14. If you are a woman, do regular breast self exams. If you are a man, do regular testicular exams. Your doctor or nurse can teach you how.
15. Get regular checkups at the doctor's and follow the doctor's advice for screening tests.
16. Make friends who can be a "support system" for you.

(Adapted from "Let's Talk About Health: What Every Woman Should Know," Arc of New Jersey, 1996)

What should I do if I have a health emergency?

Calling 911 is usually the best thing to do in an emergency (for example, bleeding that can't be controlled, difficulty breathing, loss of consciousness for reasons other than predictable seizure activity). Phones can be programmed so that just pushing one button can dial the number you need.

Most importantly, you should have a plan in place for what to do in an emergency, and anyone who helps care for you should know the plan as well.

Also, don't forget to always have with you the card or paper that has in writing your important medical information.

Can't I just go to the emergency room if I have a problem?

Emergency rooms are for emergencies such as those described above.

They are NOT good for regular health care because there's no one there to provide follow-up care after the emergency, or to follow your health conditions over time to see what has changed. Emergency rooms are usually busy with long waits to be seen, and are not set up to have conversations with doctors about health concerns other than the one that brought you to the emergency room. They're also very expensive!

If you have a health problem that is not an emergency, call your doctor to find out what you should do.

Some insurance plans have specific rules about using emergency rooms, and you might want to check with your insurance company about that as well.

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