ASD TRANSITION:

Pediatric to Adult Healthcare for Young Adults with ASD

Student Workbook



Table of Contents

Table	e of Content	2
Welco	ome	3
1	Lesson 1: Healthcare Checklist & Timeline	4
	Lesson 2: Medical Home	8
	Lesson 3: Emergency Medical Information	10
	Lesson 4: Identifying When to Visit the Doctor	12
	Lesson 5: Scheduling an Appointment with a Medical Professional	15
1	Lesson 6: Preparing for a Medical (or Dental) Appointment	17
	Lesson 7: Prescription Information	21
1	Lesson 8: Health Insurance Information	24
Gloss	sary	27

Welcome to the Transition to Adult Healthcare Workbook for Students!

This workbook will aid you in learning about healthcare transition information as you transition from pediatric to an adult model of healthcare. Transitioning from pediatric to adult health care is a process that should involve planning and support from a team. This team consists of a variety of stakeholders, institutions, and individuals, such as the community, parents, teachers, health care providers, other health care assistants, social service workers, and you.

The workbook is designed to increase these transition skills: Self-advocacy, planning and scheduling, self-monitoring, and health knowledge.

This workbook is broken down into two sections:



Acknowledging the depth and variance of the autism spectrum, this workbook serves as a guide for the adaptation and implementation of educational materials. Certain lessons may need to be tailored to suit the individual and developmental stage of each child. However, differentiated activities/materials are suggested throughout each lesson and are indicated by a \diamondsuit . We look forward to going on this exciting journey with you in making a difference in the health of youth with ASD!

Lesson 1: Healthcare Checklist & Timeline

What healthcare transition skills do I need to work on?

Do you know your 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, such as diabetes or hypertension. 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.

Many young people have never thought about the questions you are about to answer in the health care checklist. Most people would find it difficult to answer "yes" to many of them. You are ahead of the game just by doing the checklist. Place a checkmark in the column you think best fits you.

Let's do a few together:

Healthcare Checklist	Yes	Working on it
Personal Information:		
Can I state my first, middle, and last name?		
Do I know my birthdate, including the year?		

Now you can answer the rest by yourself!

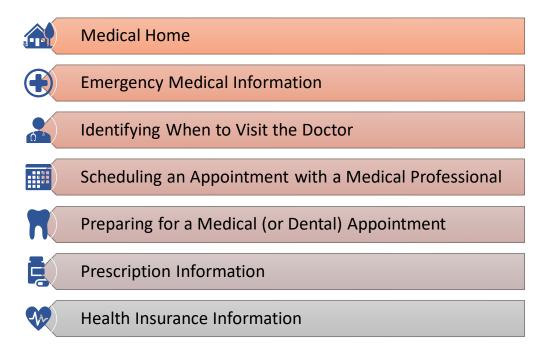
Lesson 1: Healthcare Checklist & Timeline (cont.)

Healthcare Checklist	Yes	No	Working on it
Medical Home:	1	,	
Can you identify your current healthcare providers?			
Can you identify which of those providers are pediatric healthcare providers and which are adult healthcare providers?			
Emergency Medical Information Card:			
Do you have an emergency medical information card?			
Do you know your medical information that is/would be listed on an emergency medical information card? (i.e. name, allergies, diagnosis, current medications, emergency contact)			
Identifying When to Visit the Doctor:			
Do you know how to identify severe symptoms from non-severe symptoms?			
Do you communicate your healthcare concerns directly to a medical professional?			
Do you know what to do when you get sick?			
Scheduling an Appointment with a Medical Professional:			
Do you schedule your own medical appointments?			
Do you keep track of your medical appointments?			
Do you follow-up on any referrals for tests, check-ups, or labs?			
Preparing for a Medical (or Dental) Appointment:			
Do you know how/why to keep healthcare notes before, during, and after a medical appointment?			
Can you describe your healthcare needs to a medical professional when at your appointment?			
Do you know what to bring to your appointment?			
Prescription Information:	T	ı	1
Can you read and understand the information on a prescription label?			
Do you call in your own prescription refills at the pharmacy?			
Do you know what medications you take?			
Do you manage your medication correctly? (i.e. take them as prescribed)			
Health Insurance Information:	1	ı	ı
Can you read and understand a health insurance card?			
Do you have a basic understanding of health insurance? (i.e. copay, deductible, etc.)			
Do I know what my health insurance covers?			

Lesson 1: Healthcare Checklist & Timeline (cont.)

How can I practice those healthcare skills I marked as 'no' on my healthcare checklist?

After completing the healthcare checklist, you likely noticed that there are many possible goals to work toward as part of transitioning to the adult-healthcare system. We have taken the healthcare checklist items and divided them into seven key categories.



The transition timeline on the following page will help you to organize and keep track of the above topics that you need to learn before making the transition to an adult care provider. This timeline will allow you to organize the topics you may need to learn and suggests that you set target dates you would like to have mastered each topic by. Setting a target date will allow you to create a specific plan, prepare for upcoming topics, and track progress as you go! *Note: refer to the glossary if you are unfamiliar with some of the healthcare topics and would like a definition.*

I am most interested in learning about...

1.	 	
2.	 	
3.		

Lesson 1: Healthcare Checklist & Timeline (cont.)

Medical Home	Emergency Medical Information Card	Identifying When to Visit the Doctor?
Target Date:	Target Date:	Target Date:
Schedule an Appointment with a Medical Professional	Preparing for a Medical (or Dental) Appointment	Prescription Information
Target Date:	Target Date:	Target Date:
Health Insurance		
Information Target Date:		
<u> </u>	!!!	
		— —

Who will support me with my healthcare needs?

Health care transition may seem like a big task, but you will have several people helping you along the way. Can you hink of anyone who can help you during your healthcare transition process? If so, answer below:							

Once you turn 18, you will legally be an adult, and may not be able to see your pediatric doctor anymore. That's why it's important to start looking for a doctor who will see adults. You may have heard about a Medical Home as a way that some healthcare teams work together. The title Medical Home can be a little confusing because we usually think

of a "home" as a place. A Medical Home is not a place. It is an approach that identifies where primary care is provided, who provides that care, and how they all work together. A medical home:

- ➡ Identifies where primary care is provided
- ➡ Identifies who provides that care
- ➡ Identifies how they all work together
- Patients experience enhanced access and communication
- Patients can expect care that is coordinated across care settings and disciplines
- A care team takes collective responsibility for the patient's ongoing care and healthcare needs.
- Patients have a relationship with a personal physician



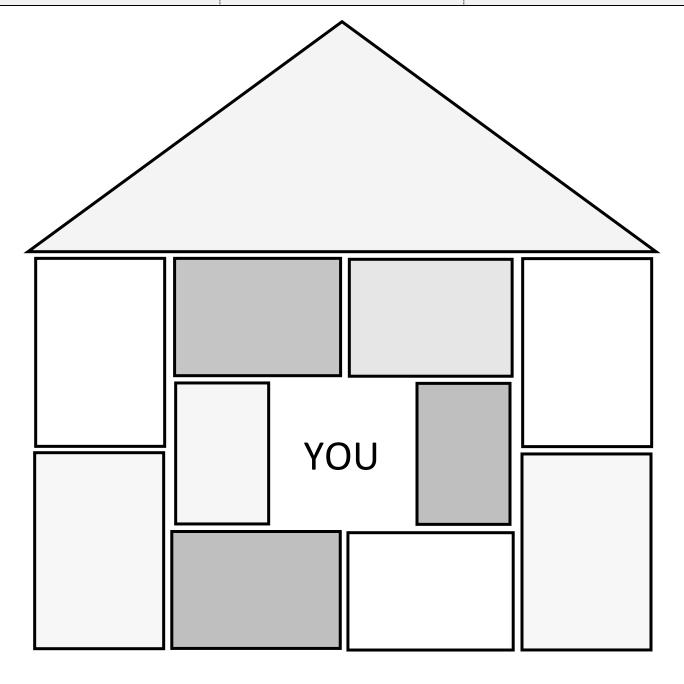
What is a medical home?

Lesson 2: Medical Home (cont.)

Who is part of my medical home?

Use the healthcare professionals below to complete your medical home:

Primary Care Provider	Psychiatrist	Physical Therapist
Nutritionist	Psychologist	Occupational Therapist
Dentist	Mental Health Counselor	Speech Therapist
Pharmacy	Specialty Care	Eye Doctor
ENT	Gynecologist	Other (identify)



Lesson 3: Emergency Medical Information

Why do I need an emergency medical information card?

An emergency medical information card contains your personal medical information. You can give this card to medical professionals who are trying to help you, or medical responders may refer to this card if you are unable to provide information in the moment. Listen to the following story on how John's medical information card saved his life:

John was in a motorcycle accident and passed out due to a head injury. Because John was passed out, he was unable to provide the necessary medical information to the first responders. Because the first responders did not have access to any of John's medical information, they were unaware he was allergic to latex and an antibiotic. The first responders unfortunately used latex gloves, which caused John to break out into a terrible rash. Fortunately, they did not use the antibiotic John was allergic to. After healing from his accident, John decided to create and carry a medical information card in case of another emergency.

How would an emergency me	dical in	formation card	have he	lped Jo	hn?
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An emergency medical information card contains the following information:



Name, age, gender, pronouns



Physical address



Medication names, dosages, and schedules; medical equipment



Medical conditions



Asepcts of your health hisotry that could be helpful for emergency respnders, such as allergies



Phone numbers for professional emergency contacts, such as your doctor



Phone numbers for a personal emergency contact, such as a friend or a family member who you have asked to serve in this role

Lesson 3: Emergency Medical Information (cont.)

What information should I list on my emergency medical information card?

Emerge	ency Medical Information
Name:	DOB:
Conditions:	
Medications:	
Allergies:	
Blood Type:	Organ Donor: Y N Pregnant Y N
Personal Information:	
Address:	
Phone Number:	
Emergency Contacts:	
Name:	Phone:
Name:	Phone:
Doctor:	Phone:
Other Information:	

Lesson 4: Identifying When to Visit the Doctor

How do I know when I should visit the doctor?

Should I see a doctor? Many people ask this question. Despite what you may tell yourself, major symptoms and incidents aren't the only reasons to go see the doctor. While some symptoms require you to visit a medical professional, others are not serious enough to visit a medical professional. Sometimes identifying which symptoms require a professional opinion can be difficult.

Below are 10 signs it's time to go see the doctor. Keep in mind that this list is by no means exhaustive; above all, go with your gut—if instinct tells you something is wrong, it's a good idea to seek medical attention.



Below are some symptoms that I have experienced in the past that did <u>not</u> require medical attention...

Lesson 4: Identifying When to Visit the Doctor (cont.)

Which definitions go with the correct signs?

Directions: Use the definitions on the following page to match with theirs signs.

Signs	Definitions
You have a persistent, high fever	
Your cold becomes unusually bad	
You've lost weight suddenly and without explanation	
You're short of breath	
You experience severe chest, abdominal, or pelvic pain	
Your bowl movement or urination has changed	
Bright flashes interrupt your vision	
You experience confusion or changes in mood	
You develop unexpected symptoms after a procedure or starting a new medication	
You are due for your annual check-up	

Lesson 4: Identifying When to Visit the Doctor (cont.)

Definitions (in a randomized order):

Changes in mood and sudden confusion can occur with mental health issues as well as physical conditions, such as an infection or drug interaction. Watch out for: trouble focusing, irregular sleeping patterns, and feelings of anxiety or depression.

Anytime you undergo a medical procedure or surgery, get an immunization, or start a new medication, ask your doctor in advance about the known symptoms. Monitor for these and if anything out of the ordinary occurs, call the doctor's office to see if an appointment is advised.

An unexplained drop in weight could indicate overactive thyroid, diabetes, depression or liver disease, among other things.

A fever is one way your body naturally fights infection. However, if you have a fever above 103° Fahrenheit (39.4° Celsius) or a fever that lasts more than three days, you should call your doctor.

It's not always easy to know when to go to the doctor for a cold. Watch for the following: a severe cough, a fever, muscle aches or other flu-like symptoms, extremely difficult swallowing, chest pain, shortness of breath, or if you can't keep anything down.

High altitude, strenuous exercise, obesity and extreme temperature are all normal causes of shortness of breath. If none of these are causing your breathlessness, ask your doctor about the possibility of asthma, bronchitis or another condition.

If you suffer from migraines, you may sometimes experience bright flashes or spots in your vision. Outside of these cases, you should visit the doctor if you experience sudden bright flashes.

Abnormal, intense and sustained pain in the chest, abdomen or pelvis can indicate an underlying issue that demands a doctor's attention.

Once a year you should visit your primary physician for an annual physical check-up.

Keep in mind that bowel movement and urination can vary from person to person, so the most important thing to look for is a sudden change in your own pattern, whether that's bloody or black stools, diarrhea or constipation, or excessive urination.

Lesson 5: Scheduling an Appointment with a Medical Professional

How do you schedule an appointment with a medical professional?

Scheduling an appointment may be a difficult and/or an anxiety provoking task for some. So, it is important to prepare yourself before contacting a doctor's office. Some ways to better prepare yourself include:

Be Prepared. If you have never done this before, have someone help you. You might even want to practice with a trusted adult.

Give your name and birth date.

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

Get an appointment that works for you. Let the office know if another doctor told you to call, or if it is urgent.

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?

Have our insurance information available. The front office will most likely ask you about insurance.

Let the front office know if you will need extra time to talk during the visit.

Confirm appointments at least one day ahead of time

Explain if you have special needs or limits (such as needing wheelchair access)

Ask about special instructions (such as fasting) or if there's anything you need to bring (like an X-ray)

Remember, it is always helpful to practice with a friend or trusted adult before you attempt to schedule an appointment for the first time. The more your practice, the more comfortable you will feel! Refer to the script on the following page for guidance.

Who can I practice	making a medical	appointment with?	

Lesson 5: Scheduling an Appointment with a Medical Professional (cont.)

I should have the following items ready before calling:

- 1. Physician/Clinic phone number.
- 2. Name of Physician you want to see.
- 3. Health insurance card, if you have one.
- 4. Pen and paper so you can take notes.
- 5. Calendar, so you know your schedule

Find out if you need to bring anything to the visit.

- ✓ Medical records
- ✓ Current medications
- ✓ Insurance card
- ✓ Identification card



Call the doctor office. Say, "Hello, my name is _____ and I need to schedule a doctor's appointment.

The doctor's office will respond. Saying, "Hi, _____, can you provide me with your date of birth and the reason for scheduling a visit with us?





You will then respond. Saying, "Sure! My date of birth is _____ and my reason for a visit is because _____.

The doctor's office will respond. Saying, "Thank you, _____. The earliest appointment we have available is for _____. Does that work for you?





You will then respond with if you are or are not available. Saying, "Yes, that appointment will work with my schedule. Thank you.

or

"No, I am unavailable on _____. Do you have any availability for _____?

The doctor's office with respond. Saying, "Great, we will see you on _____.



"Yes, we have an availability on _____ at ____ o'clock.



You will then respond. Saying, "Thank you and see you then! Goodbye"

Lesson 6: Preparing for a Medical (or Dental) Appointment

How can I prepare for my medical appointment?

It will be important for you to think about the reason why you are going to the doctor so that you can accurately share with the doctor your concerns. You should think how you have been feeling lately and any special concerns.

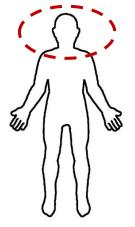
If you are not sure how to describe your symptoms out loud, you can point to the ache. You can also write down your symptoms so that you can share each with your healthcare provider and not worry about forgetting anything. You may also have questions you wish to ask your doctor. Make sure you think about these questions and come prepared to your appointment to ask them.

You may also choose to write down information and future instructions at your medical appointment so that you can remember any needed and/or important information. If you need help doing this, you can ask the provider or the person attending the appointment with you for help.

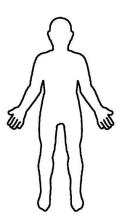
Remember, your doctor needs to know your true feelings and concerns in order to help you. It is okay to ask for information to be repeated or explained again if you do not understand it the first time.

Describe a recent medical concern using the visual below.

Example: headache



Concern: _____



Describe a recent medical concern you had below.

You may choose to use the sample care plan on the following pages to write down your concerns before visiting the doctor so that you can be sure not to forget what all you intend to share with the medical professional.

Lesson 6: Preparing for a Medical (or Dental) Appointment

My Medical Concerns:	
\bigcirc	
Circle the area (s) of concern	

Lesson 6: Preparing for a Medical (or Dental) Appointment (cont.)

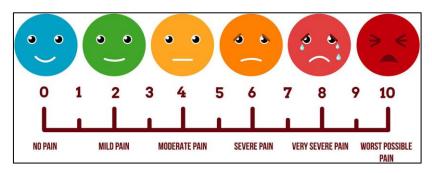
My Sample Care Plan

Section 1: Background Information

Name:		
Date of Birth:	Phone:	
Address:		
Emergency Contact:		
How I Communicate Best:		
Vrite the names of your doctors, the endors):	rapists, other health providers (includ	ling pharmacy, equipment, and supply
Name	Specialty	Phone Number
	medical decisions and/or follow up?)	
Name:		
Name: Relationship:	Phone:	
Name: Relationship: Power of Attorney for Healthcare (a	Phone:	
Name: Relationship:	Phone:	
Name: Relationship: Power of Attorney for Healthcare (a) If yes, who:	Phone:	
Name: Relationship: Power of Attorney for Healthcare (a) If yes, who:	Phone:	
Name: Relationship: Power of Attorney for Healthcare (a) If yes, who: Phone: ection 2: Concerns to Share with Me	Phone:	
Name: Relationship: Power of Attorney for Healthcare (a) If yes, who: Phone:	Phone:	
Name: Relationship: Power of Attorney for Healthcare (a) If yes, who: Phone: ection 2: Concerns to Share with Me	Phone:	
Name: Relationship: Power of Attorney for Healthcare (a) If yes, who: Phone: ection 2: Concerns to Share with Me	Phone:	
Name: Relationship: Power of Attorney for Healthcare (a) If yes, who: Phone: ection 2: Concerns to Share with Me	Phone:	
Name: Relationship: Power of Attorney for Healthcare (a) If yes, who: Phone: ection 2: Concerns to Share with Me	Phone:	

Lesson 6: Preparing for a Medical (or Dental) Appointment (cont.)

This is how I feel (circle one):



Medications:

Name	Dosage	When Taken

My Medical History:

Important information you should know about my medical history:
Allergies:
Past surgeries & hospitalizations:

Follow-up Information:

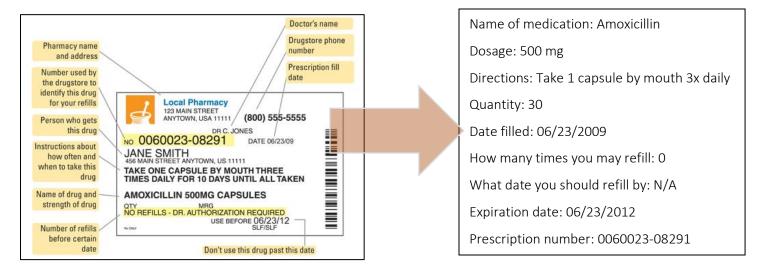
Upcoming to-dos:	
Questions I have:	
Questions I have:	
Questions I have:	

Lesson 7: Prescription Information

What does the information on my prescription labels mean?

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 Medicaid and/or insurance card with you. There may be a co-pay charge so you will want to have some money too.

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. To order a refill on a medication, you will use the information on the medication label.



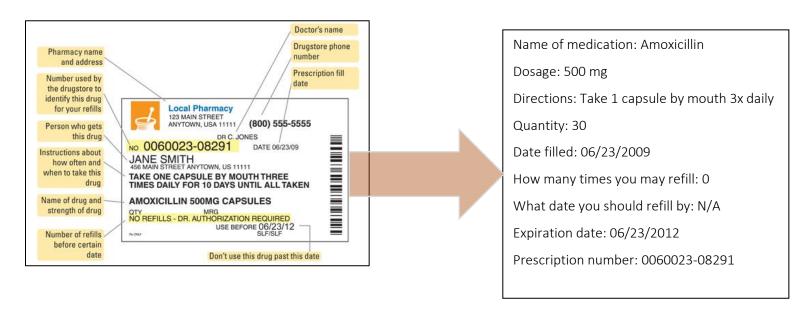
How do I order a prescription refill?

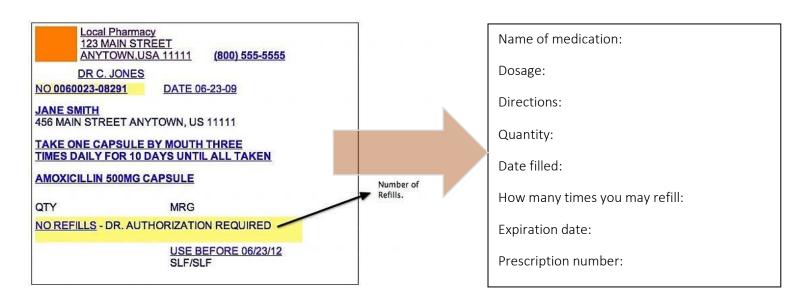
When you call the pharmacy, a person may answer and take all the information. Sometimes you may get an answering machine telling you how to give the information the pharmacy needs to refill your prescription. Follow the script on the following pages to practice ordering a prescription refill with a friend or a trusted adult.

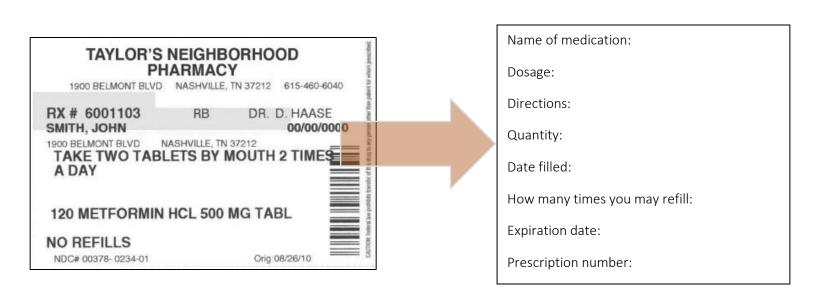
Patient:	Hello, my name is prescription.	(give your first and last name)	_ and I need a refill on my
Pharmacist:	Hi number?	What is your	date of birth and prescription

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.

Lesson 7: Prescription Information (cont.)







Lesson 7: Prescription Information (cont.)

Script: Ordering Prescription Medication from the Pharmacy

Patient:	Hello, my name is and I need a refill on my prescription. (give your first and last name)
Pharmacist:	Hi What is your date of birth and prescription number?
Patient:	My birth date is and my prescription number is (give your birth date) (give your prescription number)
Pharmacist:	Thank you very much. We will fill your prescription shortly. Please be sure to bring in your insurance card and a valid ID when you come to pick-up this prescription.
Patient:	Thank you, when will this prescription be available for pick-up? Is there a cost?
Pharmacist:	It will be available by today. It looks like it will be a \$5.00 charge.
Patient:	Great! Thank you for your assistance.
Pharmacist:	You are welcome. Have a nice day!
Patient:	Thank you, you too!

What does the information on my health insurance card mean?

When you attend a medical appointment for the first time, the receptionist will ask for your health insurance card. Your medical insurance will help cover some of the costs. Most receptionists will look at your card and fill out the necessary information. Occasionally, if you are calling over the phone to schedule an appointment, or if your insurance changes, you may need to provide the information to them. So, it is important for you to know some key information on your card.

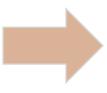
The most important pieces of information you need to provide is:

- ⇒ ID number
- **⇔** Group number

The insurance card will also contain other information like:

- ⇒ Primary card holder's name
- ➡ Health insurance provider's name
- ⇒ Expiration date
- Types of services covered





Insurance company: Blue Cross Blue

Shield

ID number: YBC999999999

Group number: 27255000

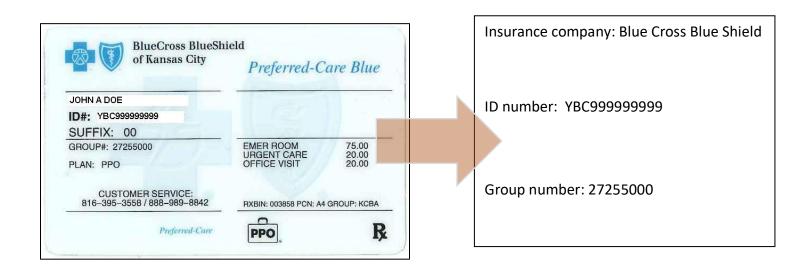
What do all these health insurance terms mean?

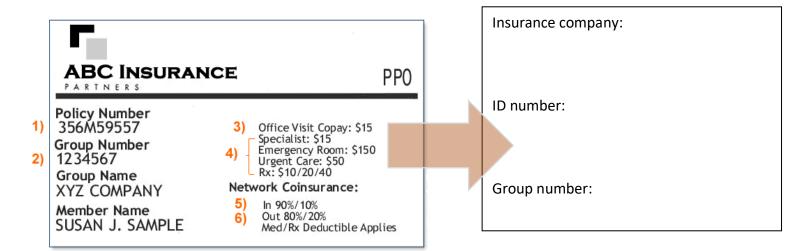
Health insurance information can get confusing. So, it will be important that your practice reviewing some key terms that are most often used when describing health insurance. Those include:

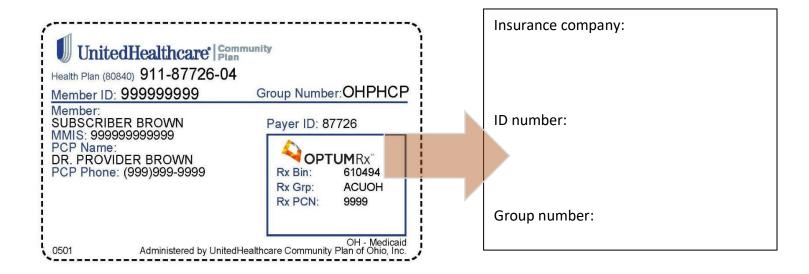
- ➡ Premium
- Co-insurance
- ⇒ Insurer & Insured
- Co-pay
- Out-of-pocket money
- **⇒** Benefits
- ⇒ Deductible

Terms	Definitions
	Services received for paying monthly premium
	The company you have insurance through that is assuming the risk.

Lesson 8: Health Insurance Information (cont.)







Lesson 8: Health Insurance Information (cont.)

Use the health insurance terms below to match with their correct definitions:



Premium	Co-pay	Benefits
Coinsurance	Insured	Deductible
Insurer	Out-of-pocket money	

Terms	Definitions
	Services received for paying monthly premium
	The company you have insurance through that is assuming the risk.
	The amount of money you pay at the time of service
	Dues or monthly payment you make for health insurance.
	Total amount you spend for healthcare, after which the insurance company pays for your medical care for the year
	You, the person covered by the policy
	How much you pay, in total for certain services before the insurance starts to pay
	The part of the medical bill you pay for services after the deductive is met

Glossary

C-

Co-pay charge: A copay is a fixed out-of-pocket amount paid by an insured for covered services.

E-

Emergency medical information card: Communicates to rescuers what they need to know about you if they find you unconscious or confused, or, if they need to quickly help evacuate you.

H-

Healthcare: Prevention and treatment of diseases through medical professional services

Healthcare transition: Switching from a pediatric care provider to an adult care provider.

Health Insurance: A contract that requires your health insurer to pay some or all of your health care costs in exchange for a premium

|-

Insurance card: Different insurance companies have different formats for their insurance cards, but all cards will contain the same basic information: The insurance company name. Your name, or the name of the head of your family if coverage is part of a family plan. Your group number.

M-

Medicaid: A federal and state program that helps with medical costs for some people with limited income and resources.

Medical Home: An approach to providing comprehensive and high-quality primary care

P-

Pediatric doctor: Doctors who manage the health of a child, including physical, behavior, and mental health issues.

Prescription: A written direction for medication

Glossary

S-

Side effects: A secondary, typically undesirable effect of a drug or medical treatment.

Symptoms: A symptom of an illness is something wrong with your body or mind that is a sign of the illness

T-

Transition timeline: A plan that shows how long something will take or when things will happen.

ASD TRANSITION:

Pediatric to Adult Healthcare for Young Adults with ASD





http://psychiatry.emory.edu/programs/autism/