



Women's Health Guide

Developed By



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Developmental Disabilities

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Overview

The purpose of this guide is to empower and support women with Intellectual and Developmental Disabilities (IDD) as they navigate their healthcare journeys. It offers practical, accessible information on a wide range of health topics that are important to women, including nutrition, reproductive health, mental wellness, routine medical visits, cancer screenings, and more.

This guide was created by the Kansas Council on Developmental Disabilities in collaboration with female self-advocates, healthcare professionals, and researchers from across Kansas. Each section reflects the lived experiences and insights of women with IDD, as well as the expertise of clinicians and public health leaders committed to inclusive, person-centered care.

Whether you're exploring your healthcare options for the first time or looking to better understand your body and health needs, this guide is designed to help you make informed decisions, ask questions, and feel confident advocating for yourself. We believe that every woman deserves respectful, accessible, and high-quality healthcare—and that starts with having the right information in your hands.

Women's Health Guide

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01. Women's Healthcare Basics

What is Healthcare?

Healthcare is the help you get to stay healthy, feel good, and take care of your body and mind.

It includes things like going to the doctor, taking medicine, getting shots, having your eyes or teeth checked, and learning how to eat healthy food or exercise.

Healthcare helps you feel better when you are sick and stay well when you are not sick.



Why is Healthcare Important for Women with I/DD?

Women with intellectual and developmental disabilities have the same health needs as all women. But sometimes, they don't get the care they need.

That's why it's important to speak up, ask questions, and go to regular check-ups.

Good healthcare helps you:

- Stay strong and healthy
- Catch problems early, before they get worse
- Learn about your body and how it changes
- Make choices about your own health
- Feel confident and in control of your life



NOTES

02. What to Expect During Doctor Exams

Common Questions Doctors May Ask You

Going to the doctor can feel overwhelming, especially if you're not sure what to expect.

Doctors ask questions to understand how you're feeling, what kind of support you might need, and how to help you stay healthy. These questions are not meant to be scary – they are a way for your doctor to get to know you and your body better.



You can always bring a support person with you, ask for things to be explained in a different way, or take your time answering.

Here are some questions your doctor might ask you during a visit:

COMMUNICATION AND CONSENT

- ☐ How do you prefer to communicate? (Talking, using a device, gestures, etc.)
- ☐ Do you understand why you're here today?
- ☐ Is it okay if we talk about your health?
- ☐ Would you like someone you trust to be in the room with you?

GENERAL HEALTH

- ☐ How are you feeling today?
- ☐ Are you in any pain or discomfort?
- ☐ Have you been feeling tired or low on energy?
- ☐ Do you have any trouble sleeping?
- ☐ Have you had any recent illnesses or infections?

MEDICAL HISTORY

- ☐ Do you have any health conditions like epilepsy, diabetes, or heart problems?
- ☐ Are you taking any medications? What are they and how often do you take them?
- ☐ Have you had any surgeries or stayed in the hospital before?
- ☐ Do you have any allergies?

MENTAL AND EMOTIONAL HEALTH

- ☐ Have you been feeling sad, worried, or upset lately?
- ☐ Do you feel safe at home and in your community?
- ☐ Are you still enjoying the things you usually like to do?
- ☐ Has anything about your behavior or mood changed?

DAILY LIFE

- ☐ Can you do everyday tasks like bathing, dressing, and eating by yourself?
- ☐ Do you have help at home?
- ☐ How is your appetite?
- ☐ Do you get regular exercise or movement?

REPRODUCTIVE HEALTH

- ☐ When was your last period?
- ☐ Are your periods regular?
- ☐ Do you have pain or heavy bleeding during your period?
- ☐ Are you sexually active? If yes, do you use birth control?
- ☐ Do you have any questions about protecting yourself from sexually transmitted infections?
- ☐ Have you ever had a Pap smear or a breast exam?
- ☐ Do you want to have children one day?

PREVENTIVE CARE

- ☐ Have you had any recent health screenings, like for blood pressure or cholesterol?
- ☐ Are your vaccinations up to date?
- ☐ Do you go to the dentist and eye doctor regularly?

SAFETY

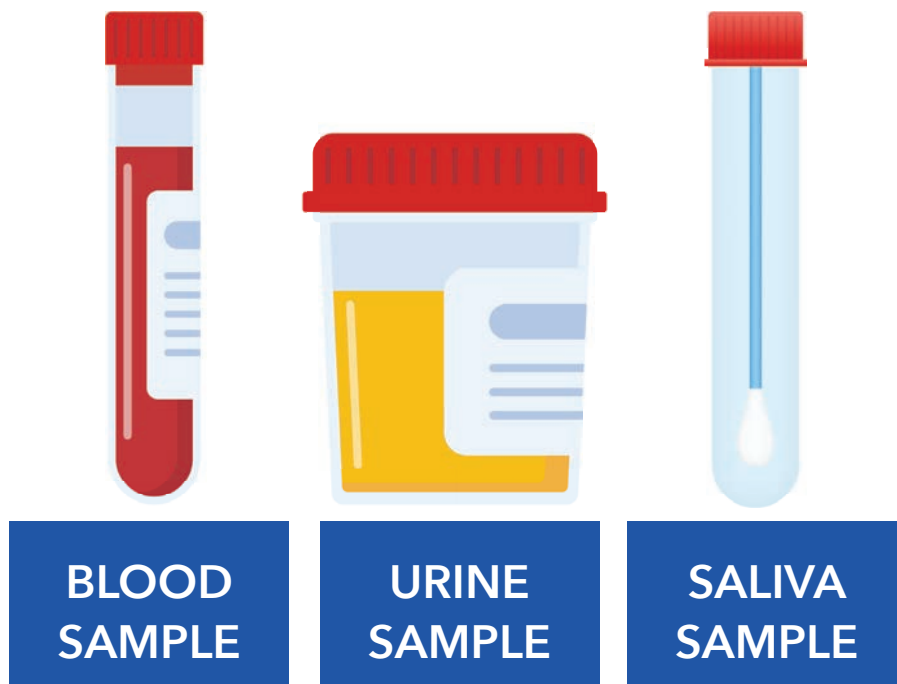
- ☐ Has anyone ever touched you in a way that made you feel uncomfortable?
- ☐ Do you feel safe where you live and spend time?
- ☐ Do you trust the people who help you?

Tips to Prepare for your Doctor Visit

- Bring a list of current medications and dosages.
- Keep a health history summary or care notebook.
- Have a trusted support person present if desired.
- Use communication aids or visual supports if needed.
- Let the doctor know if extra time or plain language is helpful.

Assessment samples that may be taken during your doctors visit:

- A urine (pee) sample
- Blood sample
- Saliva (spit) sample





After the Visit

After your doctor's visit, you may receive follow-up instructions based on your check-up or lab results. Below are a few steps that may happen next:

- **Lab Test:** If you had lab tests done, the results are usually ready within a few days. Your doctor or nurse will contact you to go over the results, or you can check them through your online medical portal.
- **Follow-Up Appointments:** Depending on your lab results or overall visit, your doctor may ask you to come back for another appointment or give you additional health advice.
- **Prescriptions:** If your doctor prescribes medication, make sure you know the name and address of your preferred pharmacy. Once the pharmacy receives the prescription, they will prepare your medication. When you pick it up, the pharmacist will explain how to take it and answer any questions you may have.

These steps help ensure you get the care and support you need after your visit.

Terms to Know

Health Evaluations and Lab Test

Assessment: A thorough evaluation done by the doctor to understand your health condition.

Vitals: Basic body measurements taken during an exam: height, weight, heart rate, temperature, blood pressure.

Saliva Sample: A small amount of saliva collected from the mouth, used for medical testing.

Breast Exam: When a doctor checks a woman's breasts to feel for any lumps or changes that could be signs of a health problem.

Sexually Transmitted Infections (STI's): Infections you can get from sexual contact with another person. They can affect your health, but many can be treated if caught early.

Diagnosis and Treatment

Diagnosis: An identification of a medical condition by a doctor.

Prescription: A note from your doctor that says what medicine you need, how much to take, and when to take it.

Prevention and Wellness

Vaccination: A shot that helps your body fight off certain diseases and stay healthy.

Preventative Care: Taking steps to stop sickness before it starts. This includes regular doctor visits, tests to find health problems early, vaccines, and advice to help you stay healthy. you get better and should be followed carefully.

Healthcare Terms

PEOPLE WHO HELP YOU

Doctor: A qualified practitioner of medicine; a physician.

Nurse: A trained health professional who helps take care of you, gives medicine, and supports the doctor.

Nurse Practitioner: An experienced nurse who can also do the same tasks as a doctor, such as prescribe medication, diagnose and take care of you

Physician Assistant: A trained healthcare professional who works under the doctor or physician to prescribe medication, take care of you, perform exams and make diagnosis

PLACES YOU GO FOR CARE

Clinic: A type of health center, a place where you get healthcare.

Hospital: An institution providing medical, surgical treatments, and nursing care for well, sick, or injured people.

Urgent Care: Used for non-life threatening illnesses or sicknesses.

APPOINTMENTS AND VISITS

Appointment: A scheduled time to visit your doctor, clinic, or other healthcare provider.

Check-Up: A regular visit to the doctor to make sure you are healthy, even if you are not sick.

Follow-Up: Another appointment to check on your health after a test, treatment, or hospital visit.

Wait Time: How long you wait before seeing the doctor.

MEDICINE AND TREATMENT

Pharmacy: Where you go to get the medicine that your doctor wants you to take.

Treatment: The care or medicine you get to help you feel better or manage an illness.

Prescription: Medicine your doctor tells you to take. You get it filled at a pharmacy.

Refill: Getting more of your prescription medicine after you run out.

Doctor's Recommendations: These are what the doctor thinks you need to do to heal or feel better.

Allergy: A reaction your body has to something, like food or medicine, that can make you feel sick.

TYPES OF CARE

Outpatient: When you get care or a procedure but don't stay overnight at the hospital.

Inpatient: When you stay in the hospital overnight or longer to get care.

Pre-Op (Operation): What is done before and during a surgical procedure

Post-Op (Operation): What is done after a surgical procedure

Discharge: When you are allowed to go home after staying in the hospital or clinic.

Chronic Condition: A health problem that lasts a long time, like diabetes or asthma.

Acute Condition: A health problem that comes on quickly, like a broken bone or the flu.

HEALTH INFORMATION AND TESTING

Physical Exam: Checks your overall health and body

Lab: A laboratory where tests are conducted on clinical specimens to obtain information about the health of a patient to aid in diagnosis, treatment, and prevention of disease.

Screenings: A medical test that checks for a certain health problem

Symptoms: They are changes in your body that can help let you know that something is not right. Examples of symptoms include fevers, throwing up, headaches, etc.

Prognosis: The likely course of a disease or ailment

Diagnosis: Finding out what illness or problem you have by looking at your symptoms.

Vital Signs: Basic checks of your health like your temperature, heart rate, and blood pressure.

Medical History: Information about your past illnesses, treatments, and medicines.

Symptoms Tracker: A list or chart where you keep track of how you are feeling over time.

Health Record / Chart: A file that has your health information and test results.

Test Results: Information from a lab or scan that helps your doctor understand your health.

INSURANCE AND PAYING FOR CARE

Health insurance: A program where you pay each month and then the program pays for your health care.

Co-Pay: A fee that you pay every time you see the doctor. Insurance covers the remaining cost of your visit.

Insurance: Insurance helps you afford things like doctor visits or hospital stays.

OTHER HELPFUL TERMS:

Emergency: When someone needs a doctor's care immediately.

Blood Pressure: A measure that your heart uses to pump blood around your body.

Medical Equipment: Tools used to help you stay healthy, like a wheelchair, hearing aid, or blood pressure monitor.

Patient: A person who is getting care from a doctor, nurse, or hospital.



NOTES

03. Staying Healthy, Eating Right and Wellness

Nutrition: Portion Your Plate

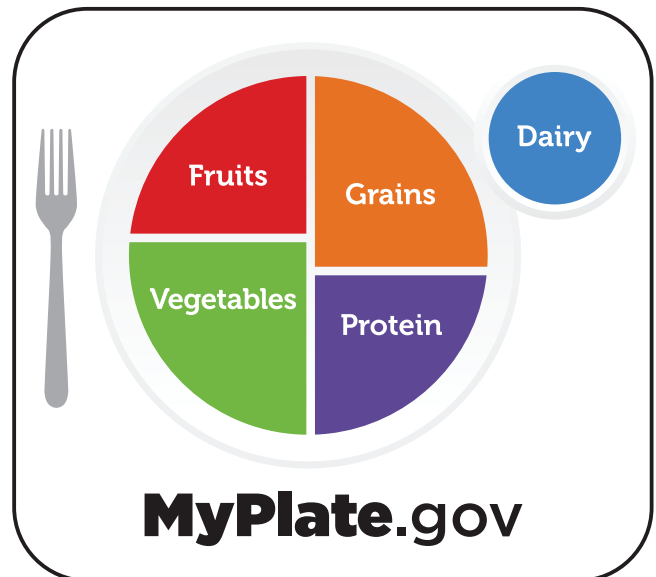
You want to try and eat foods from each food group because each food group provides different nutrients that help you stay healthy.

Food groups are:

- Vegetables
- Fruits
- Grains
- Protein
- Dairy

The plate division method is a simple and effective way to see how much food you are eating at each meal of each food group.

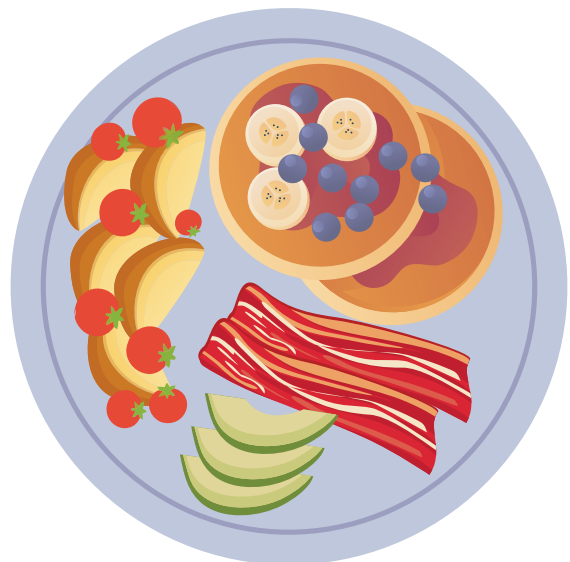
For more information, visit the MyPlate website at [myplate.gov](https://www.myplate.gov)



HEALTHY PLATE EXAMPLE 1



HEALTHY PLATE EXAMPLE 2



Nutrition: Stoplight Guide

Stoplight food ratings are a color-coded approach to communicate the nutritional quality of food. The stoplight labeling system focuses on healthy foods that are lower in calories yet high in nutrition.

Red stoplight foods are HIGH in calories and LOW in nutrition. Just like traffic signals, red means “stop” – limit these foods.

Yellow stoplight food means the food has more calories. If a food is rated yellow, you want to slow down these foods.

A **green** stoplight food means the food is LOWEST in calories and HIGHEST in nutrition. Like a traffic signal, green means “go” – go ahead, eat plenty of these!

EXAMPLES OF GREEN FOODS

Eat plenty of these!

Vegetables

- Asparagus
- Broccoli
- Beets
- Cabbage
- Carrots
- Cauliflower
- Celery
- Cucumbers
- Green Beans
- Lettuce
- Mushrooms
- Onions
- Peas
- Peppers
- Spinach
- Squash
- Tomatoes
- Zucchini



Fruits

- Apples
- Apricots
- Berries
- Cantaloupe
- Cherries
- Grapefruit
- Grapes
- Melon
- Kiwi
- Mango
- Nectarines
- Oranges
- Peaches
- Pears
- Pineapple
- Plums
- Pomegranate
- Tangerines

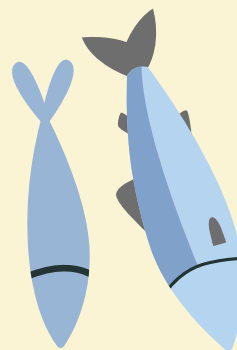
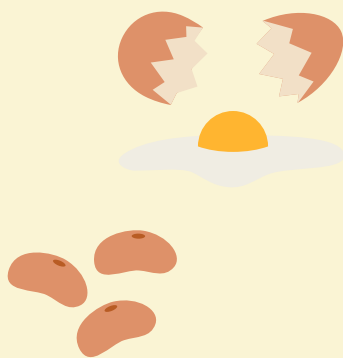


EXAMPLES OF YELLOW FOODS

These foods still have lots of nutrients, they also have more calories than green foods- try and go slow with these. Fill your plate with green foods and then add yellow foods in!

Protein

- Chicken
- Turkey
- Eggs
- Fish
- Lentils
- Beans



Grains

- Whole Grain Bread
- Brown Rice
- Whole Grain Pasta
- Unsweetened Oatmeal



Dairy

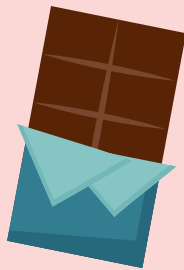
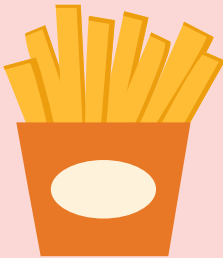
- Low Fat Cheese
- Low Fat Milk
- Light Yogurt
- Fat Free Cream Cheese



EXAMPLES OF RED FOODS

Try and limit foods that have a lot of calories and not a lot of nutrition.

- Bacon
- Hot Dogs
- Breaded Chicken or Fish
- Fried Food
- Doughnuts
- Cake
- Biscuits
- Cookies
- Candy
- Soda



Nutrition: Nutrition Facts Labels

Nutrition facts tell you what nutrients are in the foods you eat.

You can use nutrition facts to make choices for which foods to buy and eat.

Nutrition facts show serving size, calories, and important nutrients like fat, sodium (salt), cholesterol, carbohydrates, protein, fiber and vitamins and minerals.

This is what a nutrition fact looks like.

They are on all food that is in a package.

SERVING SIZE AND SERVINGS PER CONTAINER

Serving size is what the nutrition facts use to show how many nutrients are in a certain amount of the food.

Portion size is how much of the food you will actually eat. If you eat TWO servings instead of ONE, you will have to double (x2) everything else on the label.

CALORIES

This part shows how many calories (or energy) the food has. Sometimes, if you are trying to lose weight or maintain weight, food with less energy is better. It is important to look at the rest of the numbers on the nutrition fact label, too. On average, most adult women need between 1,600 and 2,400 calories a day, but fewer if you are not very active.

Nutrition Facts	
8 servings per container	
Serving size	1/2 cup (55g)
Amount per serving	
Calories	230
% Daily Value*	
Total Fat 8g	10%
Saturated Fat 1g	5%
Trans Fat 0g	
Cholesterol 0mg	0%
Sodium 160mg	7%
Total Carbohydrate 37g	13%
Dietary Fiber 4g	14%
Total Sugars 12g	
Includes 10g Added Sugars	20%
Protein 3g	6%
Vitamin D 2mcg	10%
Calcium 250mg	20%
Iron 8mg	45%
Potassium 235mg	4%
*The % Daily Value (DV) tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.	

Nutrition Facts	
8 servings per container	
Serving size	1/2 cup (55g)

Amount per serving	
Calories	230

LIMIT THESE NUTRIENTS

You can make healthy choices by choosing food that has less than 10% of total fat, saturated fat, cholesterol and sodium.

Nutrition facts list the amount of added sugars in foods. Try to keep your added sugars to under 10% of your daily value.

Total Fat 8g	10%
Saturated Fat 1g	5%
<i>Trans</i> Fat 0g	
Cholesterol 0mg	0%
Sodium 160mg	7%
Total Sugars 12g	14%
Includes 10g Added Sugars	20%

GET ENOUGH OF THESE NUTRIENTS

You can make a healthy choice by choosing food that has 10% or more of these:

- **Fiber** is very important for your body and helps you poop regularly. It also makes you feel more full. Foods that have lots of fiber in them are fruits, vegetables and whole grains.
- **Vitamin D:** Most of our vitamin D comes from the sun, but you can still get some by eating fatty fish, mushrooms or eggs. Vitamin D works with calcium to keep your bones strong. It also helps support immune health. Some foods like dairy are fortified with vitamin D which means vitamin D has been added to the food.
- **Calcium:** If there is a lot of calcium on the label you are probably eating dairy foods (milk, yogurt and cheese). Calcium is a mineral that helps build strong bones. Calcium is especially important for women to maintain strong bones!
- **Iron:** Protein (meat) foods have a lot of iron. Some foods like cereals are fortified with iron. Iron helps your blood carry oxygen from your lungs to the rest of your body. Women are more likely to have iron-deficiency anemia, which can make you feel weak, tired or dizzy, so it's especially important to make sure to get the right amount of iron (usually 8-18 mg per day).
- **Potassium:** Fruits and vegetables have a lot of potassium: Potassium helps keep your muscles, heart and nervous system healthy

Dietary Fiber 4g	14%
Vitamin D 2mcg	10%
Calcium 250mg	20%
Iron 8mg	45%
Potassium 235mg	4%

There is no % daily value for:

- **Trans fat:** You do not need any of this kind of fat so try and get as little as possible. Eating too much of this kind of fat can make you sick when you get older (heart disease).
- **Sugar:** This will tell you how much sugar is in the food naturally plus how

much the food company added in. You don't need a lot of sugar, so try and pick foods that don't have very much.

- **Protein:** Americans usually get enough protein each day, we don't need a percent for it.

Note: Sometimes women have different nutrition needs during different life stages, for instance during pregnancy, breastfeeding or menopause. For example, pregnant women need more iron and more calories. Breastfeeding women will need to drink a lot of water! Always talk to your doctor or a dietician to learn more about what your body needs at these times.

NATURAL SUGAR VERSUS ADDED SUGAR

Natural sugar is the sugar that is already in foods that grow naturally, like fruit and milk. These foods also give your body vitamins, fiber, or protein.

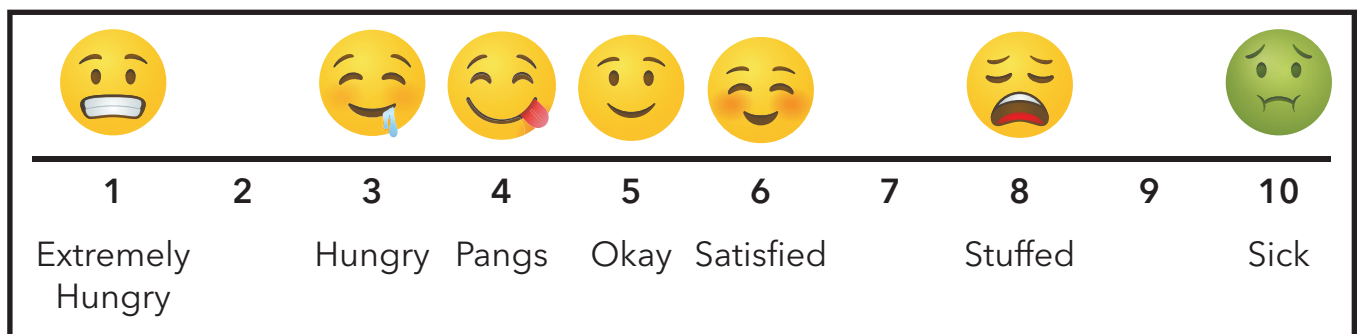
Added sugar is sugar that is put into foods when they are made or cooked, like in cakes, cookies, candy, or pop. These foods usually don't have many other nutrients your body needs.

NUTRITION: HUNGER VERSUS CRAVINGS

Hunger is when your stomach is growling, and any food sounds good.

A good way to see if you are hungry is to use The Hunger Scale:

- Try and start eating when your stomach is rumbling (Hunger Scale 3 = uncomfortable)
- Stop eating when you feel good (Hunger Scale 5 or 6 = Comfortable, Perfectly comfortable)



Make sure to listen to what your body is telling you. If your stomach is growling or feels empty, you may be hungry and need to eat. If you feel full your body is telling you it has had enough food for now.

What is a craving?

A craving is different than being hungry. A craving is when you really want to eat a certain food because it tastes good, not necessarily because you are hungry. Cravings happen when you really want a certain food, and it might be due to your mood. You might have cravings when you are happy, sad, lonely or bored. Or you might have a craving when you see or smell a certain food you really like. You may also have cravings right before or during your period.

Cravings are NORMAL. It is ok to give in to your cravings occasionally to treat yourself, try to also make sure you are eating healthy when your body is telling you that you are hungry. Listen to your body when you are full.

Sometimes you may have a craving for a food you like that has a lot of sugar, fat or salt in it. This could be your body's way of telling you that you need nutrients found in these foods. You can choose healthier options to get these nutrients. Check out the table below for ideas.

Your Craving	You Might Need	Try Instead
Chocolate	Magnesium	Nuts, seeds, spinach, raisins, raspberries, spinach, dark chocolate
Sugary foods	Chromium	Broccoli, whole grains, eggs, cheese
	Tryptophan	High protein foods (meat, dairy, eggs, nuts and seeds)
	Zinc	Seafood, meat, beans
	Iron	Meat, eggs, seeds, dried fruits, berries
	Calcium	Milk, cheese, yogurt, leafy greens
	Vitamin B	Meat, fish, milk, cheese, eggs, fortified breakfast cereal
Bread, pasta, other carbs	Energy (complex carbohydrates)	Whole grains, starchy vegetables-squash, sweet potatoes
Oily foods	Fat soluble vitamins (A, D, E, K)	Nuts, seeds, avocados
Salty foods	Water, sleep	Drinking water, getting rest, destressing

Physical Activity

Physical activity has long-term health benefits. Women of all ages, shapes and sizes can benefit from exercising. Exercising can increase your strength, helps you maintain a healthy weight, improves your balance and energy levels and helps you sleep better.

Tips for exercise:

- Have fun, try activities that you enjoy
- Try and exercise for at least 30 minutes a day 4-6 times a week
- You can start with just 10 minutes of exercise at a time. Add on as you feel more comfortable
- There are many different types of physical activity. It is important to find types of physical activity that you enjoy doing. This will help get you excited about being active.

TYPES OF PHYSICAL ACTIVITY

Aerobic activities make you breathe harder and make your heartbeat faster. Walking, swimming, biking, dancing, running are all aerobic activities.

Muscle strengthening activities make your muscles stronger. Body weight exercises like push-ups and squats, lifting weights or using resistance bands are all muscle strengthening activities.

Bone strengthening activities make your bones stronger. Activities like jumping produce a force on the bones that promotes bone growth and strength.

Balance and stretching activities help with stability and flexibility which can help you avoid falling. Gentle stretching, yoga, dancing, martial arts and T'ai chi are examples of balance and stretching activities.

On the next page is a physical activity pyramid that can help you get moving throughout the week.

PHYSICAL ACTIVITY PYRAMID



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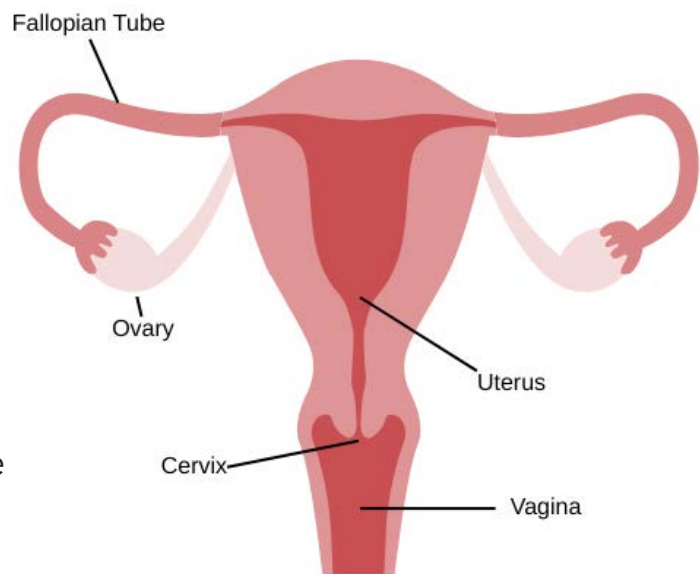
Reproductive Health

What is the Reproductive System?

The reproductive system is the part of the body that helps women have babies.

It includes body parts like:

- **Uterus:** An organ in a woman's body where a baby can grow.
- **Ovaries:** The part of a woman's body that holds and releases eggs.
- **Vagina:** A stretchy tube inside the female body that connects the uterus to the outside, and allows for periods, sex, and childbirth.



These parts work together to prepare the body for pregnancy. Even if someone doesn't want to have a baby, the reproductive system is still very important for overall health.

The reproductive system also affects hormones, which can influence mood, energy levels, and how the body feels. Keeping it healthy helps prevent infections, pain, and other health problems.

It's important to have regular check-ups with a doctor to make sure your reproductive system is working properly and staying healthy.

What is Puberty?

Puberty is the time when a girl's body (born a female) changes from a child's body to an adult woman's body. This is when her body starts to be able to have a baby. It is a normal and expected part of growing up.

These changes happen because of hormones. Hormones are special chemicals in the body.

Puberty usually starts between ages 8 and 13 and can last 2 to 5 years. Everyone's body is different, so it can happen at different times and speeds for each person.

It is important to talk with a trusted adult such as a parent, doctor, or school nurse during this time. They can answer questions, help you feel better, and support you as your body changes.

What Happens During Puberty?

PHYSICAL CHANGES

Breast Development

The breasts (often called boobs or boobies) start to grow. Small lumps called breast buds form under the nipples. It is normal for one breast to grow faster than the other. They might feel sore or tender at first.

Body Hair Growth

Hair starts to grow on the legs, under the arms, and around the private area. This hair gets thicker and darker over time. Sometimes hair in the private area grows before the breasts start to grow.

Growth Spurt

You may grow taller quickly during puberty. You could grow several inches in one year. This fast growth usually slows down after your first period.

Changes in Body Shape

The body stores fat in new places, like the hips, thighs, and chest. The hips may get wider.

Periods (Menstruation)

Periods usually start about two to three years after breast buds appear. A period is when blood comes from the vagina because the body is not pregnant. Periods usually last three to five days. They may be irregular at first, which means they do not come at the same time every month.

Skin Changes

Skin can get oily. Pimples or acne may appear. This is common and part of puberty.

Body Odor

Sweat glands become more active. This can cause stronger body odor.

Vaginal Discharge

You may notice clear or whitish discharge from the vagina before your first period. This is normal.

EMOTIONAL CHANGES

Mood Swings

You may feel happy one moment and sad or angry the next. This is normal during puberty.

Body Image Concerns

You may start to notice how your body is changing. Changes can be hard, but everyone goes through these changes at some point. You are not alone. Please talk to a trusted adult like your parents or doctor if you need support through this transition time.

Need for Privacy

You may want more time alone or more privacy during this time. This is a normal part of growing up.

THINGS IN YOUR ROUTINE OR DAILY LIFE THAT MIGHT CHANGE DURING PUBERTY

Bathing / Washing your face

As your sweat glands become more active, you will sweat more and need to shower regularly.

You will also have changes in your skin due to hormonal changes. This may cause pimples and oily skin on your face, back, or chest. It is important to wash your face in the morning and at night (after you brush your teeth) to keep your skin clean. If you have pimples you might also want to see a dermatologist (skin doctor) to offer you skin advice.

Showering regularly is always important, but it's especially helpful during your period or when you have discharge to stay clean and comfortable.

Shaving

When girls reach middle school, many start to think about shaving their legs or underarms. Shaving is a personal choice—there's no health reason you have to shave.

If you do decide to try it, here are some tips to keep your skin safe:

- Shave on wet skin. It's best to shave in the shower or bath when your skin is soft and wet. Always use shaving cream, gel, or lotion so the razor can glide and not scratch your skin.
- Use gentle pressure. Don't press too hard with the razor—this can cause cuts. Be extra careful around your knees and ankles.
- Change razors often. Old or dull blades can pull at your skin and cause irritation.
- Don't share razors. Sharing can spread germs and cause skin infections.

Deodorant

When you start puberty, your sweat glands become more active. This means your sweat can start to smell stronger, especially under your arms.

Using deodorant every day helps control odor and keeps you feeling fresh and confident around others.

What is Menstruation or "Having a Period"?

Menstruation (or a "period") is when blood comes out of the vagina each month. This usually starts when a woman is in puberty and stops later in life during menopause.

During a period, some people feel cramps, get tired, or experience mood changes.

There are different ways to manage a period, including:

- Wearing a pad, tampon, or period underwear
- Taking pain medicine if needed
- Using a heating pad for cramps
- Everyone's period is different, and that's okay.

Social Story: How to Change Your Pad

1



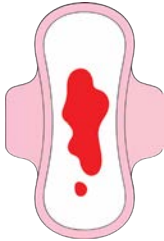
Sit on the toilet

6



Pee or poop if you need to

2



Take dirty pad out of underwear

7



Wipe

3



Throw away dirty pad

8



Pull clothes up

4



Open new pad

9



Wash your hands

5



Stick the pad onto clean underwear

10



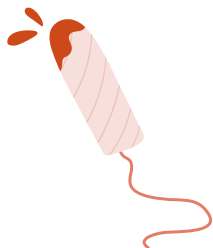
Ask for help if you need it

Social Story: How to Change Your Tampon

- 1



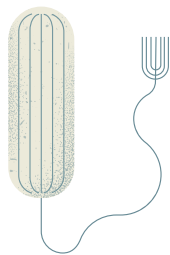
Sit on the toilet
- 2



Pull string to take dirty tampon out
- 3



Throw away dirty tampon
- 4



Open new tampon
- 5



Insert applicator into vagina and push to insert the tampon into your vagina
- 6



Throw applicator in trash
- 7



Pee or poop if you need to
- 8



Wipe
- 9



Wash your hands
- 10



Ask for help if you need it

What is Discharge?

Vaginal discharge is fluid that comes out of a woman's vagina. It is normal and helps keep the vagina clean.

Discharge can change throughout the day or month because of things like hormones, the menstrual cycle, or different activities.

As women get older, discharge may also change, and it is normal for it to have a small smell.

DISCHARGE COLORS *and what they might mean*



Clear / watery

This is normal. It can change during your cycle.



White

Usually healthy, but if it looks thick and clumpy, it might mean infection.



Gray

This could mean a bacterial infection and might have a strong smell.



Red

Usually blood from your period. It can also mean spotting or, sometimes, a miscarriage.



Brown

Old blood from your period or spotting. In pregnancy, it might mean labor is coming soon.



Pink

Fresh blood or spotting. It can also happen if the cervix or vagina gets irritated.



Green

Might mean an infection, like an STI or UTI. You may notice a different smell.



Yellow

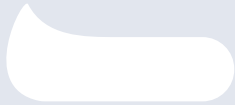
Can be blood mixed with mucus. If it looks greenish, it could mean an infection like PID or an STI.

DISCHARGE TEXTURES *and what they might mean*



Stretchy or slippery like raw egg whites?

Could indicate: you are about to ovulate



Thick, pasty and dry

Could indicate: your vagina is taking care of itself



Thick and lumpy, like cottage cheese

Could indicate: yeast infection



Thin

Could indicate: pregnancy (if color is clear), bacterial vaginosis (if color is green or grey)



Watery or bubbly

Could indicate: a sexually transmitted infection (STI)



Thick and mucus-like

Could indicate: noninfectious vaginitis

If you are concerned about discharge, it's best to get in touch with your doctor.

What is Pregnancy?

Pregnancy can happen when a person with a uterus and a person with sperm have sex without using birth control. The sperm joins with an egg, and the egg grows into a baby inside the uterus for about nine months.

During pregnancy, the body goes through many changes to support the growing baby. Doctors and nurses can help pregnant people stay healthy and check that the baby is growing well.

What is Menopause?

Menopause happens when a woman stops getting her period. This usually happens between ages 45–55, but can happen earlier for some women with IDD, even in their 30s. After menopause, a woman can no longer get pregnant naturally.

Some changes people may notice during menopause include:

- Hot flashes (sudden feelings of warmth)
- Trouble sleeping
- Mood changes

Menopause is a normal and natural part of aging.

What is a Pap Smear?

A Pap Smear is a test that helps doctors check if your reproductive system is healthy. It can find early signs of problems like cervical cancer. Getting regular Pap smears is an important part of taking care of your health. We will talk more about Pap Smears in Section 5.

Let your doctor know if you have questions. It's okay to ask for help—you deserve to understand your body and feel supported in your health journey.

Other Important Information About Reproductive Health

HYGIENE AND REPRODUCTIVE HEALTH

Hygiene means keeping your body clean to help prevent infections and stay healthy. It's especially important for reproductive health.

Here are some hygiene tips:

- Wash your body every day with soap and water, especially around your vagina and anus.
- Change your underwear daily and make sure it's clean.
- After using the bathroom, wipe from front to back to avoid spreading bacteria.
- Do not use scented soaps or sprays inside the vagina.
- During your period, change your pad or tampon regularly (every 4–6 hours).

BIRTH CONTROL

Birth control helps prevent pregnancy.

If a person wants to have sex but does not want to have a baby, there are different birth control options, like:

- Pills
- Patches
- Shots
- Condoms
- Diaphragm or cervical cap
- Intrauterine Device (IUD)
- Implant in your arm

Talk to a doctor to find the method that works best for you.

COMMON INFECTIONS TO KNOW ABOUT

Some common infections include:

- Yeast infections
- Bacterial vaginosis (BV)
- Urinary tract infections (UTIs)

Signs of infection might be:

- Itching or irritation
- Pain or discomfort
- A strong or unusual smell
- Needing to pee more often
- Colored or thick discharge

If you notice any of these signs, talk to your doctor. These infections are common and can be treated with medication. Don't worry—you're not alone, and help is available.

SEXUALLY TRANSMITTED INFECTIONS (STIS)

Some infections can spread through sex. These are called STIs. Using condoms reduces your risk of receiving or spreading an STI.

It's a good idea to get tested if you've had sex. Testing helps keep you and your partner safe.

Reproductive Health Terms

Birth Control: This can be a pill, patch, small bar placed in your arm, a shot with medicine, or a small t-shaped device put inside your uterus. Birth control can help with cramps, shorten your period, stop it completely, or prevent pregnancy.

Cervix: The small opening between the uterus and the vagina. It changes during your period and pregnancy.

Consent: Saying "yes" to something freely and clearly. You have the right to say "yes" or "no" to anything involving your body.

Cramps: Pain in the lower belly or pelvis before or during your period.

Cycle (Menstrual Cycle): The number of days from the first day of one period to the first day of the next. A cycle usually lasts about 28 days but can be shorter or longer.

Discharge: Fluid that comes out of the vagina. It helps keep the vagina clean. If it smells bad or looks unusual, talk to a doctor.

Estrogen: A hormone that helps with changes in your body like starting your period, growing breasts, and keeping bones strong.

Fertility: Being able to get pregnant and have a baby.

Hormones: Special chemicals in your body that help it do important things, like go through puberty or have a period.

Hormone Replacement Therapy: When a doctor gives you extra hormones to help your body during or after menopause.

Menopause: When your period stops forever and you can no longer get pregnant.

Menstruation (Period): Monthly bleeding from the vagina that usually lasts 2–7 days. This is also called your period.

Mood Swings: When your feelings change quickly. This can happen during your period or other times when your hormones change.

Osteoporosis: A disease that makes bones weak and more likely to break. It can happen after menopause when hormone levels change.

Ovulation: When your body releases an egg from the ovary. This happens about halfway through your cycle and is when you are most likely to become pregnant.

Pap Smear / Pelvic Exam: A test where a doctor checks a woman's cervix and vagina to make sure they are healthy. Usually starts around age 21 or earlier if you're sexually active.

Premenstrual Syndrome (PMS): Feelings or body changes before your period starts, like mood swings, headaches, or bloating.

Puberty: Usually starts between ages 8 and 13. This is when your body changes from a child to an adult.

Sanitary Products (Pads, Tampons, Menstrual Cups): Items used to collect period blood. Pads stick to your underwear. Tampons go inside the vagina. Cups are soft and collect the blood inside.

Sex: When a man's penis enters a woman's vagina. It is also called "sexual intercourse." It is an activity that adults choose to do when they both agree and are ready. During intercourse, sperm from the man can join with an egg from the woman, which can lead to the start of a pregnancy.

Sexual Health

Taking care of your body and feelings related to sex. This includes safe relationships, understanding your body, and preventing pregnancy or infections.

Sexually Transmitted Infection (STI): An infection you can get from sexual contact. Some STIs have symptoms and some don't, but many can be treated with medicine.

Uterus: A part inside your lower belly where a baby can grow during pregnancy. During your period, blood comes from the uterus.

Vagina: The part of a woman's body between the legs. Blood comes out during your period. It is also where a baby comes out during birth.

NOTES

05.

Preventable Cancer Screenings

Research shows that women with disabilities are less likely to get important cancer screenings, like Pap smears and mammograms. Because of this, they are more often diagnosed with breast cancer at later stages, when it can be harder to treat.

That's why it's very important for women with intellectual and developmental disabilities (IDD) to learn about their options for cancer screenings and prevention.

This chapter answers common questions and explains what to expect during check-ups, screenings, and preventive care.

What is a Pap Smear (Cervical Screening)?

A Pap smear is a test that checks for early signs of cervical cancer by looking at cells from the cervix (the lower part of the uterus).

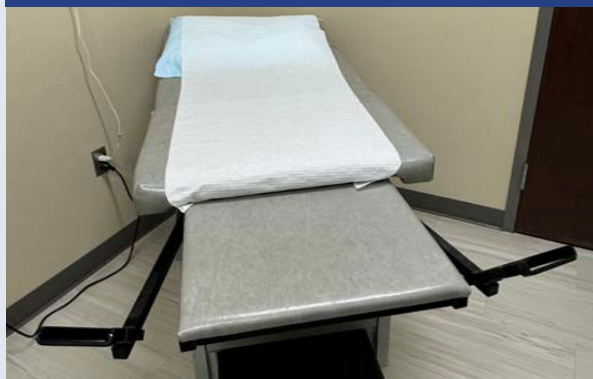
WHAT HAPPENS DURING A PAP SMEAR?

1. You'll go to a doctor's office.



2. You'll be asked to take off your pants and underwear and lie on an exam table. A sheet or gown will be provided for your comfort.

3. You'll bend your knees and place your feet in footrests (called stirrups).



4. The doctor or nurse will gently insert a tool called a speculum into the vagina to see the cervix. This may feel uncomfortable but should not hurt.



5. A small swab is used to collect a few cells from the cervix. The test only takes a few minutes, and then you can get dressed.



TIPS TO FEEL MORE COMFORTABLE:

- Focus on slow, deep breaths.
- Tell the doctor if you feel nervous. They can go slowly and explain each step.
- Ask questions—your comfort matters.
- If you have never been sexually active, talk with your doctor about whether the test is necessary.

What is the HPV Vaccine and Why is it Important?

The HPV vaccine protects against a virus called human papillomavirus (HPV), which can cause:

- Cervical cancer
- Throat cancer
- Genital warts

HPV is very common and can spread through sexual contact—even when there are no symptoms. The vaccine works best before a person becomes sexually active, but older teens and adults can still benefit.

Most people get the HPV vaccine between ages 9 and 26.

Ask your doctor if it's right for you.

How Do I Talk to My Doctor About Screenings?

You have the right to understand and feel comfortable with your healthcare.

Here are some questions you can ask your doctor or nurse:

- When should I start getting mammograms or Pap smears?
- How often do I need these tests?
- Should I get the HPV vaccine?
- Are there other screenings I need based on my health or family history?

Tip: Write down your questions before the visit. It's okay to ask the doctor to repeat or explain things in a different way. You can also bring a trusted friend, family member, or support person with you.

Taking care of your health is important. Screenings can find problems early—when they are easiest to treat.

Your body belongs to you, and you deserve respectful, clear, and caring healthcare.

What is a Mammogram?

A mammogram is a special X-ray that checks for signs of breast cancer. It can find lumps or changes in your breast before you feel them.

Most women start getting mammograms between the ages of 40 and 50. Some may need to start earlier.

WHAT HAPPENS DURING A MAMMOGRAM?

- You'll go to a doctor's office or clinic for the test.
- You'll be asked to take off your shirt and bra and put on a medical gown.
- A trained healthcare worker will help you stand in front of a mammogram machine.
- One breast is placed on a flat surface. A clear plastic plate gently presses down on it to take a picture.
- You may feel pressure or discomfort, but it only lasts a few seconds.
- You might be asked to hold your breath for a short time when the mammogram is taken.
- The same steps are done for your other breast.
- The test usually takes about 10–15 minutes.

How Should I Dress for My Appointment?

Wear comfortable clothing that is easy to take off—like a shirt with pants or a skirt.

For a mammogram, a top and pants may be easier than a dress since you'll need to remove your shirt and bra.

What If I Use a Wheelchair?

Many doctor's offices have accessible equipment like height-adjustable exam tables and mammogram machines.

Call ahead to ask if they have accessible equipment.

If you need help transferring, let them know. They should work with you to find a safe, respectful option.

Preventable Cancer Screening Terms

FEMALE ANATOMY

Reproductive System: The part of the body that helps a person have babies. It includes parts like the uterus, ovaries, and vagina.

Uterus: The place inside a person's body where a baby can grow during pregnancy.

Ovaries: Two small organs that release eggs and make hormones.

Vagina: The opening between a person's legs. It is part of the reproductive system.

Cervix: The small opening between the vagina and uterus.

FEMALE CYCLES AND REPRODUCTION

Menstruation / Period: When blood comes out of the vagina every month. This means the body is getting ready for pregnancy.

Menopause: When a person stops having periods, usually between ages 45 and 55.

Hormones: Chemicals in the body that control things like mood, energy, and periods.

Pregnancy: When a baby grows in the uterus. This can happen when sperm and an egg join together.

PREVENTATIVE CARE

Birth Control: Ways to stop a person from getting pregnant if they have sex. Examples are pills, condoms, and shots.

Mammogram: An X-ray of the breasts that checks for signs of breast cancer.

Pap Smear: A test where the doctor collects cells from the cervix to check for signs of cancer.

HPV Vaccine: A shot that helps protect against HPV and the cancers it can cause.

Cancer Screening: A test that checks for cancer before you feel sick.

Hygiene: Keeping your body clean to stay healthy and avoid infections.

INFECTIONS

STI (Sexually Transmitted Infection): An infection that can be passed from one person to another during sex.

Yeast Infection: An infection that causes itching, discomfort, or white discharge from the vagina.

Bacterial Vaginosis (BV): An infection that can cause a fishy smell or discharge from the vagina.

Urinary Tract Infection (UTI): An infection in the bladder or pee area that can cause burning, pain, or the need to pee a lot.

HPV (Human Papillomavirus): A common virus that can cause cancer. There is a vaccine to protect against it.

TOOLS DOCTORS USE DURING AN EXAM

Speculum: A tool that gently opens the vagina so the doctor can see the cervix.

Accessible Equipment: Medical tools and machines that are made to work for all bodies, including people who use wheelchairs or have other support needs.

Stirrups: Footrests on an exam table where you place your feet during a Pap smear.

NOTES

06. Requesting Accommodations During Exams and Doctor's Visits for Self- Advocates and Caregivers

Leading Your Own Care: How to Self-Advocate, Request Accommodations, Access Patient Advocate Support

PREPARING FOR YOUR DOCTOR VISIT

Gathering Materials:

- Write down your goals for your doctor's visit. What do you hope to accomplish for this visit?
- Prepare a list of current symptoms, concerns, medications, assistive devices used (e.g., wheelchair, walker), and previous diagnoses to review with your doctor.
- If you are seeing a new doctor, request a release of your medical records from your previous doctors so they have your health history.
- The doctor might give you a prescription to pick up from your local pharmacy. Be sure to know the name and address of your pharmacy.

Self Advocate Scheduling a Visit: Ask for what you need

- When scheduling the appointment, inform the clinic of your disability and request any accommodations you may need (e.g., accessible exam room, assistance with mobility, extended appointment time).
- Talk to the doctor's office to make sure they accept your insurance and ask if there will be any costs, like a copay, for your visit.
- Inform doctors that you may need additional time to discuss your visit.
- Ask for clear directions to your doctor's office, such as the building name, floor number, and room number.
- Ask whether the facility has accessible entrances, elevators, restrooms, and exam tables that lower or can be adjusted.

Very Important: If you ever feel uncomfortable during a doctor's visit, you do not have to stay. You have the right to leave and find another provider who makes you feel safe, respected, and heard.

Requesting for a Patient Advocate, Extra Support Before, During, and After: If you feel you need more assistance, seeking a patient advocate or case worker can be assigned to help you navigate your appointment.

A patient advocate is a person assigned to help you schedule and navigate through your doctor's visit.

If you do not have a patient advocate you can request one through connecting to agencies that provide this support.

These contacts can be found in the resource support section below. It will be important for you to share the following information with them so they can assist you with all aspects of your appointment.

- If needed, request assistance for a patient advocate with scheduling your doctor's appointment.
- Tell them why you need a doctor's visit and your concerns
- Share your medical history with them
- Have them help you create a list of questions you may want to ask your doctor regarding your concerns
- Assist with communicating any special accommodations you will need during your visit
- If your caregiver or advocate is going with you to the appointment, make sure to tell them the date, time, exact location, and where to meet you

Patient Advocate During the Doctor's Visit

- The patient advocate can help communicate your concerns to the doctor
- Take notes and assist the doctor with instructions provided during your visit.
- Assist the doctor with explaining the next steps and summary of your visit.

Patient-Advocate Assistance After the Doctor's Visit

- Assist with scheduling following appointments
- Keep a copy of your notes and information for future visits
- Keep in contact regarding your progress and assist with helping to communicate with any additional questions you may have for the doctor.

Resources and Support

There are multiple organizations and agencies that provide a variety of support and accommodations to help make your doctor's visit go smoothly.

Below are some common services and resources available to assist you.

FINDING A PATIENT ADVOCATE:

Caseworker and In-Person Support

Kansas Department for Aging and Disability Services (KDADS): Provides services such as Medicaid waivers, in-home care, behavioral health support, and nursing facility care.

Phone: 1-855-200-2372

Website: <https://www.kdads.ks.gov/>

Medical Financial Support

KanCare (Kansas Medicaid Program): Health coverage for low-income individuals, including people with disabilities. Services include doctor visits, prescription coverage, and long-term services and support.

Phone: 1-800-MEDICARE

Website: <https://www.kancare.ks.gov/>

Medical Equipment Support

CPRF Equipment Fund: Offers financial assistance for medical equipment and assistive devices to Kansans with disabilities.

Phone: 316-688-1888

Website: <https://www.cprf.org/equipment-fund/>

This is a partial list of resources available to support you during your doctor's visit. Please review the website below for links to various nonprofit organizations that assist with accessing medical doctor visits.

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07. Annual Checklist

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Annual Checklist

Visit your Doctor for a Check-Up

- ☐ Talk about how you feel, any pain, or changes in your body.
- ☐ Ask questions. There are no bad questions to ask your doctor.

Get your Blood Pressure Checked

- ☐ This checks how hard your heart is working

Get a Flu Shot

- ☐ This helps protect you from getting sick with the flu.

Talk about Blood Work or Lab Tests

- ☐ Your doctor may check your blood to see how your body is working inside.

Talk about Mental Health

- ☐ Share how you've been feeling. Happy? Sad? Worried?

Mental health is just as important as physical health!

Ask about Your Period (Menstrual Health)

- ☐ Talk about your period, cramps, or any changes that feel different or uncomfortable for you.
- ☐ Ask if you need a pelvic exam or a pap smear
- ☐ These help check your reproductive health

Review your Medications

- ☐ Make sure you are taking the right medicines, and talk about any side effects you are experiencing

Talk about breast health

- ☐ Ask your doctor how to check for lumps or changes
- ☐ You may need a mammogram starting at age 40 or earlier if your doctor says so

Talk about healthy eating and exercise

- ☐ Ask for tips that work for YOU! Everyone's body is different.

NOTES

MY HEALTH JOURNAL

Name:

I like to be called:



photo here

Birthday:

Age:

Important Contacts

Emergency Contact:

Phone Number:

Relationship:

Primary Care Physician:

Phone / Clinic:

Pharmacy:

Phone / Location:

ABOUT ME

I Communicate Using:

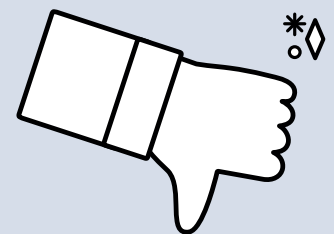
(Ex: speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)



Things that are Important to Me:



What I Do Not Like:



HEALTH INFORMATION

Diagnosis list:

Medications:

Allergies:

Medical Equipment I Use:

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Works Cited

COMMON QUESTIONS DOCTORS MAY ASK:

What to Expect During Doctor's Exams

Kansas Department for Aging and Disability Services (KDADS). Aging and Disability Resource Center – Helpful Links. Kansas Department for Aging and Disability Services, <https://www.kdads.ks.gov/services-programs/aging-and-disability-resource-center/helpful-links>. Accessed 15 May 2025.

Kansas Department for Aging and Disability Services (KDADS). Home Page. Kansas Department for Aging and Disability Services, <https://www.kdads.ks.gov/>. Accessed 15 May 2025.

KanCare. Kansas Medicaid Program. KanCare, <https://www.kancare.ks.gov/>. Accessed 15 May 2025.

CPRF. Equipment Fund. Cerebral Palsy Research Foundation, <https://www.cprf.org/equipment-fund/>. Accessed 15 May 2025.

PREVENTABLE CANCER SCREENINGS

Andresen, E. M., Peterson-Besse, J. J., Krahn, G. L., Walsh, E. S., Horner-Johnson, W., & Iezzoni, L. I. (2013). Pap, mammography, and clinical breast examination screening among women with disabilities: a systematic review. *Women's health issues : official publication of the Jacobs Institute of Women's Health*, 23(4), e205–e214. <https://doi.org/10.1016/j.whi.2013.04.002>

REQUESTING ACCOMMODATIONS DURING EXAMS & DOCTOR'S VISITS FOR SELF-ADVOCATES & CAREGIVERS

Kansas Department for Aging and Disability Services (KDADS). Aging and Disability Resource Center – Helpful Links. Kansas Department for Aging and Disability Services, <https://www.kdads.ks.gov/services-programs/aging-and-disability-resource-center/helpful-links>. Accessed 15 May 2025.

Kansas Department for Aging and Disability Services (KDADS). Home Page. Kansas Department for Aging and Disability Services, <https://www.kdads.ks.gov/>. Accessed 15 May 2025.

KanCare. Kansas Medicaid Program. KanCare, <https://www.kancare.ks.gov/>. Accessed 15 May 2025.

CPRF. Equipment Fund. Cerebral Palsy Research Foundation, <https://www.cprf.org/equipment-fund/>. Accessed 15 May 2025.



KCDD

Kansas Council on
Developmental Disabilities

VISIT US ONLINE AT
kcdd.org