

Moving Into Adult Health Care



What Do Young Adults With and Without Disabilities Need to Know?

A guide for young adults with and without disabilities

Connecticut Edition, 2012

This booklet was written by

CT-KASA

Connecticut Kids As Self Advocates

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Introduction

So Now You Are an Adult! Now What?

Turning 18 is a magical moment for most young adults. According to the law, all you have to do to be an adult is become 18 years old. Just like that, you are legally an adult! That may sound simple, but turning 18 doesn't mean you just know everything you need to know about being an adult. As an adult, you may have to make a lot of decisions about your health care. You don't have to make them alone. You have parents, teachers, doctors and others who can help you make decisions about your health now. When you turn 18 these people can still help you, and there may be others you will want to involve.

This booklet will help you think about the things you need to do to take care of your health as an adult. It will help you think about your health care needs, organize your information, talk with doctors and other health care providers, and manage your medications.

This booklet is about being healthy and ready for the life you want to live.



What Do I Need to Know About My Own Health Care Needs?

What Do I Need to Know About My Diagnosis?

@ Know what help or assistance you will need at the doctor's office

- Physical support
- Assistance in understanding what the doctor says
- Sign language interpreter
- Other forms of help

@ Know your own body

- Your weight
- Your height
- Your normal body temperature
- How you usually feel

Make sure you get a check-up EVERY YEAR.

It is important that the doctor knows what you are like when you are healthy. That way, they can see what's wrong or different when you are sick.

Know When You Feel Different

- You know when there is something wrong with you, but you have to let the doctor know.
- Your health care provider may not believe you or understand why you are worried, but they need to listen; otherwise you might become more sick. It is your job to help them understand your concerns.
- If you have a lot of health care issues, you may want to keep a medical journal that keeps track of things you notice about how you feel from day to day. Include what you are doing when you feel a certain way. Think about what medicine you took, how active or inactive you are at the time, what food you ate, how much sleep you got and anything else that might affect how you are feeling.
- You may also want to record changes in medications or your daily activities. This can help you and your doctors to notice when things are or are not working.





What Do I Need to Know About My Medicines?

Why do you take the medicine?

What are the side effects of the medicine?

Which doctor ordered which medicine?

How much and how often do you take the medicine?

@ How much medicine is in each dose?

- You may be told to take your medication by mouth, by dropper, or by spoonful.
- Make sure you have the right measurement — correct dropper or spoon size.
- You should know how many grams or milligrams are in each tablet.

@ How do you take the medicine?

- Some medicines are crushed, some are cut in half, some are liquid, and some have to be taken with meals or before or after meals.
- Know what time(s) to take your medicine(s).

@ How long does it take for your medicine to work?

- Some medicines work almost right away, some take an hour, some take longer.
- Talk about this with your doctor and the pharmacist so you can plan your daily schedule of activities.

@ How does your medicine affect what you want to do?

- If your medicine makes you sleepy, there may be good and bad times to take it.
- If you are going out to a special activity or event, you may need to plan ahead on when and how to take your medicines.

@ How will you remember to take your medicine?

- You or someone else can help you count out pills and put them into a pillbox for each day of the week.
- If you take medicine many times a day you may need timers or alarms to help remind you when to take them.

@ What does your medicine look like?

- Know the shape, color and size of your medicine.
- If you get a medicine from the pharmacy and it looks different from the medicine you usually get, **ALWAYS** ask the pharmacist why it is different. It may be a generic drug, or a drug from a different manufacturer, or it may be incorrect.

@ If your medicine is prescribed to be taken PRN (that means take as you need it), how much and how often can you take it?

- This can be pain medication like Tylenol, or other medicines.
- Ask your pharmacist and health care provider how often you should take these medicines, and what the side effects are when taking them.

@ When do you need to refill/re-order the medicine?

- Do not wait until your medicine runs out. Order when you have a week's supply or more left to take.

How to Find the Answers to Your Questions for Each Medicine

- Read the medication labels if you are able to, or ask someone to read it to you if you need help.
- Always follow the directions on the medication labels.
- If you still don't know the answer to your question, ask your doctor or pharmacist. Make sure you tell your doctor and the pharmacy about all of the other medicines and vitamins you are taking, even if they are not prescription medicines.
- Sometimes when the doctor is writing you a prescription for a medicine, he or she will often write codes on the prescription form. Below is an interpretation key of the most commonly used codes written on prescription forms. If you do not understand what was written on the prescription form, ask your doctor or pharmacist to explain it to you.

Pill Interpretation Key

- Ⓢ Daily = QD
- Ⓢ Twice a day = BID
- Ⓢ Three times a day = TID
- Ⓢ Four times a day = QID
- Ⓢ Every other day = QOD
- Ⓢ By mouth = PO



Pharmacy

What Happens If I Am Diagnosed With A Disability or Special Health Care Need When I Am Older?

- Sometimes, you are not born with a disability, but may be diagnosed later in life with a special health care need.
- You might have an accident, a serious illness, or be diagnosed with a mental health condition when you become older.
- You will need to learn a lot about your newly diagnosed condition. You may have to change or add new doctors when this happens.
- Talk with your doctor, other health care providers or other youth who have the same diagnosis to find out more information. You can also read about your diagnosis on reliable websites.
- Your new diagnosis may also change the supports you need or the insurance you need to help pay for your medical care.



How Do I Want to Live?

- Know your goals in life.
- Know what kinds of activities you like and are determined to continue doing.



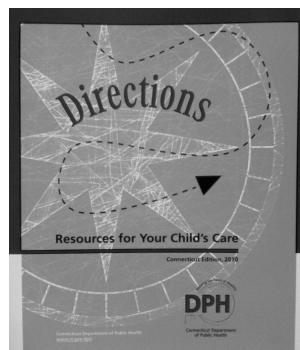
Think About What Is Important to You

- If you use a wheelchair, think about how long you want to stay in it each day.
- What recreational activities do you like?
- What kind of foods do you like? If you are on a special diet, get help from your health care provider in finding foods you like that you are able to eat. Ask if you can NEVER eat certain foods, or if you can eat them once in a while, and how often.
- What are some things that may get in the way of what you need to do in your daily life? If you are taking medicines that make you sleepy when you are at school or work, talk with your health care provider about different medicines, or about the time of day you take your medicines.
- Sometimes your disability may influence how health care providers respond to your lifestyle. It may be necessary for you to raise their awareness of your abilities.



How Do I Organize Information About My Health Care?

- ☉ Use an organizer, like DIRECTIONS, to help you keep track of your health information.
- ☉ You should organize information about all your doctors and other health care providers, including why you see them, and how to contact them.
- ☉ Keep a calendar with appointments.
- ☉ Keep a list of medicines with their dosages and why you take them.
- ☉ Keep a list of all your insurance information.
- ☉ Keep your health diary here.



The link to **Directions** is located on page 30 of this Guide. Click on 'Connecticut Department of Public Health Youth with Special Health Care Needs' and scroll down to find **Directions** in English, Spanish and Portuguese.

What Do I Need to Do Before a Doctor's Appointment?

How Do I Choose a Doctor?

@ Ask Yourself Why You Need to See the Doctor

Answering this question will help you narrow down the selection of doctors in your city or town. The kind of doctor you choose will depend on what you need to see the doctor for. You might go see a doctor to take care of regular health problems or you might see a specialist for a health problem that is caused by your disability.

@ Is the Office Accessible?

If you can't physically get in the building, you will automatically know that you need to choose a different doctor.

@ Does the Doctor Take My Insurance? If So, Will I Have a Co-Pay? How Much Will It Be?

When you are choosing a doctor, find out if the doctor accepts your insurance. If not, you will have to see a different doctor or pay for all doctors costs yourself. This can be very costly. If the doctor does take your insurance you may have a co-pay. This means that you have to pay something towards each visit or treatment. This can be \$5, \$10, \$25 or more per visit.

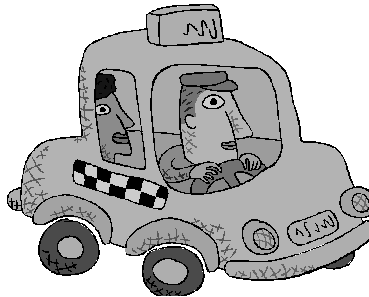
You need to find out how much your co-pay will be before your appointment. You can take the money with you to pay at the time of your appointment or you will receive a bill in the mail from the doctor after the appointment. You can find out about your co-pay by looking at your medical insurance card or calling your insurance company. Find someone to help you if you don't know who to call or what to ask.

How Will I Get to My Appointments?

At some point in your life, your parents or guardian will no longer be able to drive you to the doctor's office. You will need to know how to get there on your own. This might include a city bus or other forms of public transportation.

Sometimes you cannot use public transportation because it is not accessible in your area, or because of the distance from your home to your appointment, or the time of the appointment. You will have to look for other ways to get a ride, which can include friends, a taxi, dial-a-ride, or medical transportation.

If you need a wheelchair accessible taxi or van, they are available. Check your local resources for transportation companies that provide wheelchair accessible vehicles for people with mobility disabilities.



If you have Medicaid, or Title 19, then you can get medical transportation at no cost to you. Unless it is an urgent last minute appointment, Medicaid requires you to schedule a ride at least 48-72 hours before your appointment. However, there is no guarantee the transportation company will be able to assist you. It is best to arrange transportation several weeks before your appointment.

The transportation company will need to fax a form to your doctor to make sure that it is a medical appointment. If you live in the Northwestern, Eastern, South Central, or Southwest part of the state you can call Logistic-Care. Their phone number is 1-888-248-9895. If you live in the North Central part of the state you can call First Transit. Their phone number is 1-888-743-3112. When you call, you will need:

- **Your Medicaid card**
- **The date and time of your appointment**
- **The address you are going to**
- **The phone number and fax number of the doctor you will see**

When your medical transportation company faxes forms to your doctor, call the doctor's office to make sure they received the fax. Also, have the doctor's office call you or check in with you so you know when they send the fax back to the transportation company.

There is a very long wait time on the taxi companies' phones, so make sure you are prepared before you make the call. They will give you a confirmation number which you can use when you call back to make sure you are scheduled. Call frequently after that, to make sure you have a ride scheduled to get to your appointment.

Going to the Doctor on Your Own

- Ⓢ **Many young adults who do not have disabilities begin to see their doctor alone for at least part of a visit by the time they are 11 or 12.** Their parents still drive them to appointments, and may go in for some of the appointment, but not all of it.
- Ⓢ **Many young adults with disabilities don't have the same chance to see the doctor alone, even for part of a visit.** Therefore, these young adults may not have the opportunity to learn how to manage their own health care, because someone else is always there with them.

If you are nervous about going to see the doctor alone, go in for part of a visit alone and then bring in your parent or a friend for part of the visit until you feel comfortable doing the entire doctor's visit on your own.

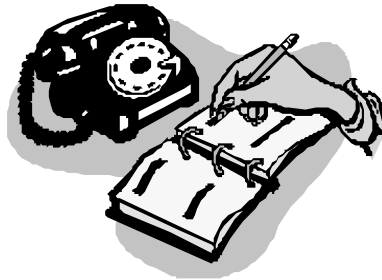
- Ⓢ Write down your questions for the doctor. If you have difficulty writing, have someone else write your questions down for you. You could e-mail them to the doctor ahead of time if that is something the doctor will let you do.

Scheduling Your Appointments

By the time you are 16 or 17, you should be calling the doctor to make your own appointments. If you need special transportation, you should make those plans at the same time.

Even if someone else makes your appointments for you, you need to know the date, time and location of your appointment.

This is YOUR responsibility!



Use a calendar to write down your appointments, when to order or refill medicines, and when to call for transportation. Also, make sure you keep your doctor's number with you at all times.

What Will Happen During the Appointment?

In the Waiting Room

☉ Check in

- Sign your name (If you have difficulty writing, you can get a signature stamp).
- Let the receptionist know you have arrived.

☉ Show your insurance card

- Find out if you have to pay a co-pay or a fee.
- Many times, if you have to pay, the receptionist will ask you to pay before the doctor will see you.

☉ Wait

- You might have to wait a while for your appointment, so bring something to keep yourself busy.

In the Exam Room

☉ Someone will come in to talk with you who is **NOT** the doctor.

- This is usually a nurse or other staff who will record your height, weight and blood pressure.
- This person should introduce themselves to you. If they do not, you should ask who they are.

☉ They will ask you why you are there and how you are feeling, what medications and doses you are taking, and will write it down for the doctor.

- You might want to bring a list of your medicines with you and any notes or record from other doctors.

☉ When the doctor comes in you will be asked questions again about how you are feeling.

- If this is a doctor you have not seen before, you may need to share more information about your disability (it should be in your chart, but doctors do not always read all the reports).
- Before your appointment, think about what you need to discuss with the doctor.

What Will Happen at the End of the Appointment?

- Ⓢ **After the doctor's exam, the doctor may want to order tests or treatment.**
 - You don't have to agree to all the tests or treatments the doctor may want you to do. You can ask questions about them beforehand, and make your own decisions.
 - If you have had a lot of the same tests before, you may not want to get them again.
- Ⓢ **Once you and the doctor have agreed about what you are going to do next, you may need to get written instructions.**
- Ⓢ **If you need written instructions so you will remember what to do, ask the doctor to write them down for you.**
- Ⓢ **The doctor may give you a prescription.**
 - If you were on a medication and did not like how it made you feel, tell the doctor you do not want that same one again. They can then try and find a different medication.
 - Don't be afraid to question a new medication. Ask what it is for and how it will make you feel. Make sure that you ask what the side effects are; how often you should take it; and if you should take it with a drink or food. Ask when you should stop taking the new medication.
- Ⓢ **Ask the doctor when you will need to have another appointment.**
- Ⓢ **Schedule the appointment at the front desk before you leave.**
 - Make sure you write it down or ask someone to write it down for you so you will remember.

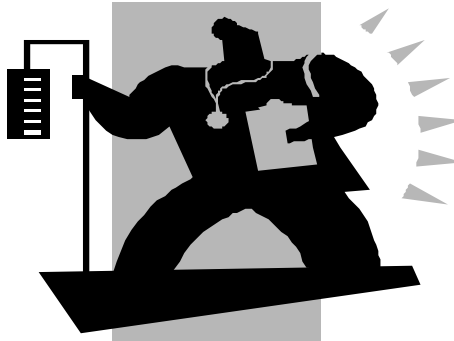


How Do I Change Doctors If I Need or Want To?

Sometimes the doctor you are using just does not work out for you, and you need to change doctors.

You can look up doctors by their specialty, or call your insurance company for local providers. You can ask other people you know about doctors they suggest.

You can also check www.rateMD.com or www.HealthGrades.com, and other web sites to see how other people have rated doctors.



Once you have identified a doctor that seems appropriate, call to set up an appointment. When you go to the new doctor, you can complete a form to request that records from your previous doctor are sent to your new doctor.

How Do I Make Sure I Get the Right Care Even When I Am Too Sick to Make/Voice My Own Decisions?

- ☉ Once you are age 18, unless your parents or someone has guardianship or conservatorship, ***YOU are responsible for making your own health care decisions.***
- ☉ It is important that there is always someone to make sure you get the care you want, even if you are too sick to make and/or voice your own decisions about your care.
- ☉ Think about who that person might be. It could be your parents, a sister or brother, a friend, a husband or wife.
- ☉ You can get forms, through the Probate Court, to name the people who can make decisions about your care, as well as have access to your medical reports and records. This is called Power of Attorney or Health Care Agent.
- ☉ The website Legacy Writer (located in the resources section) has a medical short form for power of attorney. Complete the form, print it and have it notarized by the Probate Court or any other person authorized to notarize papers (to find out who is authorized you can ask people in your Town Hall).



What Information Do I Need to Share with My Power of Attorney/Health Care Agent?

The short answer is **EVERYTHING** (and a little more), so it is important to select a person you trust and know very, very well!! Some of the information you should share include:

🕒 Information about Your Disability

It is most important that this person knows what you are usually like and how your disability affects you.

🕒 Information about the Medicines You Take

This person should be able to answer all the questions about your medicines that you take (reviewed in the section "Knowing Your Medicine").

🕒 Your Medical Records

🕒 Who You Want Contacted When You Are in The Hospital

🕒 Anything Occurring or Changing with Your Health

🕒 What Decisions You Would Make in Different Situations

This includes how you want to be treated in different medical situations.

🕒 Their Contact Information for Anytime You Are in The Hospital or Emergency Room

If this person is your Emergency Contact, they need to know what is happening with you and your health at all times!! (reference Page 27 "What If I Need Emergency Care?")

Sometimes You and Your Parents/Guardian

Don't Agree About Your Health Care

- Ⓢ It is important to work out these issues ahead of time and write it down so that this conflict does not happen during the appointment.**

Decide on the role you want your parents to play during the visit.

- Ⓢ If you want your parents there only to remind you in case you forget something, then be clear.**

Maybe you do not want your parents to say anything at all. Maybe you would rather they have a very active role.

- Ⓢ Whatever that role is, you need to be clear and tell your parents or guardian before you get to the doctor.**

What Happens When You Get a Bill for Your Health Care?

When you get a bill for your health care, **DO NOT IGNORE IT!** The faster you take care of it, the less you will owe. It is helpful to get your parents or someone else to help you with this. They can help you keep notes and organize your information. When you do get a bill, if you have questions about it, you should call the phone number on the bill to find out more information.

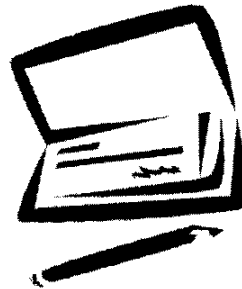
When you call the phone number on the bill these are questions you should ask:



- Ⓢ What is the total amount of the bill I owe?
- Ⓢ What are the dates of office visits and other services that are charged to this bill? Make sure that the bill is accurate and that you received the services that are being charged to you.
- Ⓢ If there is a bill, was it sent to your insurance company to be paid?
- Ⓢ If it was not sent to your insurance company, you need to ask the service provider to send it to your insurance company. Make sure they have the right insurance information. Ask who to call and when to call to follow up — how many days?
- Ⓢ Ask if anything went to collections. Collections means you have not paid your bill for a long time and they have sent the bill to another company to get the money from you. If a bill goes to collections you need to take care of it immediately or it will negatively affect your credit. If it affects your credit you will have a hard time buying a house, a car or other things.
- Ⓢ Ask the name of the person you spoke to on the phone, and write it down, along with the day and time that you called. Make sure to take notes on what they tell you. Keep an ongoing log of phone calls for bills, so you can look at your phone record and say who you spoke to and what they told you. That way, you can refer back to any conversation if you get another bill from the same organization for the same date and service you called about before.

What Should I Do if the Insurance Company Sends Me a Check?

- Ⓢ When you receive payment from an insurance company, it is a payment for a health care bill. This could be a piece of equipment, an office visit or hospitalization, or other medical service.
- Ⓢ Look at the Explanation of Benefit (EOB) to see the date of service and who provided the service.
- Ⓢ Use the payment from the insurance company to pay the bill sent from the service provider.
- Ⓢ When you send the payment to the organization you owe, specify the date of service the payment is for.



What If I Need Emergency Care?

In case of an emergency, you need to have important health care information and emergency contacts with you at all times. There are many ways to do this. What you should do depends on what your needs are.

Here are a few things that you can do:

📍 Program ICE Into Your Phone

ICE stands for "In Case of Emergency". You can put your emergency contact under ICE in your address book on your phone. When someone looks in your address book on your phone they will realize that whoever is listed as ICE is your emergency contact.

📍 Carry a Laminated Emergency Information Form with You at All Times

There are many health care forms available or you can create your own. Fill it out and laminate the paper or get someone to help to do this. If you want to change the form, you can scan it and modify the information to fit your needs. **Put it in your purse or wallet.** The link to the Emergency Information Form is located on page 29 of this Guide.

📍 Medic Alert Bracelets

These silver bracelets have the most important, immediate information about your medical condition on them. You can buy a bracelet that is pre-engraved for simple things like an allergy or well known disorder like diabetes. You can also buy one that is custom engraved, meaning you decide what information is printed on the bracelet. There is limited space on the bracelet, so you need to decide carefully what to print. You can get these bracelets through the Medic Alert Foundation, Sticky Jewelry, other organizations, or your local pharmacy may carry them. More information can be found in the Resources section at the end of this booklet.

📍 About the Medic Alert Foundation Service

Medic Alert is a service that stores medical information. You sign up for the service, pay a small yearly fee, and give them your important medical information. They will help you figure out which information is important. You are then given the Medic Alert phone number, an ID number, and a Medic Alert identification card. You can get the phone number and the ID number engraved on your medic alert bracelet along with your most important medical information. If you get your bracelet through the Medic Alert Foundation, when you sign up for the service, it will automatically have your ID number and the Medic Alert number engraved on it. If you want other styles you can sign up for the service and receive your ID number from Medic Alert. Then you can order your bracelet from a different place, like Sticky Jewelry, and have a custom-made engraving on the bracelet.

📍 Portable Health Care Records

Medic Tag makes a special USB that you can store your health care information on. A USB is a device that will plug into your computer so that all of your information can be accessed. You can update it on your computer as well. In an emergency, the hospital can plug your USB into their computer to get the information. In case your USB doesn't work or there are things that people need to know immediately, like your disorder or allergies, you should have a Medic Alert bracelet in addition to the Medic Tag USB. <http://www.medictag.com>

RESOURCES

Website for Short Form Power of Attorney:

Ⓢ <http://www.legacywriter.com/poa.asp?src=g15state8&gclid=CLGf48-Rmp4CFc5L5Qod8jQzpA>

Website for Emergency Information Form:

Ⓢ <http://www.fcsn.org/pti/topics/medconcerns/tools/eif.pdf>

Websites to Find Ratings of Doctors:

Ⓢ www.rateMD.com

Ⓢ www.HealthGrades.com

Connecticut Medicaid Transportation Phone Numbers:

Ⓢ Logistic Care 1-888-248-9895

Ⓢ First Transit 1-888-743-3112

Websites for Storing Medical Information:

Ⓢ Medic Alert Foundation <http://www.medicalert.org/>

Ⓢ Sticky Jewelry <http://www.stickyj.com/>

Ⓢ Medical USB <http://www.medictag.com/>

Quick Links to Health Care Transition Resources

Connecticut Department of Public Health Youth with Special Health Care Needs

© <http://www.ct.gov/dph/cwp/view.asp?a=3138&q=432684>

Connecticut Kids As Self Advocates (CT KASA)

© <http://www.ckasa.org/>

Center for Children's Advocacy - Adolescent Health Care: The Legal Rights of Teens

© www.kidscounsel.org/

Got Transition? National Health Care Transition Center

© <http://www.gottransition.org/>

Health Care Transitions: The Institute for Child Health Policy at the University of Florida

© <http://hctransitions.ichp.ufl.edu/hct-promo/>

Healthy and Ready to Work National Resource Center

© <http://www.syntiro.org/hrtw/>

United Way of Connecticut 2-1-1 Infoline

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