

The Workbook for Youth



Wisconsin Community of Practice on Transition
Practice Group on Health



Developed by Debra Gillman in consultation with Ben Schlicht

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The Wisconsin Community of Practice on Transition is comprised of a statewide group of key stakeholders who join together to continue to improve collaboration among agency representatives and community partners. The Community on Transition provides a vehicle to share information, bring forth emerging issues and problem solve. Practice groups form around topics of interest, bringing stakeholders together to share their work. The Practice Group on Health recognizes that health is a critical part of every person and must be incorporated into all aspects of transition.



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The Waisman Center is dedicated to the advancement of knowledge about human development, developmental disabilities and neurodegenerative diseases. It is one of 9 national centers that encompass both an Intellectual and Developmental Disabilities Research Center designated by the National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) designated by the Administration on Developmental Disabilities.

To view or download a copy of *The Workbook for Youth*, go to <http://www.waisman.wisc.edu/wrc/pub.html>



The Workbook for Youth Table of Contents

- Life is a Team Sport! 1
- What it Means to be Adult 2
- Some of the “Rules of 18” 3
- What Do I Know and Where Can I Grow? 4
- Health Care Checklist 4
- Everyone Needs A Health Care Team 6
- What To Expect From Your Health Care Team: Medical Home 8
- Communication Tips 10
- Healthy Lifestyle Habits 11
- My Daily Log 12
- Sample of Daily Log Filled In 14
- Room for Improvement 16
- Paying for Health Care 17
- How to Make an Appointment 18
- How to Arrange Transportation for your Appointments 20
- How to Get Prescription Medications and Refills 22
- Getting Ready for your Medical Appointments 24
- Sample Notebook Page 26
- Questions to Ask at your Regular Appointment 28
- Questions to Ask at an Appointment When You Are Sick 29
- Questions to Ask About Surgery or Hospitalization 30
- Getting Ready for a Dental Appointment 31
- Questions to Ask your Dentist 32





Life is a Team Sport!

Like any sport, life can be a lot of fun. It can also be challenging. Being part of a team makes both the fun and the challenges better.

Nobody is good at everything but everybody is good at something. That's what makes teamwork so effective.

Being part of an effective team does not happen overnight. It takes time.

- Time to learn new information
- Time to develop new skills
- Time to practice putting the new information and skills into action

This handbook is about getting ready for adult life – especially your health and health care as an adult. It has information and suggestions for you about your health and health care. It also has ideas about how to build a health care team.

This handbook can help you:

- Learn about some of the rules you will need to know and what may be expected of you as an adult;
- Figure out the skills you may already have and the skills you may need to work on;
- Decide who to have on your team and how to work well together

Remember you don't have to do everything at once. The important thing is to get started.

Start small. Start Slow. Start Now. **Life is a Team Sport!**

“Football is a team sport.
So is life.”
-Hall of Fame Quarterback
Joe Namath





What it Means to be Adult

Technically, as soon as you are 18 years old you are an adult. That sure sounds easy doesn't it?

But of course, just having the clock strike midnight at the start of your 18th birthday does not mean you will magically know everything you need to know about being an adult and being ready to assume those responsibilities.

Being ready for adult life doesn't happen overnight.

As an adult you may be responsible for making a lot of decisions. You may need help with some of those decisions. Most people have parents, friends, or other individuals they trust to help them think through important questions and concerns.

You may already have people you rely on to help you make decisions. You'll want to think about how to keep some or all of those people involved in the years ahead. There may be others you will add to your team. There's no need to "go it alone." Getting advice or suggestions from those you can trust does not make you any less of an adult. In fact, it is a sign of being a mature, responsible adult.

Parents must also understand that they do not continue to be the legal decision-maker for their adult son or daughter. Even in situations where severe disabilities are involved, adults are presumed to be able to act on their own behalf unless a court of law decides otherwise.

Having a legal guardian is the most well known option for people who need this total assistance in making decisions. There are different types of guardianship. Full guardianship may not be needed. Sometimes a limited guardianship can be established so that the individual who has a guardian can still keep some of his/her decision making rights. Maybe a person needs help with legal and financial decisions but he/she is still capable of deciding who they want for president. That person might be able to have a guardian for other decisions but still keep the right to vote in elections.

The different types of guardianship include: Guardian of the Person, Guardian of the Estate, Temporary Guardian, Limited Guardian, Standby Guardian and Successor Guardian. Parents do not necessarily need to serve as their adult son or daughter's guardian. Another family member, a friend or a volunteer guardian appointed by the judge can fulfill this role.

Sometimes naming someone to have Power of Attorney for certain decisions or having a Representative Payee for financial matters may be other options. Good information is needed to make informed decisions in this area. All options deserve serious consideration. You may want to ask a few people you trust to come together and help you decide which option is best for you. Having someone who understands the legal implications is an important part of this process.



Some of the “Rules of 18”

In Wisconsin, when a person reaches his or her 18th birthday, he or she becomes a legal adult. Unless a guardian has been appointed through a judge in a court of law, all of the rights and responsibilities that are part of being a legal adult go into effect.

At age 18 you have certain legal rights, such as the right to:

- Vote
- Get married
- Make a will
- Make a contract (such as renting an apartment, buying a car, taking out a loan, ...)
- Give or refuse consent for medical treatment
- Make independent decisions free from parental control
- Apply for credit (including credit cards)

Remember, in Wisconsin drinking beer, wine or other alcohol is not legal until age 21.

At age 18 you also have certain legal responsibilities, such as:

- Being tried in an adult criminal court if you break the law
- Self support (parents are not required to support their adult children)
- Serving on Jury duty if called to do so
- Being liable for all contracts entered into (such as making loan payments)
- **Every male citizen and alien living in the United States must register with the military within 30 days of his 18th birthday.** Even a male with severe disabilities who could not possibly serve in the military must register. **Not registering is a federal crime. This does not mean you are joining the military.** There is no military draft right now where males of certain ages are required to serve in the military. However, the military still needs to know the name of every male citizen and alien living in the United States in case there would be the need for a military draft in the future.

Every adult should have someone identified who would make medical decisions in the event of an emergency and the person was unable to make their own decisions. This decision should be in writing and should clearly name someone to have Power of Attorney for Health Care. This is important because even if you make all of your own decisions, if there was an accident or illness where you were not able to do so, important medical decisions about your care could be affected.

It is extremely important to have discussions with your family members and others you trust to get the best information possible about the legal and decision making aspects of adult life. Talk with your parents. You can also ask a social worker or care coordinator at your clinic or hospital for information and assistance. If you have a county social worker or case manager that person can also help you.





What Do I Know and Where Can I Grow?

Everyone has health care needs.

Some people have more than others but everyone has health care needs. Some people have a disability or chronic medical condition. Others may have risk factors for certain diseases. That's why it's a good idea for each of us to know about our own health care needs and how to be involved in our own health care.

Most people would find it difficult to answer yes to many of these questions. In fact, many young people have never even thought about many of these questions, so you are ahead of the game just by doing the checklist. Just put a checkmark in the column you think fits you best.

Health Care Checklist

	Yes	Working on it
Can I describe my health care needs?		
Are there ways my health care needs affect my day-to-day life? (for example, do I need medication, a special diet, help with personal equipment or supplies, physical therapy...)?		
Do I know what to do when I get sick?		
Do I know what medications I take and why I take them?		
Do I know when to take my medication and possible side effects to report to my doctor?		
Do I know how to get my prescriptions filled and refilled?		
Can I make my own appointments?		
Do I know how to check in and what to bring to my appointments?		
Do I give information and answer questions at my appointments?		
Do I know how to ask questions at my appointments?		



	Yes	Working on it
Do I have someone I trust who can go to appointments with me?		
Is there someone to help me make medical decisions?		
Do I use a calendar/planner to keep track of my appointments/activities?		
Do I have healthy lifestyle habits?		
Do I know what kind of health insurance I will be able to have when I am 18?		
Do I know what kind of help I might need with making decisions after I am 18?		
Do I know about Power of Attorney for Health Care and Advanced Directives?		
When I need to learn something new, do I know how I learn best? (by reading, listening, watching, one-on-one, in groups)		

The next question is “Where do I go from here?”

Where you are starting from is not as important as where you are going. Now you can make a plan for how to learn more about the items on the checklist and more about yourself.

Select three items from the checklist to begin working on right away and how you will go about doing so. If you need help getting started, ask someone you trust to help you.

Remember: Start Small. Start Slow. Start Now.





Everyone Needs a Health Care Team

Can you name the people on your health care team and what they do? Use this worksheet to see who you already have on your team. Think about who else you might want to add.

You – Remember in addition to being the patient, you are part of the team.

Primary care Doctor _____

Specialty Doctor(s) _____

Physician Assistant _____

Nurse(s) _____

Dentist _____

Dental Hygienist _____

Therapists _____
(physical, occupational, speech/language, etc.)

Dietician/Nutritionist _____

Pharmacist _____

Mental Health Professional _____
(counselor/psychologist/psychiatrist)



Social worker _____

Care coordinator _____

School nurse _____

Home Health care workers _____

People you trust to help you with medical decisions. These may include:

Parents/other family members _____

Friends _____

Others _____





What to Expect from your Health Care Team: Medical Home

You may have heard about Medical Home as a way that some health care teams work together. The title Medical Home can be a little confusing because we usually think of a home as a place.



Medical Home is not a place. It is an approach to how care is delivered that combines where primary care is provided, who provides that care and how they all work together along with the patient and family to make sure that quality care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective.

To help understand what that means let's use another example from sports. It might be helpful to think about a baseball game as a way to understand Medical Home.

When you go to a baseball game you have to go to a stadium or some other place where the game is played. The playing field is set up in the shape of a diamond. That diamond has a home plate where the batter stands, three bases, a pitcher's mound and the field surrounding the diamond. That place is where the game is played but the game involves much more than that.

To play the game you have to have teams of players and every player has their own special position. They play in those positions when the other team is batting. But they also each take a turn at hitting the ball when their own team is up to bat.

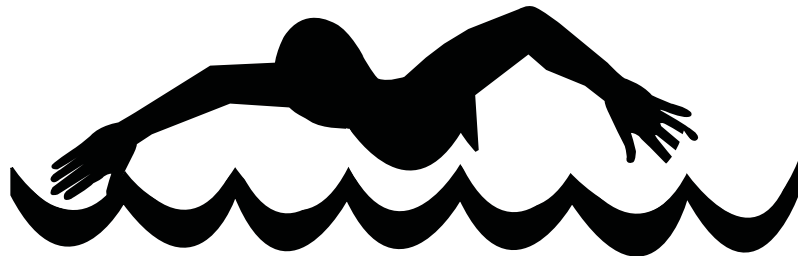
Each player has to be good at what they do and they have to be able to work together. They need to practice their own skills but they also have to practice together to get good at working together. They learn how to communicate with each other and how to coordinate their efforts.

When everything comes together at game time, the team may score by hitting the ball and taking bases one at a time or several at a time. Sometimes a player hits a home run. When that happens we see more than the efforts of just one team member, but the combined effort of all involved.

In some ways Medical Home is like a Medical Home Run.



Another example from sports might be a relay race. In the 2008 Olympics, United States swimmer Michael Phelps won a total of eight gold medals. This was more than any other Olympic athlete had ever won. He competed in individual races but even then he was part of the USA Olympic Swim Team. The last race for Michael Phelps and the USA Olympic Swim Team as the relay race where four team members would each swim part of the race. Each had to do their part so the team could win and so that Michael Phelps would be able to win his eighth medal. The first thing he did after the race was to thank his teammates. He said, "Without the help of these guys it wouldn't be possible. The relays and putting guys together that really may it possible. It just shows how much teamwork and togetherness we have." An interesting fact about Michael Phelps that millions of people learned about through his competition in the Olympics is that he has Attention Deficit Hyperactivity Disorder(ADHD). In an interview after he won, he talked about how he and his mom joke about how a middle school teacher once told him he would never be successful. He sure found a way to be successful. When he was younger Michael Phelps was bullied and made fun of but now he has millions of fans. He and his mom figured out something he was good at and focused his energy on becoming productive and happy in his own life.



The clinic may be the place you go to for your Medical Care. That may be where you see your primary health care provider but with medical home it is much more than that. Within a Medical Home there is a team of health care providers who work together along with you and your family as full partners. The clinic staff knows who you are and remember you from visit to visit. They allow extra time for your appointments if that is usually what is needed. The team considers the big picture of life and works to identify and communicate with community resources (including school). There may be an actual care coordinator to help make sure all the pieces of the puzzle are pulled together. A care plan is often developed and maintained to help all of those involved stay current and make sure they are working together toward the same goals.





Communication Tips

People sometimes say that communication is a two-way street. But when it comes to communication and medical appointments for youth it is usually a three-way street:

parent(s) + health care provider + youth

Transition is a time of changing roles and expectations. It is a time for youth to actively assume more responsibility and for parents as well as health care providers to encourage this change to the greatest extent possible even when they have special health care needs. Open communication is essential to this process so that the three-way street becomes:

youth + health care provider + parent(s) as needed

Key Questions for Youth, Health Care Provider and Parent(s)

- Do I show others the respect that I want to receive?
- Do I listen carefully and completely to questions or comments before responding?
- Do I participate in discussions willingly and with an open mind?
- Do I accept responsibility for my actions and opinions?
- Do I ask for further explanation when I don't understand something?
- Do I actively participate in planning and problem solving?

Key Questions for Youth

- Do I participate in my appointments by offering information, answering questions, expressing my concerns and asking questions?
- Do I express my own thoughts and feelings even when they differ from my parent(s) or health care provider?
- Do I ask for some time alone with my health care provider at my appointments for private discussion and am I able to ask questions without feeling embarrassed?

Key Questions for Providers

- Do I focus my attention primarily on the youth rather than the parent?
- Do I discuss topics that are age and developmentally appropriate and include but are not limited to the youth's special health care needs?
- Do I offer time alone with the youth for private discussion?
- Do I respect confidentiality as much as possible?
- Do I create a comfortable environment that encourages collaboration?

Key Questions for Parents

- Do I actively encourage my son or daughter to participate as fully as possible?
- Do I actively encourage the health care provider to do the same?
- Do I facilitate confidential communication between my son or daughter and his or her health care provider to the greatest extent possible?
- Do I recognize my own legitimate needs as a parent during the transition process and seek appropriate supports and resources to meet these needs?



Healthy Lifestyle Habits

Lifestyle habits are the things we do every day such as:

- what we eat and drink
- how much we exercise
- how much we sleep
- our personal cares and grooming
- leisure and relaxation activities (hobbies and other interests)
- relationships and social network
- family traditions
- spiritual practices
- work and/or school
- safety and security practices

What we do can affect how we feel?
How we feel can affect what we do?

It's important for each person to develop a regular routine that works best for that person.

It's also important to figure out what to include in a daily routine and what to include on a weekly, monthly or some other schedule. For example:

- Combing my hair is something I will do everyday and even several times a day. But I may wash my hair every other day. And I may get a haircut every six weeks.
- Going out with friends several evenings a week may be fun but I may also spend several evenings at home by myself just to relax.
- I brush my teeth and use mouthwash at least twice a day (every morning and before bedtime) and I floss my teeth at least once a day. But I also have a regular cleaning and check-up with my dentist every six months.

What do you include in your daily routine?
How about your weekly or monthly routine?

It's easy to lose track of how we use our time. Sometimes it is a good idea to write down everything we do for a day. Then we can make changes in our routines.



My Daily Log

Time	Activity	Special Reminders or Notes
6:00 am		
7:00 am		
8:00 am		
9:00 am		
10:00 am		
11:00 am		
12 Noon		
1:00 pm		
2:00 pm		



My Daily Log

Time	Activity	Special Reminders or Notes
3:00 pm		
4:00 pm		
5:00 pm		
6:00 pm		
7:00 pm		
8:00 pm		
9:00 pm		
10:00 pm		
11:00 pm		



Sample of Daily Log

Time	Activity	Special Reminders or Notes
6:00 am	Get up by 6:15 Take a shower/wash hair	Do some stretching exercises before breakfast
7:00 am	Eat breakfast Take medication Brush teeth Use mouthwash	Hot or cold cereal during the week Pack lunch for work and put it in carry case near the front door
8:00 am	Leave for bus stop by 8:15	Be sure to check the weather Before leaving
9:00 am	Punch in at work	Put lunch in refrigerator
10:00 am	Break time – eat fruit And something to drink	Milk or water – not soda
11:00 am		
12 Noon	Eat lunch Take medication	No orange juice with this medication
1:00 pm	Talk to supervisor about Time off for doctor appointment	Write down best dates and times to take off work
2:00 pm	Break time - Check on plans for bowling after work Call to make doctor's appointment	Try to get dates/times my supervisor said would work best for time off



Sample of Daily Log

Time	Activity	Special Reminders or Notes
3:00 pm	Meet group for bowling at the bus stop by 3:15	Make sure to have bus pass and money for bowling
4:00 pm	Leave for bus stop by 4:45	
5:00 pm	Eat supper	Make sure to eat salad and vegetables. Not too much bread!
6:00 pm	Call Mom or Dad about ride to doctor appointment	Also check on grocery shopping this weekend
7:00 pm	Favorite TV show on tonight!	
8:00 pm	Work on puzzle	
9:00 pm	Get ready for bed – Brush teeth and floss	Set alarm clock for 6:00 am Lay out clothes for tomorrow Make sure door is locked
10:00 pm		Listen to some relaxing music before going to sleep
11:00 pm		





Room for Improvement

Sometimes what we want is different from what we need or what may be good or bad for us in terms of healthy lifestyle habits. For example, I may want to maintain a healthy weight or even lose some weight but I may also want to eat a hot fudge sundae every night. Or I may want to exercise for 30 minutes every day but I find that I am watching TV after I get home from work and after supper. I may want to make more friends but I usually stay home every weekend.

These are the kinds of things that may be revealed when I fill out my own daily log and then look at how I use my time. This gives me an opportunity to plan some of the things I want to do into my day. For example, I may schedule a 30 minute walk after work and before I eat supper on Monday, Wednesday and Friday. I may volunteer at the local library every other Saturday afternoon. By scheduling these activities into my day, I am showing that they are important to me. I also have a better chance of doing them when I schedule them into my time instead of just hoping that I will do them.

Getting to know ourselves and our priorities is an important aspect of becoming a mature adult. We can do this by thinking about:

- Our strengths
- Our challenges
- What we want
- What we need
- What we think is important
- Our responsibilities

Our strengths include our natural abilities, the way we affect the world around us just by existing, talents we have developed and personality traits that are helpful to us.

Challenges may include visible and invisible disabilities, chronic illness, undeveloped or underdeveloped skills and personality traits that are not helpful to us.

Sometimes what we want is not the same as what we need. If we think about what we want and what we need, we can make choices about how to spend our time and energy.

We also need to think about our responsibilities to ourselves and others, and see how they are affected by the things we want and need. We want to have fun and yet meet our responsibilities.



Paying for Health Care

Health care is expensive. Teens and young adults need to know how they will meet their cost of their health care as adults. Families need to think about family insurance limits, types of health insurance coverage that might be available and the ways eligibility is determined. Attention also needs to be given to learning about other possible resources and how to access them. While this fact sheet provides some basic information, it is only a start and each individual situation needs to be considered in a comprehensive and detailed manner. Health benefits counseling and advocacy services may also be helpful.

If the teen has been covered under the parent's private insurance, careful attention must be given to what will happen when the teen becomes an adult (age 18). Parents need to read their policies carefully **before** their teen reaches 18. Some policies allow the adult child to continue coverage if he or she is a full time student. Some policies put additional conditions on continued coverage. Some policies allow continued coverage until age 21 or 25. Some will allow indefinite continued coverage if the adult child is disabled and the disability occurred before age 18 and the parent continues to provide 50% or more of the adult child's support or maintenance. This must be carefully considered if the adult child will be receiving Supplemental Security Income (SSI) because some aspects of SSI payments are based on the adult child no longer being claimed as a dependent by the parents, while others allow the parents to continue to provide support to the adult child but then SSI payments are at a reduced rate. In Wisconsin, SSI is paired with the medical assistance (MA) benefit. For children on the Katie Beckett program, at age 18 they may be eligible for SSI even if they had not been previously because of parent income.

An adult child who no longer qualifies for continued coverage under the parent's private health insurance plan can continue to get coverage for a period of time under a current insurance plan by paying the individual premiums. This is known as COBRA coverage. A young adult may continue COBRA coverage for up to 36 months after leaving the parent's family insurance plan due to losing their status as a dependent. This can be quite expensive but may still be worthwhile. It may also prevent the 63 day lapse in continuous coverage that might disqualify future insurance coverage due to a pre-existing condition. If the health and dental plans are separate, each should be considered based on its own cost and potential value. For example, given some of the access problems with dental care for MA patients, it may be well worth it to continue dental insurance under COBRA for as long as possible as it may be very affordable.

A young adult who does not have access to full insurance coverage through some other means can apply for BadgerCare Plus. For eligibility information check this website <http://dhs.wisconsin.gov/badgercareplus/>

The Transition to Health Care Checklist: Preparing for Life as an Adult is another resource that can be downloaded from www.waisman.wisc.edu/cshcn/publications.php





How To Make an Appointment

- Be prepared. Fill in as much of this form as you can before you make your phone call. Use it as a guide when you make your call. If you have never done this before have someone help you. You might even want to practice before you actually make your call.

- Have your calendar ready so you can check the date and time. Put your appointment on your calendar right away.

- You may need to repeat some of the information if the first person you speak to transfers you to someone else.

- You may need to know your date of birth. You may need information from your insurance or Forward Card so have that ready as well.

- Know the name of the person you need to see. It may be a doctor, a nurse practitioner or another health care provider.

- Know the reason you need the appointment. Is it for a regular check-up or are you having a problem or concern?

- If you will need a lift or other assistance to get onto the exam table or some other type of help be sure to mention it when you call. (Interpreters)

Phone number _____



Sample Script

Here is a sample of what you can say when you call to schedule an appointment.

Hello, my name is _____
(use your first and last name)

I need an appointment to see _____

because _____
(example: I need a check-up, I'm having headaches, I'm having back pain...)

How soon can I get in?

Write the date and time here _____

If this date and time are ok, just say: **Thank you that will be fine.**

If not, just say: **That won't work for me. Can you look for something else?**

How long is the appointment?

Write amount of time here _____

If you think you will need more time, just say: **I think I will need more time.**

If you will need some equipment like a lift or extra help just say:

I will need _____
(example: a lift to get onto the exam table)

Before you end the phone call, repeat the date and time of your appointment

OK, I will be there on _____ **at** _____
(Date) (Time)

Thank you. Good-bye.

Follow-up step: _____
(example: I will write this appointment on the family calendar right now so I won't forget about it)





How to Arrange Transportation for your Appointments

Start making plans for transportation as soon as you make your appointment.

- You may be asking a friend or relative to drive you or you may be using a transportation service. Your chances of being able to get a ride are better if you plan ahead. Remember to check on a ride back home after your appointment if you will need one.
- If you are taking a city bus you will want to make sure you know which bus to take and how long it will take so you are not late. You may even want to take a practice ride on the bus if you have not done this before just to make sure you know where and when to get on the bus.
- If you are using a regular taxi cab you probably won't need to call until the day before or the day of the appointment but you will want to check with the company ahead of time.
- If you are not sure who to call or what to do, ask your parents, your county case manager or social worker at the clinic or hospital.
- You can fill in the blanks on this form and then use it as an outline when you make your call. If you are using a transportation service you may also need to have your Medical Assistance (MA) number ready when you call.

Name of driver or service _____

Phone number _____



Sample Script

Here is a sample of what you can say when you call to schedule a ride.

Hello, my name is _____
(use your first and last name)

I need to arrange a ride to a medical appointment.

The date and time are _____

I am going to _____
(say the clinic or hospital name and the address)

You will need to pick me up from _____
(say your address)

Can you do this? _____ Yes _____ No

If the answer is **Yes**, ask: **What time will you pick me up?** _____
(write the time here)

If the answer is **No**, you can ask:
Is there someone else you can recommend? _____
(write the name here)

I will also need a ride home from the appointment.

It should last _____
(say how long the appointment should take)

Who do I call if there is a problem? _____
(write the name and phone number here)

Will I need any paperwork or money? _____
(write the answer here)

Thank you. Goodbye.

Follow-up Step: _____





How to Get Prescription Medications and Refills

- When your doctor wants you to take medication, a prescription may be called in by telephone to a pharmacy. You will need to go to the pharmacy to pick up your medicine. If the doctor gives you a written prescription you will need to take it to the pharmacy to get it filled. Be sure to take your Forward and/or insurance card with you. There may be a co-pay charge so you will want to have some money too.
- Sometimes there is a pharmacy located right in the clinic where you see your doctor. You may have a neighborhood drug store or another pharmacy you use.
- If you will be taking the medication for a while, the doctor may write on the prescription that you may have refills.
- You will want to make sure you order your refill before your medication is gone so you don't miss any doses. Mark your calendar to remind you of when to call in your prescription refill. Call to order your medication when you have one week of medicine left, so you don't run out on a weekend, holiday or while on a trip.
- There are some special rules about certain drugs. These are also known as controlled substances. These prescriptions cannot be ordered too far ahead, the prescription cannot be faxed and the use of these substances are carefully monitored.
- To order a refill on a medication you will use the information on the medication label.
- You can take your medication bottle to the pharmacy or you can call ahead and order the refill by telephone.
- When you call the pharmacy, a person may answer and take all the information. Sometimes you may get an answering machine that tells you how to give the information the pharmacy needs by punching in certain numbers on the phone. If this is too hard or confusing, you can usually stay on the phone or push a number to get help from a person.
- Make sure you understand how and when to take your medication. Make sure you understand any possible side effects to be aware of and what to do if you experience them. You will get written information along with your medication but be sure to ask the pharmacist any questions you may have.
- If you get home and have a question or concern about your medication, call your pharmacist. You can also contact your doctor's office and ask to speak to your doctor's nurse. Nurses can also answer a lot of questions and can check with your doctor if needed.



Sample Script

Here is a sample of what you can say when you call to get prescription medications and refills.

Hello, my name is _____
 (give your first and last name)

I need a refill on a prescription.

The prescription number is _____

The name of the medication is _____

When can I pick it up? _____

(Can you deliver it? If yes, when? _____)

(Can someone else pick it up for me? _____)

Is there a co-pay charge? _____ How much? _____

Thank you. Good-bye.

Follow-up Step: _____

Clinic Name	Clinic Address/Phone number
Prescription number	Doctor's name
Patient name	Date prescription was filled
Instructions such as: Take one tablet daily by mouth at bedtime Do not take with orange juice.	
Medication Name	Dosage amount per tablet or capsule
Refill information	Number of tablets/capsules in bottle





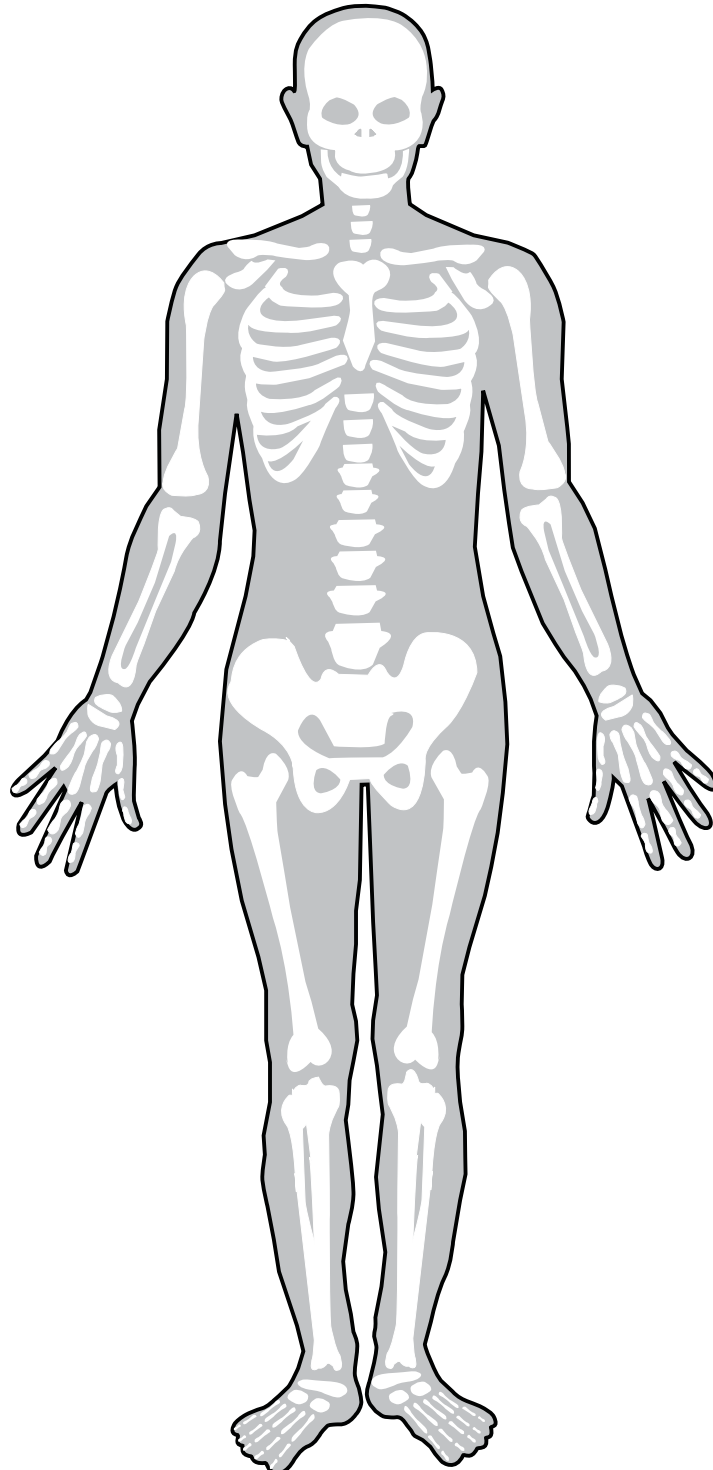
Getting Ready for your Medical Appointments

- Use a notebook or folder to get ready for your appointment. You will want to use the notebook to have some of your health information available and also as a place to write notes while you are at your appointment. This could include basic or new information, follow-up needed or care instructions.
- Put the name of the healthcare provider you are seeing and the appointment date at the top of any notes you make during your appointment.
- Write down how you have been feeling lately and any special concerns you have so you will not forget to mention anything in your appointment.
- Think about your body starting at the top of your head and all the way down to your toes. Think about any aches or pains or anything you have a question or concern about. If you are not sure how to describe your symptoms you can point to the area and your doctor can ask you questions to help you identify what is concerning you. You can also use a drawing like the one in this workbook.
- If you are not feeling well write down your symptoms so you can share them your health care provider and not worry about forgetting anything.
- You may want to have someone you trust go to the appointment with you. That person can be with you throughout the appointment or just at the beginning or end of the appointment so you can still have some time alone with your health care provider.
- Write down information and instructions at your appointment so you don't have to try to remember everything. If you need help doing this just ask your provider or the person you brought with you to help.
- Remember: You should be able to talk with your doctor about any of your health concerns or questions. Your doctor needs to know how your true feelings and concerns in order to help you. If you are sad, worried or afraid of something or someone it is important for you to tell your doctor so you can talk about options that might be available to help you. The doctor may want to make a referral to a specialist or a community resource for additional follow-up. It is ok to ask for information to be repeated or explained again if you do not understand it the first time
- Be sure to take your medications in the original containers along with you so you can review all the medications you are taking, how much and how often with your doctor or a complete listing of your medications, how much you take and when. If you have a care plan it should include this information. Remember to keep this kind of information up to date.



Think about your body starting at the top of your head and all the way down to your toes. Notice any aches or pains or anything you have a question or concern about.

If you are not sure how to describe your symptoms you can point to the area and your doctor can ask you questions to help you identify what is concerning you.





Sample Notebook Page

Upcoming Appointment with my regular doctor

Doctor's Name _____

Appointment Date _____

Why I am going to see the doctor : _____

How I have been feeling lately: _____

Information from the Appointment:

Weight _____ Blood Pressure _____ Other _____

Answers to the Questions from the Pocket Guide: _____

Follow-up _____



Sample Notebook Page

Upcoming Appointment with a new doctor

Why I am here: _____

Important information you should now about my medical history : _____

Medications and allergies: _____

Past surgeries and hospitalizations: _____

Other doctors I have seen: _____

How I communicate best : _____

Other things I want you to know about me : _____

What should I know about you? _____

(Plus all the questions to ask at a regular appointment...)





Questions to Ask at your Regular Appointment

- How do you think I am doing?
- Are there any problems I should know about?
- If yes, please explain any problem(s) and what I need to do.
- Will the problem(s) get better? Why or Why not?
- Do I need any medical tests? If yes, what kind?
- Do I need new medication or changes in my medication?
- If yes, what kind?
- Are there any side effects?
- Are there any changes in what I should do day-to-day to take care of myself?
- If yes, what kind of changes?
- Are there any changes in what I can or cannot do?
- If yes, what kind? (especially at work or in school)
- Do I need another appointment?
- If yes, when?
- Is there other information I should remember?
- Is there any follow-up/What is my next step?



Questions to Ask at an Appointment When you are Sick

- **What is wrong?**
- **What caused this?**
- **What should I do about it?**
- **How long will it last?**
- **Can I go to work/school?**
- **Do I need medicine?**
- **Are there any side effects to this medicine?**
- **Are any of the medications I take already affected by this new medicine?**
- **What if I don't start feeling better or if I start feeling worse?**
- **Are there any changes in what I'm supposed to do to take care of myself?**
- **Do I need another appointment?**
- **Are there any other instructions or information I need to know?**





Questions to Ask about Hospitalization or Surgery

- **Why is this needed?**
- **Are there any alternatives or treatments?**
- **What will need to be done?**
- **What are the risks or possible complications?**
- **How long will I be in the hospital?**
- **What will happen when I am there?**
- **How will I be different after surgery?**
- **How will I be the same?**
- **Do I need to do anything different to prepare for the surgery and/or hospitalization?**
- **Are there any special written instructions I need to have before, during or after?**
- **Where do I go and what do I need to bring along?**



Getting Ready for a Dental Appointment

- You will want to do the same things you do for any medical appointment. This includes preparing ahead of time and using your notebook or folder to write down questions and concerns to discuss with your dentist and to write notes during your appointment about follow-up needed or care instructions.
- You will want to let your dentist know if you are having pain in your mouth or teeth, pain with cold or hot food or drinks or pain that wakes you up at night.
- You will also want your dentist to know if you are afraid of dental appointments and what helps you to calm down. Sometimes listening to music or having something calming to look at or hold can help.
- You will want to mention if you gag easily or have trouble holding your mouth open. Your dentist and dental hygienist can work with you to help with these concerns.
- Your dentist may want to know your daily care routine:
 - How often you brush your teeth
 - The type of toothbrush and toothpaste you use
 - If you floss between your teeth and how often
 - If you use mouthwash, how often and what kind



Can you show where on your mouth or face you have pain?

Can you show which teeth hurt or are sensitive to hot or cold?





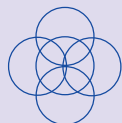
Questions to Ask your Dentist

Make sure to tell the dentist if you are afraid, if you gag easily or have trouble keeping your mouth open.

- **What kinds of dental problems do I have?**
- **What causes these problems?**
- **What can I do to make these problems better or not get any worse?**
- **Is there a special toothbrush I should use?**
- **Is there a special toothpaste I should use?**
- **How often and when should I be brushing my teeth?**
- **Can you please demonstrate how I should be brushing my teeth?**
- **Is there a special mouthwash I should use?**
- **How often should I use mouthwash?**
- **Can you please show me ways to make flossing easier?**
- **When should I floss?**
- **Are there any changes in my diet you recommend?**
- **When do I need another appointment?**

(The dentist may have the dental hygienist show you how to brush and floss. The dental hygienist usually cleans teeth and does patient education as part of the dental appointment. You can feel free to ask the dental hygienist questions as well.)





Waisman Center
University of Wisconsin–Madison
University Center for Excellence in Developmental Disabilities