

Being a Healthy Adult:

How to Advocate for Your Health and Health Care



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Department of Pediatrics



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University of Medicine & Dentistry of New Jersey

*A University Center for Excellence
in Developmental Disabilities Education, Research, and Service*

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

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The following alternate formats are also available at no cost. Please contact Kathy Roberson at 732-235-9317 or kathy.roberson@umdnj.edu for more information.

- Spanish print version
- Audio recording on CD (English and Spanish)

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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 well-being.

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.)

Activity:

- **Who are the people you know who have reached goals that were important to them? What kind of help did they have? If you don't know, go ahead and ask!**
- **Who has helped you to reach a goal?**
- **Who have you helped to reach a goal?**

What's a "self-advocate?"

An effective self-advocate is someone who's good at letting other people know what he or she is thinking, feeling, and needing. Sometimes self-advocacy means asking lots of questions (and asking them until you really understand the answers!). Sometimes it means helping other people understand what's important to you, and sometimes it means asking for help when you really need it. Self-advocacy doesn't mean you'll always get just what you want in the way you want it, but having the skills and confidence to communicate your wants and needs is an important first step in reaching your goals.

Activity:

- **Think of someone you know who is a good self-advocate (it can be you!). Why do you think that?**
- **What are some things that can make it hard to advocate for yourself?**

Activity:

Rachel is seventeen. She was born with cerebral palsy, so it's hard for her to use her legs, and her right arm isn't very strong. She uses a wheelchair to get around.

The other day, Rachel was at the doctor's for her annual check up. Her mother was asking the doctor questions about a new medication Rachel needed. The doctor said that one of the possible side effects of that medication was weight gain.

Rachel is proud of how she looks. Plus, she's afraid gaining weight will make it more difficult to get in and out of the wheelchair. She wondered if there was a special diet she could go on that would keep her healthy but also prevent weight gain.

Rachel felt embarrassed to talk about her weight in front of her mother and doctor, so she didn't say anything. She left without having her questions answered.

- **What else could Rachel have done at the doctor's appointment?**
- **What else could the doctor and her mother have done to make it easier for Rachel?**
- **Is there something else that Rachel could have done after the doctor's appointment to get the information she needed?**

Sometimes it's hard for me to understand people when they're talking about my health.

One of the things that can be useful to know about is your learning style, or the ways that you can best understand new information. Being a good self-advocate means being able to ask questions **and** request that the answers be given to you in a way that you find helpful. For example, some people learn best by **hearing** information; other people learn best by having things **written** down. It's important to be able to tell your health care providers what works best for you so that you can understand the information they're giving you.

Activity:

- **How do you think you learn best?**
(Check all the answers that make sense for you.)
 - **By hearing information** _____
 - **By seeing information** _____
 - **By doing things "hands on"** _____
- **How do you express yourself best?**
(Check all the answers that make sense for you.)
 - **By talking** _____
 - **By writing** _____
 - **By signing** _____
 - **By using a communication device** _____

I've seen the same doctor since I was a baby. He knows me really well. Can't I just keep seeing him?

That depends. Some doctors are “family practitioners” and they are trained to see people of all ages. If you've been seeing a family practitioner, it might be fine to stay with him or her. However, “pediatricians” are doctors who are specifically trained to take care of children and teenagers. As you grow up, your health needs change, and it is important that you have a doctor who understands your adult health needs. That means if you've been seeing a pediatrician, you will have to find a new doctor. While changing doctors can feel scary, try to keep in mind that the sooner you get to know the new doctor, and the sooner he or she gets to know you, the more comfortable you'll both feel when you have a health-related question or concern.

Primary care doctors are doctors that see you for your basic, overall health needs. Specialists are doctors that treat specific kinds of health needs. For example, cardiologists deal with the heart, neurologists deal with the brain (for example, seizures), gynecologists deal with women's reproductive health. Many people see both primary care doctors and specialists.

Activity:

- **List the kind of doctor or doctors you see now. Do you see a pediatrician? A family practitioner? Any specialists? If you see a specialist, do you know why you see him or her?**
- **If you're not certain how to answer these questions, ask someone who knows about your health care – including the doctors and nurses you feel most comfortable with.**

Once I'm an adult, what health decisions can I make for myself?

At 18, most people have the legal right to make their own decisions about their health care. However, while taking responsibility for your health is a part of growing up, being 18, or being an adult of any age for that matter, doesn't mean you suddenly understand everything you need to know. Nor does it mean you are expected to make big decisions all by yourself. No matter how old you are, it's important to reach out when you need help understanding information and thinking things through.

Many young adults choose to have their parents or another trusted adult provide at least some guidance when they're making medical decisions, especially if those decisions are complicated ones. Some people have a guardian who has the legal responsibility for making certain decisions for them.

Always remember, though, no matter who is involved in making decisions about your health, it is **your** health, **your** body, **your** needs, and **your** goals that matter most!

What can I say to doctors about my health that they don't already know?

It's true that doctors have a lot of medical education and experience. However, every patient is different, and having a clear understanding of who you are – how you are feeling, what your concerns are, what you want to do in life – makes it easier for your doctors (or any other health care provider) to successfully meet your individual needs. Your active involvement in your own health care helps them to be better health care providers. Think of yourself as part of a team, with each member of the team having something important to contribute...and what you have to contribute is knowing **you** better than anyone else!

Sometimes when I'm in the doctor's office it's hard to think of what I want to say or what questions to ask.

That's true of many people. One thing that can be helpful is to write down (or tape record if it's easier) your questions and concerns ahead of time. Sometimes many months can go by between doctor's visits, and it can be easy to forget what you wanted to say. It can help to keep a journal to write down important things you want to talk with your doctor about. It can also be helpful to sit down with a family member or friend to help you think about what you want to ask or tell the doctor. Remember, you may not have as much time as you'd like to talk about everything in one visit, so **first** ask the questions or talk about the concerns that matter **most** to you. And don't forget that if something isn't clear, ask the doctor to explain it again in words you can understand.

A lot of people bring someone with them when they go to a doctor's visit. That person can help ask questions, help listen to the answers, and after the doctor's visit is over, help remember what was said. It's up to you to decide if you want someone to come with you. If so, you need to decide if you want them to stay with you for the whole exam or just while you're talking with the doctor. You can also ask them to stay in the waiting room and only ask them to join you if you feel that would be helpful. It's important to ask yourself, "What will I be most comfortable with?"

It's also important that whoever comes with you understands that **you** are the patient. You don't want to have someone come with you that talks with the doctor as if you aren't there, ignores your wishes, or makes decisions without talking with you.

If you get home and still don't understand something the doctor said, see if someone else you know can explain the information. If no one can, you might need to contact the doctor's office again. Keep in mind that sometimes nurses are the most helpful people to go to for explanations. Also, some doctors are happy to communicate by email, and if you're comfortable with that, it can be a useful way to get your questions answered.

Activity:

- **Think of someone you'd like to interview (the interview can be about your health or health care, but it doesn't have to be).**
- **Write down or tape record (with help if need be) 5-10 questions you'd like to ask that person.**
- **Write down or tape record (again, with help if you need it) the answers.**
- **Go over the answers afterwards. Did the person answer the questions you asked? Do you understand their answers? If not, who might help you understand the answers?**
- **Ask yourself if there was a different way you could have worded the questions that would have been more helpful?**

I know I have a disability, but I've never been too sure about the details.

Understanding your disability is an important step in growing up and taking responsibility for reaching the goals that matter to you. The more you understand yourself – your strengths, interests, likes, dislikes, dreams for the future, as well as your disability and any health issues you might have – the easier it will be to meet new challenges successfully. If you don't understand what you need, it will be much harder for other people to understand and provide the supports and accommodations that will be most useful to you. Being a good self-advocate means first of all knowing yourself!

The following are some suggestions of ways to get information about your particular disability. Remember, your parents, your doctor(s), or other trusted adults can be great resources.

Activity:

- **Write down the questions you have about your disability. For example, what is the name of my disability? What does it mean to have this disability? How might it affect my life as an adult?**
- **For your health care provider, you might ask: What have been major health concerns in the past? What are my major health concerns now? What are future health concerns I may need to be aware of? Will my disability change over time?**

Talking with someone else with a similar disability can also be helpful.

Activity:

- **Your Centers for Independent Living (sometimes called Independent Living Centers) are run by and for people with disabilities. They may be able to link you with other people with similar disabilities who can talk about what it's like living as an adult with that disability. You can find your local CIL by calling 713.520.0232 ext. 130 (Voice/TTY) or going to**

<http://www.bcm.edu/ilru/html/publications/directory/index.html>

There are many national and state organizations that focus mostly on just one disability, and these can be helpful resources as well.

Activity:

- **See if you can find an organization that provides information about your disability.**
- **A helpful resource to start with is the directory that is published (in hard copy and on-line) by the New Jersey Division of Disability Services (DDS). DDS also has information and referral specialists that are available to connect people with disabilities and their families to a wide range of services they need. DDS can be reached at 1-888-285-3036 and www.state.nj.us/humanservices/dds**
- **Exceptional Parent magazine has a disability-specific resource guide. You can request one free copy by calling 1-800-E-PARENT.**

Where else can I get information?

There are lots of people and places you can go to for information. However, depending on whether you are trying to learn facts about your disability or health condition, talk about your feelings, or learn about what supports are out there, some resources will be more helpful than others. Also, keep in mind that some resources have more accurate information than others.

Activity:

List the pros and cons for each of the following sources of information:

- **The Internet: For example,**
 - ✓ **Pros = lots of information; I can look up information when it's convenient for me**
 - ✓ **Cons = so much information it can be overwhelming; hard to know what is accurate or not.**
- **Family: For example,**
 - ✓ **Pros = people that know and love me; parents may know more than I do about certain things**
 - ✓ **Cons = may not be people I feel comfortable talking with, especially about "adult" topics; may not have answers to some of my questions**
- **Friends: For example,**
 - ✓ **Pros = trusted people to talk with; understand me**
 - ✓ **Cons = may not have accurate information or know more than I do**
- **Doctors: For example,**
 - ✓ **Pros = have accurate information about my disability and health conditions**
 - ✓ **Cons = may not be easy to talk with; may not understand my life outside of the doctor's office**

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.
 - Wash hands before you eat
 - Wash hands before you prepare food for cooking and eating
 - Wash hands after going to the toilet
 - Take a bath or shower everyday
 - Change underwear and clothes
 - 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)

Activity:

- **Sometimes it can be hard to make healthy choices. What are some of the things that can make it hard? What are some of the things that can make it easier?**

Things like getting to doctor’s appointments, or understanding directions for taking my medicines, can be hard for me. Where should I go for help?

It depends. There are lots of different kinds of supports, and which one you choose will depend on what exactly you need help with. Here’s one way to think about the kinds of supports you may find helpful.

- “Natural” supports are family and friends.
- “Community” supports are resources that are there for everyone, with or without a disability, like libraries, YMCAs, and public transportation.
- “Disability-specific” supports are resources like Medicaid, Social Security, and para-transit.
- Assistive technology are things like wheelchairs, screen readers for the computer, and tape recorders.

Again, depending on what you need, you may use one of these kinds of supports or some combination of them.

A good strategy for thinking about what kind of help you need is writing down everything that needs to be done to solve a problem. Some of the things on the list you will be able to do yourself, and some of the things you will need help with.

Activity:

- Here's an example of someone using the strategy of writing things down. John needs to go to the doctor's. His mother is usually able to drive him, but she won't be able to this time. He wonders if he'll be able to take the bus there.

Supports Worksheet			
Problem that needs to be solved: Finding out about taking the bus to the doctor's			
List of things that need to be done	Things I can do myself	Things I need help with	Who or what will be able to help me get this done
Find out the day and time of the appointment	X		Look at the card the doctor's office gave me last time
Make sure I know where I'm going to and from	X		The address is on the card from the doctor's office and I already know my home address
Look up phone number of bus company	X	X	The internet (maybe I can do it alone or maybe I'll need help from someone – my friend Josh is good on the computer)
Write down questions to ask bus company	X	X	I can help think of questions, but I need someone to write them down (maybe my mother)
Call the bus company	X	X	I can do it if everything is written down, but it might be good to have Josh or my mother there in case I need help

Notice how John does what he can to help himself, but then asks for help when he needs it. Notice also that he uses different kinds of help, including the internet, a family member, and a friend.

Activity:

- **The following are some examples of health care-related problems that you might need to solve.**
- **If there are other things you think need to be done to solve the problem, write them down.**
- **Check what things on the list you can do yourself.**
- **Check what things you need help with.**
- **Write down who or what might be able to help you.**

Supports Worksheet

Problem that needs to be solved: I need to call my doctor

List of things that need to be done	Things I can do myself	Things I need help with	Who or what will be able to help me get this done
Get the doctor's phone number			
Write down my questions before I call			
Call the doctor			
Write down the answers to my questions			
Other thing to do:			
Other thing to do:			
Other thing to do:			
Other thing to do:			

Supports Worksheet

Problem that needs to be solved: I need to refill a prescription

List of things that need to be done	Things I can do myself	Things I need help with	Who or what will be able to help me get this done
Get the number of the pharmacy			
Get the prescription number			
Call the pharmacy to order the refill			
Pick up the prescription			
Other thing to do:			
Other thing to do:			
Other thing to do:			
Other thing to do:			

Here's a Supports Worksheet that you can use to help think out how to solve problems. Make as many copies as you'd like!

Supports Worksheet			
Problem that needs to be solved			
List of things that need to be done	Things I can do myself	Things I need help with	Who or what will be able to help me get this done

My health care needs are pretty complicated. It's hard to remember everything!

It's important that everyone keep a file (or more than one file) of their health-related information (for example, doctor's reports, dates of operations, a list of medicines you take). Some people use a health notebook, so they can keep all their information in one place, and then bring the notebook with them when they go to a medical appointment.

Files or notebooks with information about your health history, however, can get pretty big. A piece of paper or index card listing the **most** important information – for example, any allergies you have, medications you take, your primary doctor's name and phone number, an emergency contact person's name and phone number – is important to keep with you, in case of an emergency. You might also want to put a copy on your refrigerator so you can easily find it when you need it.

What about health insurance?

Health insurance is a way to pay for medical care. There's government run health insurance, like Medicaid and Medicare, and there's private insurance companies, like Blue Cross/Blue Shield. Different health insurance plans pay for different things (for example, prescriptions) and have different rules (for example, some plans require that you only go to certain doctors). Understanding your health insurance can be difficult, so don't be afraid to ask questions. At the very least, make sure you have your health insurance card which has the provider's name and contact information, and your policy number.

The Arc of New Jersey's Mainstreaming Medical Care Program may be able to help you answer some of your health insurance questions. They can be reached at 732-246-2525.

Activity:

- **Use the following worksheets to create a list of important medical information (attach additional information if necessary).**
- **Be sure to give a copy to other people you trust, such as your family and support staff.**
- **You might also want to put a copy on your refrigerator so you can easily find it when you need it.**

MY MEDICINE LIST

LIST OF MEDICINES (name of medicine, how many times a day you take it and at what time, and the amount you take)

ALLERGIES (list everything you are allergic to, including medicines)

MY DOCTORS AND HEALTH CARE PROVIDERS

Name and contact information of my primary care doctor:

Name and contact information of other health care providers, including specialists, and physical, occupational, and speech therapists:

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.

Can you sum up one more time what I need to do to be a good self-advocate for my health and health care?

Here are the most important things to remember about health and health care advocacy:

- **Communicate as best you can what you're feeling, thinking, or needing.**
- **Ask questions... and if necessary, ask them again!**
- **Do what you're able to do for yourself, but don't be afraid to ask for help when you need it**
- **Try to make healthy lifestyle choices**

Remember, taking care of your health and health care will help you reach the goals that matter most to you, and live the life that's right for you!

NOTES

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