

# ASD TRANSITION:

Pediatric to Adult Healthcare for Young Adults with ASD

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*Parent Workbook*



EMORY  
UNIVERSITY

Emory Autism Center

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## Welcome to the Transition to Adult Healthcare Workbook for Families!

This workbook aids families in supporting the health care transition of youth with autism spectrum disorder (ASD) 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, educators, the youth, health care providers, other health care assistants, social service workers, and family members like you.

Despite the increasing demand in vocational and academic transition services and education for youth with disabilities, current programs are few and lack cohesive structure and effectiveness. Out of these transition programs, health care transition is a crucial subject that is yet to be covered. Other barriers include lack of providers with sufficient knowledge and time to work with special needs populations, and a lack of guidance for parents on how to transition their youth from pediatric to adult health services. 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 six sections:

- ➡ ASD Information
- ➡ Healthcare Transition Information
- ➡ Legal Information
- ➡ Health Insurance Information
- ➡ Lesson and Activity templates
- ➡ Glossary

## What is Autism Spectrum Disorder (ASD)?

ASD and autism are general terms to describe a complex neurodevelopmental disorder. This diagnosis is generally characterized (in varying degrees) by difficulties in **social interaction** and communication, **repetitive behaviors**, and **restricted interests**.

Prior to 2013 when the most recent version of the Diagnostic and Statistical Manual of the American Psychiatric Association, the DSM-5, was published, there were 5 diagnoses that were considered part of the family of autism. These included autistic disorder, Asperger's disorder, Pervasive Developmental Disorder-not otherwise specified (PDD-NOS), Rett syndrome, and Childhood Disintegrative Disorder. Currently the diagnostic classification system has been simplified and all diagnoses fall under **Autism Spectrum Disorder (ASD)** and are categorized based on the varying levels of support that the individual needs.

In addition to core impairments in interacting and communicating with others and having unusual interests and behaviors, people with ASD may also have intellectual disability, and motor coordination conditions including seizures, sleep disturbances, and gastrointestinal difficulties.

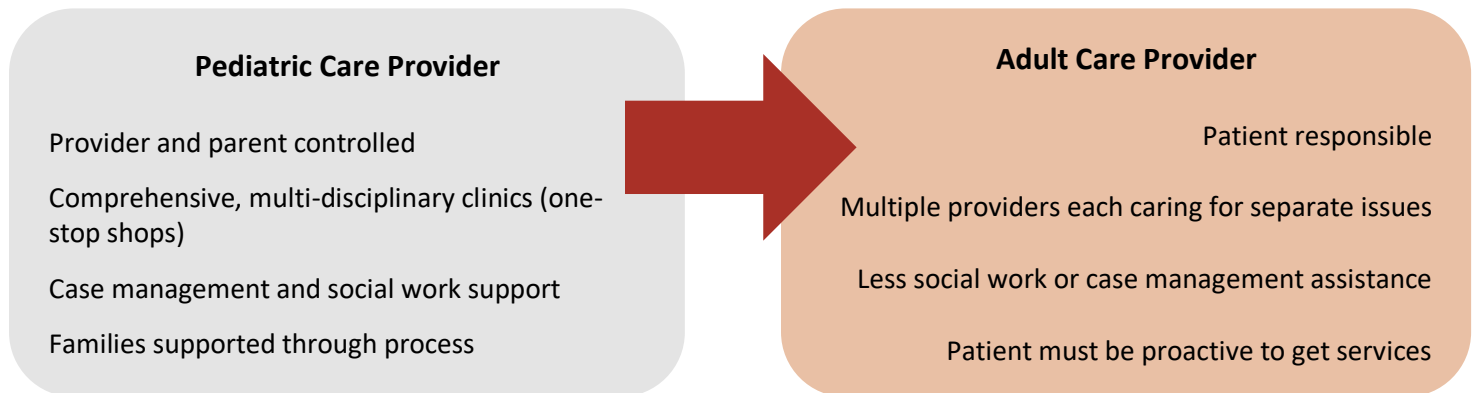
Many individuals with ASD have accompanying psychiatric symptoms that are not associated with autism. About 70% of individuals with ASD may have one **comorbid mental disorder** and 40% may have two or more. ADHD, anxiety and depression are some common comorbid disorders.

The term "**spectrum**" refers to the wide range of symptoms, skills, and levels of impairment or disability that individuals with ASD experience. Some individuals may be able to participate in typical **activities of daily living** with few supports and others may need significant support for most activities. All individuals with ASD have unique needs, but some are more mildly impaired by their symptoms while others are significantly disabled.

# Introduction to Healthcare Transition

## What is healthcare transition?

Healthcare transition is the process of changing from a pediatric healthcare provider to an adult healthcare provider. The goal of transition is to optimize health and assist you in reaching your full potential. To achieve this goal requires an organized transition process to support youth in acquiring independent health care skills, preparing for an adult model of care, and transferring to new providers without disruption in care.



## Six Core Element of Healthcare Transition

- ➔ Transition Policy: develop transition policy/statement that describes the practice's approach to transition and educate staff about this approach; post policy and discuss with families
- ➔ Transition Tracking and Monitoring: establish criteria and process for identifying transition-age youth and enter their data into a registry and track progress
- ➔ Transition Readiness: conduct regular transition readiness assessments to identify needs and goals; jointly develop and prioritize goals and document regularly
- ➔ Transition Planning: develop and regularly update plan of care; prepare for changes once adult turns 18 (legal changes, policy and consent, self-advocacy, etc.); determine level of need for decision making; plan for timing of transfer; obtain consent for release of information for guardians; assist with finding adult provider and clarify responsibilities of pediatric vs adult provider until transfer
- ➔ Transfer of Care: confirm date of first adult provider appointment and make sure transfer happens when youth is medically stable; complete transfer package and send package along with letter to the adult practitioner
- ➔ Transfer Completion: contact young adult/caregiver 3-6 months after last pediatric appointment to confirm transfer of responsibilities; communicate with adult practice confirming completion of transfer; build ongoing and collaborative partnerships between adult and specialty practices



## How does ASD Affect Healthcare Transition?

- ➡ Spectrum: Because autism exists on a spectrum, each patient's healthcare transition plan will be fairly unique. There's no "one size fits all" transition plan that can be used for everyone that has autism. Each plan will be individualized to address each person's specific needs.
- ➡ Structure: Transition will be much more successful if there is a degree of structure to the process. It will be helpful if there is a set schedule for regular doctor's visits to discuss transition (when they happen, where they happen, how the appointment flows, who is there, etc.) and this structure/schedule can eventually be transferred to an adult practitioner.
- ➡ Unexpected Changes: Individuals on the spectrum with ASD crave structure and predictability; anticipation of change and coping with changes are often challenging for adolescents with ASD; this is something to keep in mind as transition inherently requires change. Any expected or anticipated changes should be explained to the client clearly, as far in advance as possible, and repeatedly in order to raise his/her level of comfort.
- ➡ Developmental Disability: The individual will have to deal with issues related to his/her specific symptoms throughout his/her whole life and adjust accordingly. Individuals with ASD will often experience social and emotional developmental milestones later than their same-age peers. For example, many individuals with ASD may benefit from transitioning to adult healthcare after the age of 18 and may need targeted practice in understanding disclosure and self-advocacy.
- ➡ Executive Functioning: People with autism tend to have lower executive functioning skills. This will make the logistics of healthcare (making appointments, showing up on time, filling prescriptions, calling the office, filling out medical forms) much more difficult. Often visual supports, assistive technology, and structured plans to provide and subsequently face supports will be helpful to adolescents with ASD.
- ➡ Communication: Most individuals with autism struggle with everyday communication skills to varying degrees. It will be important to understand not only how the student communicates with others (verbal? Non-verbal? Somewhere in between?) but also how the student will best understand any receptive communication.
- ➡ Social Skills: Difficulties with social skills have the potential to make appointments feel odd or awkward for the nurses, doctors and other healthcare staff. It's important to understand what limitations the student has in social skills in order to have a successful interaction. (For example, just because a student is not making eye contact doesn't mean that he or she isn't listening).
- ➡ Restricted Interests: People with autism tend to have extensive knowledge about particular topics that are of interest to them. Knowing an individual's interests could go a long way in building rapport and engaging the individual with autism. Depending on the interest, it could be used to help teach him or her about healthcare needs.
- ➡ Sensory Issues: People with ASD may have various issues related to specific senses (for example, certain lights/sounds may be abrasive to someone with autism). Therefore, it may be difficult for someone with ASD to adjust to the new sights, sounds, smells, etc. of a new doctor's office. This may also affect the ease with which patients interact with various medical staff.

## How can I Prepare my ASD Youth for their Healthcare Transition?

Generally, it is best to start planning for transition early. Educators and the student's family should help in the transition process, which may take months or even years to complete. Look at the sample transition timeline below. It spans one year, beginning from August to May. The end goal is to select an adult provider and to make appointments with them, rather than the pediatrician. This timeline is suited for an older teen who is around 17 or 18. If you are planning your transition timeline at an earlier age, you can set your goals using years, rather than months.

<b>August:</b>
Address what transition is with students and parents Make initial assessments on student's transition readiness and medical knowledge (transition checklist)
<b>September:</b>
Complete 2-3 healthcare transition lessons
<b>October:</b>
Complete 2-3 healthcare transition lessons
<b>November:</b>
Complete 2-3 healthcare transition lessons
<b>December:</b>
Complete 2-3 healthcare transition lessons
<b>January:</b>
Parents start networking to identify potential adult providers Parents explore options for healthcare coverage Parents explore option of legal guardianship
<b>February:</b>
Select adult provider Transfer all related healthcare information to adult provider Work together with pediatrician and adult provider to ensure complete and total transfer package Make first appointment with adult provider
<b>March:</b>
Tour adult practitioner's office ahead of time (before any official appointments) Potentially meet nurses and/or doctors Prepare own questions for doctor appointment
<b>April:</b>
Attend first appointment with adult provider Make follow-up appointments if necessary
<b>May:</b>
Follow-up with prescription refills or other necessary information/appointments

## Communication Tips for your Family

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. Open communication is essential to this process and involves all three individuals:



Youth



Parent (as needed)



Healthcare Provider

## What questions should my healthcare team be asking ourselves?

- ➔ 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?

## What questions should my child be asking themselves?

- ➔ 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?

## What questions should my healthcare provider(s) be asking themselves?

- ➔ 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?

## What questions should I be asking myself?

- ➔ Do I actively encourage the health care provider to do the same?
- ➔ Do I actively encourage my son or daughter to participate as fully as 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?
- ➔ Do I facilitate confidential communication between my son or daughter and his or her health care provider to the greatest extent possible?



Typically, turning 18 is the defining point between being a youth and being an adult, but being prepared for the increased responsibilities doesn't happen overnight. These young adults need parents, friends, or other individuals they trust to help them think through important decisions.

## What happens when my child turns 18?

In Georgia, 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 the rights and responsibilities that are part of being a legal adult go into effect. Some of these rights include the ability to:

- ➡ Vote
- ➡ Get married without parental consent
- ➡ Make a will (you can legally make a will at the age of 14 in Georgia)
- ➡ Make a contract (e.g., renting an apartment, purchasing a car, taking out a loan, etc.)
- ➡ Give or refuse consent for medical treatment
- ➡ Make independent decisions free from parental control
- ➡ Apply for credit (including credit cards)

## What are my child's legal responsibilities at the age of 18?

At the age of 18, individuals also have certain **legal responsibilities**, such as:

- ➡ Self-support: Parents are not required to support their adult children unless the youth is enrolled into secondary school. That age of support ends at 20 years old.
- ➡ Serving on Jury Duty if called to do so
- ➡ Being liable for all contracts entered into (e.g., loan payments, credit card payments, etc.)
- ➡ Every male citizen and immigrant residing in the United States must register with the selective service 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 joining the military, as 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 immigrant living in the United States in case there would be a need for a military draft in the future.

## Should I be my child's guardian after the age of 18?

Parents need to understand that they do not continue to be the legal decision-maker for their young adult unless they have legal authority, such as a type of **guardianship**. 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. The issue of guardianship, **conservatorship**, and **independence** is important in making decisions, including healthcare decisions. Each family should consider the following items when deciding the best option for their young adult:

Guardianship	Conservatorship
For legally incompetent individuals	Not considered legally incompetent
A "guardian" is assigned by the courts to make all decisions for individual	A "conservator" is assigned by the courts to share or make limited decisions for individual
The individual under guardianship is called the "ward"	The individual under conservatorship is called the "conservatee"

**Note:** Sometimes, full guardianship may not be needed. A limited guardianship can be established so that the individual who has a guardian can keep some of their decision-making rights. For example, your young adult may need help with legal and financial decisions, but they may be capable of making medical decisions. In this situation, your young adult may be able to have a guardian for some decisions, but still keep the right to make other decisions.

## Which insurance plan is appropriate for my child?

Health insurance is a critical component of healthcare, but also one of the most confusing aspects to navigate. The different types of plans offered, eligibility, coverage, and jargon are especially daunting when trying to decide which healthcare plan is the most appropriate.

- ➔ Coverage and Insurance: Healthcare coverage and insurance mean the same thing. There are private and public options. **Private healthcare plans** are usually supplied by an employer or can be purchased through the marketplace. These include large companies such as Aetna, Blue Cross Blue Shield, and Kaiser. **Public health insurance** is funded through the government and includes programs like Medicaid and Medicare.
- ➔ Medicaid: **Medicaid** is a federal insurance program for low-income families and individuals. Medicaid coverage and laws vary by state, but the federal law mandates that all people under the age of 21 who have Medicaid are entitled to Early Periodic Screening, Diagnosis, and Treatment (EPSDT) of ASD. States also must cover all medically necessary autism-related interventions that count as “medical assistance.”
- ➔ Georgia Law: Under the state of Georgia, anyone who receives **Supplemental Security Income (SSI)** from Social Security is automatically eligible for Medicaid. Some allow **indefinite** continued coverage if the disability occurred before age 18, and the parent continues to provide 50% or more of the adult child’s care. Some SSI payments are made based on the adult child no longer being claimed as a dependent. Furthermore, there are some programs that may help youths with ASD or other disabilities.
- ➔ The Katie Beckett program: States that at age 18, individuals may be eligible for SSI even if they had not been previously due to parent income. The **COBRA coverage** also states young adults can continue COBRA coverage up to 36 months after leaving the parent’s family insurance plan due to losing their status as a dependent, but the individual is responsible for paying individual premiums. If health and dental plans are offered separately, each plan should be considered separately.
- ➔ Social Security Disability Insurance: The **Social Security Administration** has two kinds of benefits for people with disabilities over the age of 18: Supplemental Security Income (SSI) and **Social Security Disability Insurance/Disabled Adult Child Benefits (SSDI)**. Be aware that even if a family is receiving SSI for a child under the age of 18, they will need to go through a re-determination process to maintain SSI benefits as an adult. To apply for SSI disability benefits, please visit: <http://www.ssa.gov/disabilityssi>
- ➔ Affordable Care Act: Under the **Affordable Care Act**, all insurance plans must cover essential health benefits which include mental health benefits, rehabilitative and habilitative services (like occupational therapy or speech therapy), and prescription medications. Furthermore, plans cannot deny coverage on the basis of disability. In addition, young adults may remain on their parents’ insurance up until the age of 26.

## What private healthcare options are available?

If you want private health insurance, there are many choices available on the marketplace or from an insurance broker, several of which will be offered through employment.

- ➔ Large National Brands: Some commonly seen insurance brands include: Aetna, Blue Cross Blue Shield, Cigna, Humana, Kaiser, and United. Your workplace will mostly likely offer some sort of plan through these companies.
- ➔ Types of Plans: There are four common types of plans: Health Maintenance Organizations (HMOs), Preferred Provider Organizations (PPOs), Exclusive Provider Organizations (EPOs), Point-of-Service plans (POS), and high-deductible health plans (HDHPs), which may be linked to health savings accounts (HSAs). There are benefits and limitations to each plan, and you should carefully go over all your options to determine the best fit for you. An **HMO** is the cheapest plan but offers the least freedom to your health care providers. A **PPO** includes more freedom and choice regarding providers, but also will be more expensive. A **POS** is a blend of HMO and PPO plans. A **catastrophic plan** is for relatively young adults under 30 that may have lower premiums. An **HDHP** includes fewer monthly payments in exchange for high deductibles. Generally, plans with lower monthly premiums have higher deductibles and copayments, while plans with higher monthly premiums usually have lower deductibles and copayments. On the following page, you will find a chart to compare the characteristics of each plan.
- ➔ Payments and Expenses: All marketplace plans have premiums, deductibles, copays, coinsurance, and out of pocket costs that apply to most covered services. A **premium** is the amount of money you have to pay for insurance, usually paid in monthly or quarterly installments. A **deductible** is the amount you pay for covered health care services before your insurance starts to pay. A **copayment** is a fixed amount you pay for a covered health care service after you've paid your deductible. Like copays, coinsurance is another form of cost sharing between you and your insurance company. **Coinsurance** is a percentage of the cost for a health service or prescription paid by you after you have met the deductible. For example, an 80/20 coinsurance means the insurance company will pay for 80% of medical costs while you pay 20%, after meeting the deductible. Under this plan, if a person has met his deductible and needs to pay a \$100 medical bill, his insurance will pay \$80 while he pays \$20. **Out of pocket costs** are expenses for medical care that aren't reimbursed by insurance. Out of pocket costs include deductibles, coinsurance, and copayments for covered services plus all costs for services that aren't covered].

On the following page you will find a breakdown and comparison between the types of healthcare plans, coverage they offer, and expenses.

## Comparison Chart of Different Health Insurance Plans

Plans	Freedom of choice	Paperwork	Referral to specialist	Doctors you see	What you pay
HMO	Least amount	Least amount; no claim forms	Yes	HMO network No coverage for out of network providers (pay full bill yourself, except for emergency hospital visit)	Premium Deductible Copays/coinsurance (varies according to plan, counted toward deductible)
PPO	Moderate amount	In-network: little to none out of network: pay providers, then file claim to get money back from PPO	No	PPO network, some coverage for out of network providers; pay more to see out of network doctors	Premium Deductible Copay/coinsurance Other costs (if out of network doctor charges more than others in area, you may have to pay balance after insurance pays its share)
EPO	Moderate amount	Little to none	No	EPO network, no coverage for out of network providers (pay full bill yourself, except for emergencies)	Premium (lower than PPO) Deductible Copay/coinsurance Other costs (full bill for out of network doctor)
POS	More amount	Moderate amount for out of network providers- file claim to get money back from POS	Yes	In-network providers, some coverage for out of network providers; pay more to see out of network providers	Premium Deductible Copay/coinsurance (higher for out of network doctor)
Catastrophic Plan	For people under 30	Keep track of expenses before you meet deductible	Yes	In-network; individual plans may have additional rules on specialists	Premium (lower) Deductible (\$7,150 for individual, \$14,300 for a family)
HDHP/HSA	Depends on plan (HMO, PPO, EPO, or POS)	Depends on plan; keep all your receipts to withdraw money from HSA/know you've met the deductible	Depends on plan	Depends on plan	Premium (lower) Deductible (\$1,300-\$6,550 for individuals; \$2600-\$13,100 for families) Copays or coinsurance Out of pocket (higher)

# Lesson Introduction

Parents can choose to complete the following lessons and activities along with their child, who will be using the *Student Workbook*. Completing each lesson and activity with your child may serve as a motivator for your child and increase their engagement.

If the parent or the child needs extra support, you may choose to refer to the *Instructor Workbook*, rather than the *Parent Workbook*, for more organized lesson plans. Those lesson plans will include the same lessons and activities, as well as guiding questions to ask your child, objectives to reach, suggestions on how to modify each activity, and required materials.

Our healthcare transition lessons focus on the following:

- ➔ Educational Material
- ➔ Activities

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 ★. 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

## How can I support my child during their healthcare transition?

Question	Yes	Not Yet	First Steps
Do I know how my teen learns best?			
Can my teen describe his/her special health care needs?			
Do we discuss and demonstrate healthy lifestyle habits as a family?			
Can my teen name his/her doctor?			
Can my teen communicate that he/she is feeling ill?			
Can my teen describe symptoms when feeling ill?			
Do we use a family calendar for tracking appointments, activities, etc.?			
Is my teen involved when I schedule appointments?			
Can my teen schedule appointments on his/her own?			
Do I encourage my teen to give information and answer questions at appointments?			
Have I discussed transitioning to adult care providers with my teen's present providers?			
Do I involve my teen in registering or checking in for appointments (showing insurance/Medicaid card, etc.)?			
Do I involve my teen in filling and refilling prescriptions?			
Is my teen involved in maintaining/ordering monthly supplies, equipment or scheduling home care?			
Do I know what insurance or health care coverage will be available to my teen when he/she turns 18?			
If my teen is on my insurance, do I know how long that can continue?			
Have we talked about and made plans for guardianship (none, full, limited)?			
Have we discussed and planned for Power of Attorney for Health Care?			
Do I use formal and/or informal advocacy or supports and is my teen aware of this?			

# Lesson 1: Healthcare Checklist & Timeline

## What healthcare transition skills does my child need to work on?

Does your child know their health care needs? Some individuals have more than others, but everyone has health care needs. Some individuals 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. Support your child in talking through each point. Then, prompt your child to place a checkmark in the column they think best fits them.

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 your child can answer the rest by themselves!

★ You may choose to guide your child through each item on the checklist, discussing each. Or, you may choose to allow your child to take x amount of time for them to complete the checklist independently. Review the completed checklist with your child upon completion.










# Lesson 1: Healthcare Checklist & Timeline (cont.)

Healthcare Checklist	Yes	No	Working on it
<b>Medical Home:</b>			
Can you identify your current healthcare providers?			
Can you identify which of those providers are pediatric healthcare providers and which are adult healthcare providers?			
<b>Emergency Medical Information Card:</b>			
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)			
<b>Identifying When to Visit the Doctor:</b>			
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?			
<b>Scheduling an Appointment with a Medical Professional:</b>			
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?			
<b>Preparing for a Medical (or Dental) Appointment:</b>			
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?			
<b>Prescription Information:</b>			
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)			
<b>Health Insurance Information:</b>			
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?			

## How can my child practice the healthcare skills they marked as 'no' on their healthcare checklist?

After completing the healthcare checklist, your child 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. Your child may find some categories easy and other categories more difficult.

-  Medical Home
-  Emergency Medical Information
-  Identifying When to Visit the Doctor
-  Scheduling an Appointment with a Medical Professional
-  Preparing for a Medical (or Dental) Appointment
-  Prescription Information
-  Health Insurance Information

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

### My child is most interested in learning about...

1. \_\_\_\_\_
2. \_\_\_\_\_

★ Some individuals may benefit from direct guidance on what order to place the healthcare topics. You may choose to prompt your child to refer to the glossary if they are unfamiliar with some of the healthcare topics and require a more concrete definition.

# Lesson 1: Healthcare Checklist & Timeline (cont.)

Medical Home  
Target Date: \_\_\_\_\_



Emergency Medical Information Card  
Target Date: \_\_\_\_\_

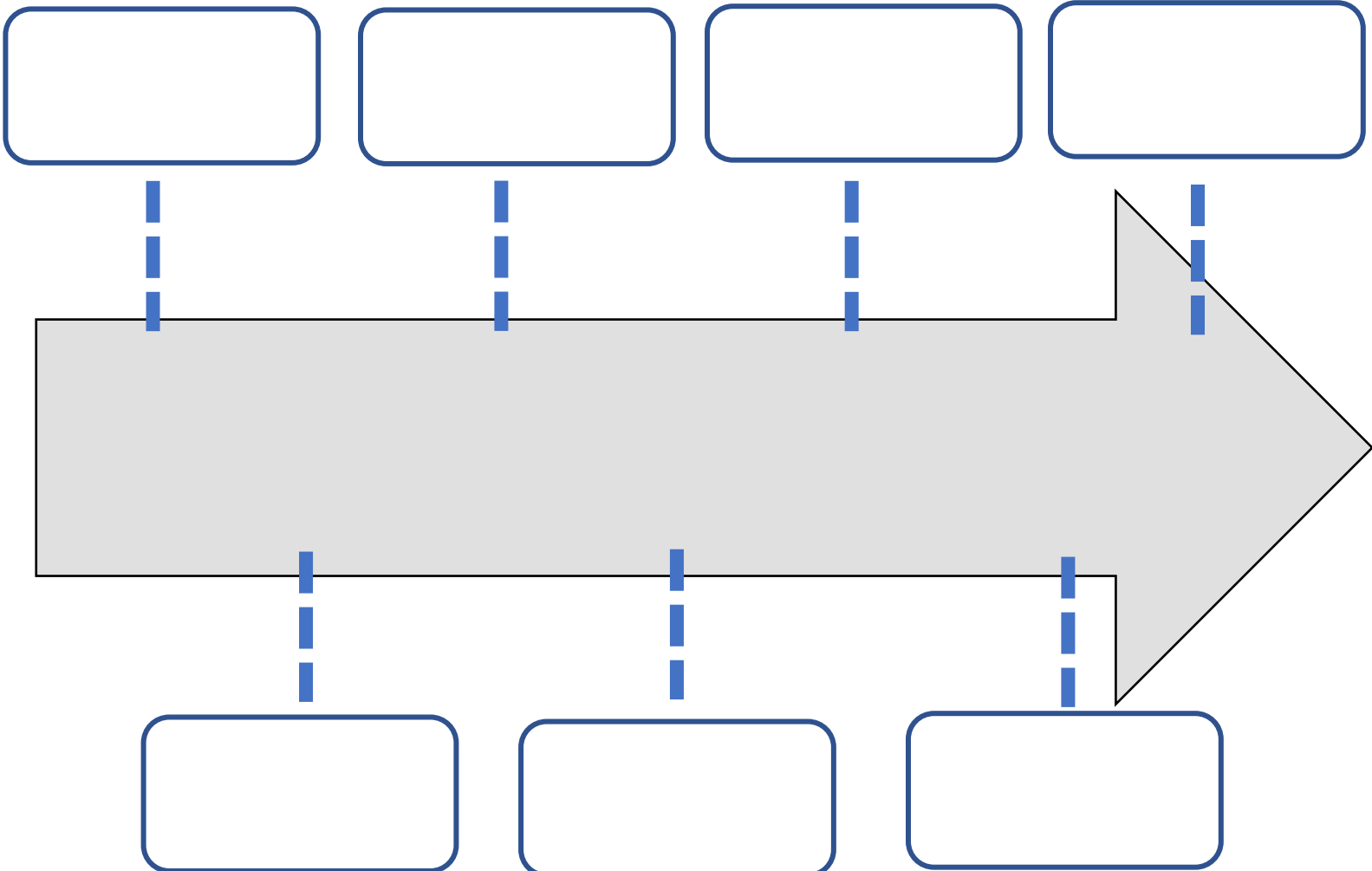
Identifying When to Visit the Doctor?  
Target Date: \_\_\_\_\_

Schedule an Appointment with a Medical Professional  
Target Date: \_\_\_\_\_

Preparing for a Medical (or Dental) Appointment  
Target Date: \_\_\_\_\_

Prescription Information  
Target Date: \_\_\_\_\_

Health Insurance Information  
Target Date: \_\_\_\_\_



# Lesson 2: Medical Home

## Who will support my child with their healthcare needs?

Health care transition may seem like a big task, but your child will have several people helping them along the way. *Challenge your child to think of who might help them during this transition process and make note of their response below:*

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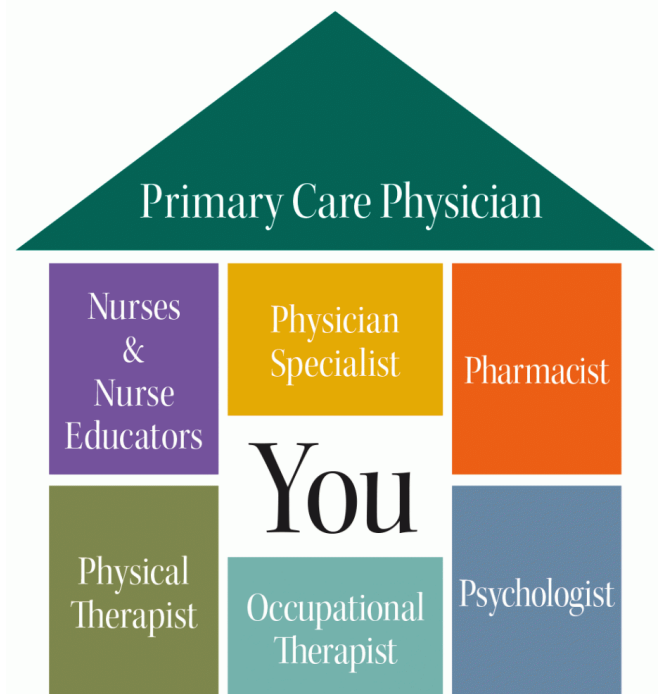
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Once your child turns 18, they will legally be an adult, and may not be able to see their pediatric doctor anymore. That's why it's important to start looking for a doctor who will see adults. You and your child may have heard about a Medical Home as a way that some healthcare providers 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?

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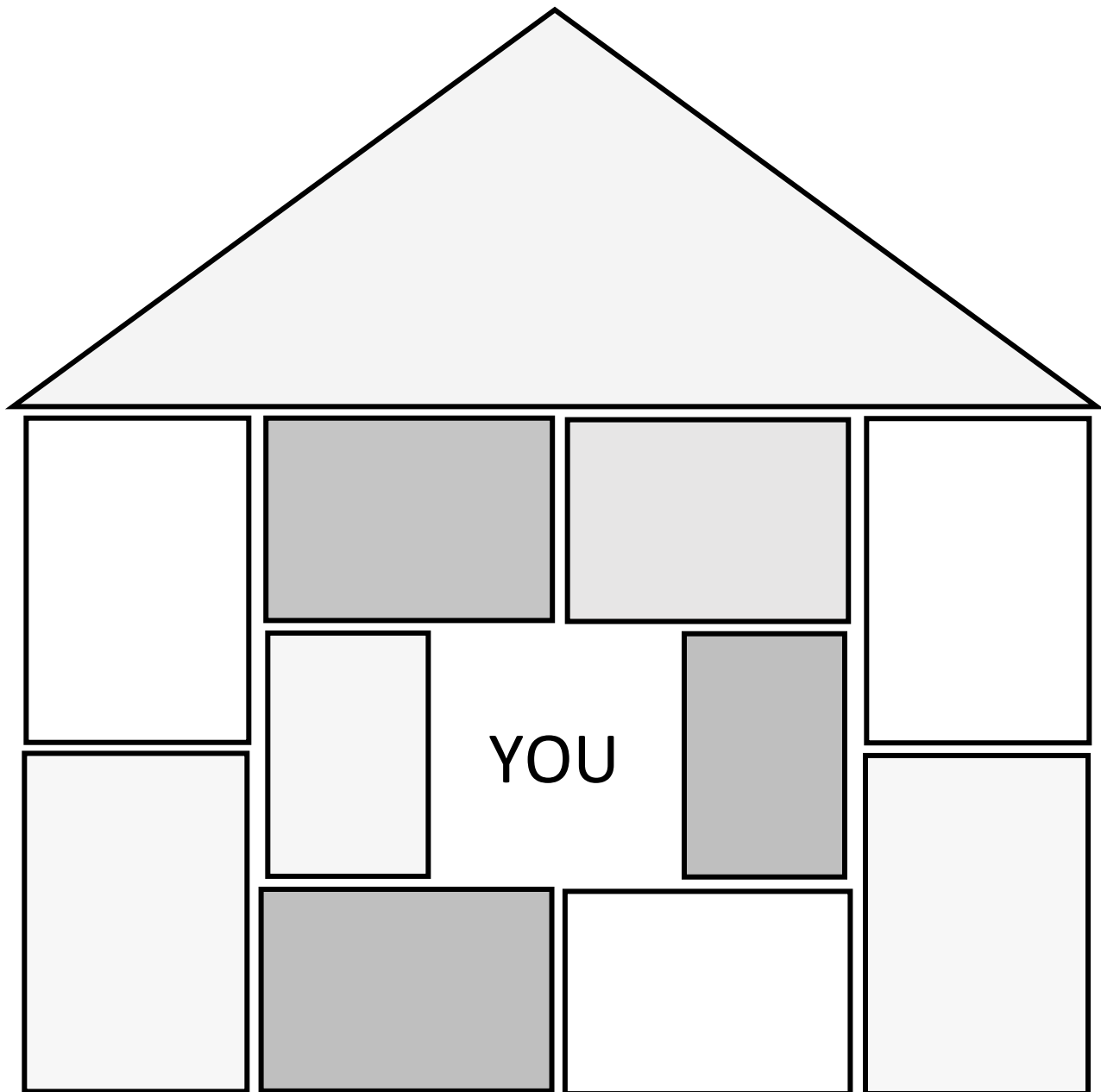
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## Lesson 2: Medical Home (cont.)

### Who is part of your child's 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 does my child need an emergency medical information card?

An emergency medical information card contains your child’s personal medical information. They can give this card to medical professionals who are trying to help them, or medical responders may refer to this card if they 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 medical information card have helped John?

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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



Aspects of your health history that could be helpful for emergency responders, 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 my child list on their emergency medical information card?

Emergency Medical Information		
Name:	DOB:	
Conditions:		
Medications:		
Allergies:		
Blood Type:	Organ Donor: Y N	Pregnant Y N




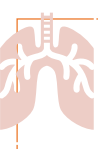






<b>Personal Information:</b>	
Address:	
Phone Number:	
<b>Emergency Contacts:</b>	
Name:	Phone:
Name:	Phone:
Doctor:	Phone:
<b>Other Information:</b>	

# Lesson 4: Identifying When to Visit the Doctor

## How will my child know when they 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, your child should go with their gut. If instinct tells them something is wrong, it's a good idea to seek medical attention.

 Persistent, high fever	 Your cold becomes unusually bad
 You lose weight suddenly and without explanation	 You are short of breath
 You experience severe chest, abdominal or pelvic pain	 Your bowel movement or urination has changed
 Bright flashes interrupt your vision	 You experience confusion or changes in mood
 You suspect you have a concussion	 You develop unexpected symptoms after a procedure or starting a new medication

Below are some symptoms that my child has experienced in the past that did not require medical attention...

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★ You may choose to narrow down the definitions for your child and, instead, provide 1 incorrect and 1 correct definition for them to choose from. Or, you may choose to provide your child with the correct answers and simply have the child go through the motions of matching the definition with its correct sign as you go.



## 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 their 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 bowel 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.

## How can my child 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 that your child prepare before contacting a doctor's office. Some ways to better prepare include:

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

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)

## Who can my child practice making a medical appointment with?

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★ You may choose to use the head to toe template if your child finds it difficult to verbalize their medical concerns. Then, you may support your child in identifying 1-5 key words they can write down to describe their medical concerns, rather than using complete sentences.

# 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 will respond. Saying, **“Great, we will see you on \_\_\_\_\_.”**

or

**“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 my child prepare for their medical appointment?

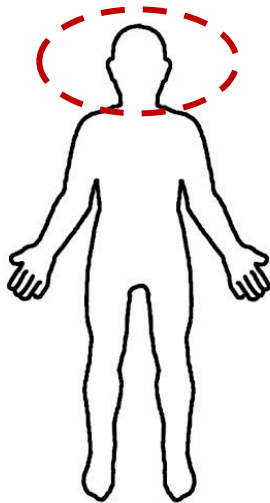
It will be important for your child to think about the reason why they are going to the doctor so that they can accurately share with the doctor their concerns. They should think how they have been feeling lately and any special concerns.

If your child is not sure how to describe their symptoms out loud, they can point to the ache. Your child can also write down their symptoms so that they can share each with their healthcare provider and not worry about forgetting anything. Your child may also have questions they wish to ask their doctor. Make sure they think about these questions and come prepared to their appointment to ask them. Your child may choose to write down information and future instructions at their medical appointment so that they can remember any needed and/or important information. If they need help doing this, they can ask the provider or the person attending the appointment with them for help.

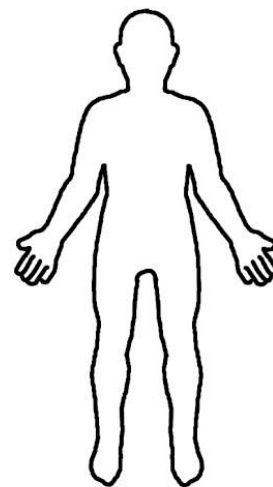
Remember, your child's doctor needs to know their true feelings and concerns in order to help them. Remind your child that it is okay to ask for information to be repeated or explained again if they do not understand it the first time.

## Describe a recent medical concern using the visual below.

Example: headache



Concern: \_\_\_\_\_



## Describe a recent medical concern your child had below.

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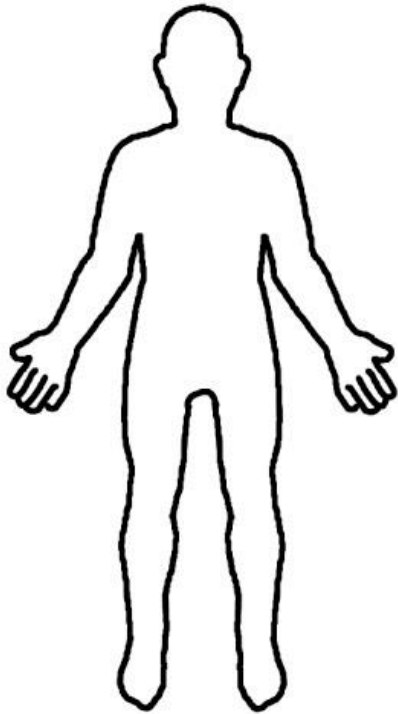
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★ Your child may choose to use the sample care plan on the following pages to write down their concerns before visiting the doctor so that they can be sure not to forget what all they intend to share with the medical professional.

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

## My Child's Medical Concerns:



Circle the area (s) of concern

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## My Child's Sample Care Plan

### Section 1: Background Information

Name:	
Date of Birth:	Phone:
Address:	
Emergency Contact:	
How I Communicate Best:	

Write the names of your doctors, therapists, other health providers (including pharmacy, equipment, and supply vendors):

Name	Specialty	Phone Number

Making Decisions (*who helps me with medical decisions and/or follow up?*)

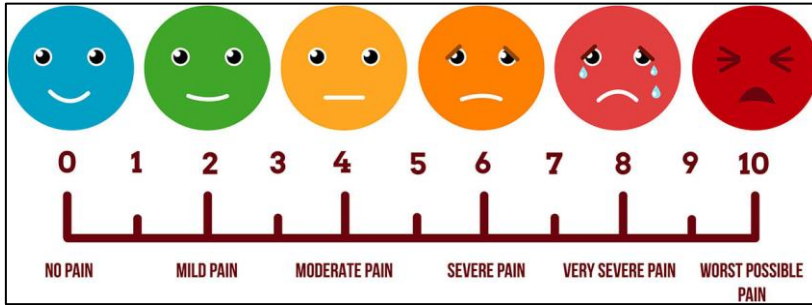
Name:	
Relationship:	Phone:
Power of Attorney for Healthcare ( <i>circle one</i> ): YES NO	
If yes, who:	
Phone:	

### Section 2: Concerns to Share with Medical Professional

Reason(s) I am here:
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# 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:



# Lesson 7: Prescription Information

## What does the information on my child's prescription labels mean?

When your doctor wants your child to take medication, a prescription may be called in by telephone to a pharmacy. You and/or your child will need to go to the pharmacy to pick up their medicine. If the doctor gives your child a written prescription, they will need to take it to the pharmacy to get it filled. Be sure your child takes their Medicaid and/or insurance card with them. There may be a co-pay charge so they will want to have some money too.

Your child will want to make sure they order their refill before their medication is gone so they don't miss any doses. They may mark their calendar to remind them of when to call in their prescription refill. Your child should call to order their medication when they have one week of medicine left. To order a refill on a medication, your child will use the information on the medication label.

The diagram shows a sample prescription label from 'Local Pharmacy' with callouts pointing to various fields. An arrow points from the label to a list of extracted information.

**Pharmacy name and address:** Local Pharmacy, 123 MAIN STREET, ANYTOWN, USA 11111

**Drugstore phone number:** (800) 555-5555

**Prescription fill date:** DATE 06/23/09

**Doctor's name:** DR. C. JONES

**Number used by the drugstore to identify this drug for your refills:** NO 0060023-08291

**Person who gets this drug:** JANE SMITH, 456 MAIN STREET ANYTOWN, US 11111

**Instructions about how often and when to take this drug:** TAKE ONE CAPSULE BY MOUTH THREE TIMES DAILY FOR 10 DAYS UNTIL ALL TAKEN

**Name of drug and strength of drug:** AMOXICILLIN 500MG CAPSULES

**Number of refills before certain date:** QTY MRG NO REFILLS - DR. AUTHORIZATION REQUIRED USE BEFORE 06/23/12 SLF/SLF

**Other information:** Don't use this drug past this date

**Information extracted from the label:**

- Name of medication: Amoxicillin
- Dosage: 500 mg
- Directions: Take 1 capsule by mouth 3x daily
- Quantity: 30
- Date filled: 06/23/2009
- How many times you may refill: 0
- What date you should refill by: N/A
- Expiration date: 06/23/2012
- Prescription number: 0060023-08291

## How does my child order a prescription refill?

When your child calls the pharmacy, a person may answer and take all the information. Sometimes they may get an answering machine telling them how to give the information the pharmacy needs to refill their prescription. Follow the script on the following pages to practice ordering a prescription refill with your child.

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?

Make sure your child understands any possible side effects to be aware of and what to do if they experience them. Your child will get written information along with their medication, but they should be sure to ask the pharmacist any questions they may have. If your child gets home and has a question or concern about their medication, they can call their pharmacist.

★ You may choose to have your child point at the various portions of the prescription label, rather than writing out their answers. If your child is verbal, you may choose to play the role of the pharmacist in the script. If you have a nonverbal child, you may choose to complete the pharmacy script using their communication device.

# Lesson 7: Prescription Information (cont.)

Pharmacy name and address

Number used by the drugstore to identify this drug for your refills

Person who gets this drug

Instructions about how often and when to take this drug

Name of drug and strength of drug

Number of refills before certain date

Doctor's name

Drugstore phone number

Prescription fill date

Local Pharmacy  
123 MAIN STREET  
ANYTOWN, USA 11111 (800) 555-5555

DR. C. JONES

NO 0060023-08291 DATE 06/23/09

JANE SMITH  
456 MAIN STREET ANYTOWN, US 11111

**TAKE ONE CAPSULE BY MOUTH THREE TIMES DAILY FOR 10 DAYS UNTIL ALL TAKEN**

**AMOXICILLIN 500MG CAPSULES**

QTY MRG  
NO REFILLS - DR. AUTHORIZATION REQUIRED  
USE BEFORE 06/23/12  
SLF/SLF

Don't use this drug past this date

Name of medication: Amoxicillin

Dosage: 500 mg

Directions: Take 1 capsule by mouth 3x daily

Quantity: 30

Date filled: 06/23/2009

How many times you may refill: 0

What date you should refill by: N/A

Expiration date: 06/23/2012

Prescription number: 0060023-08291

Local Pharmacy  
123 MAIN STREET  
ANYTOWN, USA 11111 (800) 555-5555

DR. C. JONES

NO 0060023-08291 DATE 06-23-09

JANE SMITH  
456 MAIN STREET ANYTOWN, US 11111

**TAKE ONE CAPSULE BY MOUTH THREE TIMES DAILY FOR 10 DAYS UNTIL ALL TAKEN**

**AMOXICILLIN 500MG CAPSULE**

QTY MRG  
NO REFILLS - DR. AUTHORIZATION REQUIRED

USE BEFORE 06/23/12  
SLF/SLF

Number of Refills.

Name of medication:

Dosage:

Directions:

Quantity:

Date filled:

How many times you may refill:

Expiration date:

Prescription number:

TAYLOR'S NEIGHBORHOOD PHARMACY

1900 BELMONT BLVD NASHVILLE, TN 37212 615-460-6040

RX # 6001103 RB DR. D. HAASE

SMITH, JOHN 00/00/0000

1900 BELMONT BLVD NASHVILLE, TN 37212

**TAKE TWO TABLETS BY MOUTH 2 TIMES A DAY**

**120 METFORMIN HCL 500 MG TABL**

**NO REFILLS**

NDC# 00378- 0234-01 Orig: 08/26/10

CAUTION: Federal law prohibits transfer of this drug to any person other than patient for whom prescribed.

Name of medication:

Dosage:

Directions:

Quantity:

Date filled:

How many times you may refill:

Expiration date:

Prescription number:

# 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!

# Lesson 8: Health Insurance Information

## What does the information on my child's health insurance card mean?

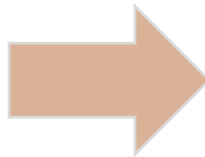
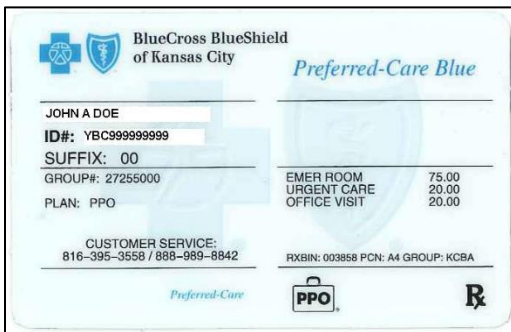
When your child attends a medical appointment for the first time, the receptionist will ask for their medical insurance card. Their medical insurance will help cover some of the costs. Most receptionists will look at their card and fill out the necessary information. Occasionally, if they are calling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

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



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 child 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.

★ Your child may point out the various portions of the health insurance card, rather than writing out their answers. Then, you may choose to narrow down the health insurance definitions for your child and, instead, provide 1 incorrect and 1 correct definition for them to choose from. Or, you may choose to provide your students with the correct answers and simply have each student go through the motions of matching the correct health insurance term with its definition.

# Lesson 8: Health Insurance Information (cont.)

BlueCross BlueShield of Kansas City  
*Preferred-Care Blue*

JOHN A DOE  
**ID#:** YBC999999999  
**SUFFIX:** 00  
**GROUP#:** 27255000  
**PLAN:** PPO

EMER ROOM 75.00  
 URGENT CARE 20.00  
 OFFICE VISIT 20.00

CUSTOMER SERVICE:  
 816-395-3558 / 888-989-8842  
 RXBIN: 003858 PCN: A4 GROUP: KCBA

*Preferred-Care* PPO R

Insurance company: Blue Cross Blue Shield

ID number: YBC999999999

Group number: 27255000

**ABC INSURANCE** PARTNERS PPO

1) **Policy Number**  
356M59557

2) **Group Number**  
1234567

**Group Name**  
XYZ COMPANY

**Member Name**  
SUSAN J. SAMPLE

3) Office Visit Copay: \$15  
 Specialist: \$15  
 4) Emergency Room: \$150  
 Urgent Care: \$50  
 Rx: \$10/20/40

**Network Coinsurance:**  
 5) In 90%/10%  
 6) Out 80%/20%  
 Med/Rx Deductible Applies

Insurance company:

ID number:

Group number:

**UnitedHealthcare** Community Plan

Health Plan (80840) 911-87726-04

**Member ID:** 999999999 **Group Number:** OHPHCP

Member:  
 SUBSCRIBER BROWN  
 MMIS: 999999999999  
 PCP Name:  
 DR. PROVIDER BROWN  
 PCP Phone: (999)999-9999

Payer ID: 87726

**OPTUMRx™**  
 Rx Bin: 610494  
 Rx Grp: ACUOH  
 Rx PCN: 9999

0501 Administered by UnitedHealthcare Community Plan of Ohio, Inc. OH - Medicaid

Insurance company:

ID number:

Group number:

# 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 deductible is met

## A-

**Activities of daily living:** A term used in healthcare to refer to people's daily self-care activities

**Affordable Care Act:** The comprehensive health care reform law enacted in March 2010 (sometimes known as ACA, PPACA, or “Obamacare”). The law has 3 primary goals: 1) Make affordable health insurance available to more people. The law provides consumers with subsidies (“premium tax credits”) that lower costs for households with incomes between 100% and 400% of the federal poverty level; 2) Expand the Medicaid program to cover all adults with income below 138% of the federal poverty level. (Not all states have expanded their Medicaid programs); 3) Support innovative medical care delivery methods designed to lower the costs of health care generally

**Autism Spectrum Disorder (ASD):** A developmental disorder that affects communication and behavior. Although autism can be diagnosed at any age, it is said to be a “developmental disorder” because symptoms generally appear in the first two years of life.

## C-

**Catastrophic plan:** A type of health plan that offers coverage in times of emergencies as well as coverage for preventive care. Catastrophic health plans typically come with low monthly premiums and a high deductible.

**COBRA coverage:** Gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan for limited periods of time under certain circumstances such as voluntary or involuntary job loss, reduction in the hours worked, transition between jobs, death, divorce, and other life events.

**Coinsurance:** The percentage of costs of a covered health care service you pay (20%, for example) after you've paid your deductible

**Comorbid mental disorder:** Refers to the occurrence of more than one disorder at the same time. It may refer to co-occurring mental disorders or co-occurring mental disorders and physical conditions.

**Conservatorship:** A guardian or a protector is appointed by a judge to manage the financial affairs and/or daily life of another due to physical or mental limitations, or old age

**Copayment:** A fixed amount for a covered service, paid by a patient to the provider of service before receiving the service. It may be defined in an insurance policy and paid by an insured person each time a medical service is accessed

## D-

**Deductible:** The amount paid out of pocket by the policy holder before an insurance provider will pay any expenses. In general usage, the term deductible may be used to describe one of several types of clauses that are used by insurance companies as a threshold for policy payments.

## G-

**Guardian:** A person who has the legal authority to care for the personal and property interests of another person, called a ward

**Guardianship:** Appointed by the court when a disabled individual cannot make or communicate responsible decisions regarding his personal care. This guardian will make decisions about medical treatment, residential placement, social services and other needs.

## H-

**HDHP:** A High Deductible Health Plan (HDHP) is a health plan product that combines a Health Savings Account (HSA) or a Health Reimbursement Arrangement (HRA), traditional medical coverage and a tax-advantaged way to help save for future medical expenses while providing flexibility and discretion over how you use your health care dollars today. HDHPs have higher annual deductibles and out-of-pocket maximum limits than other types of Federal Employees Health Benefits (FEHB) Program plans. With an HDHP, the annual deductible must be met before plan benefits are paid for services other than in-network preventive care services, which are fully covered. HDHPs also protect you against catastrophic out-of-pocket expenses for covered services. Once your annual out-of-pocket expenses for covered services from in-network providers, including deductibles, copayments and coinsurance, reaches the pre-determined catastrophic limit, the plan pays 100% of the allowable amount for the remainder of the calendar year.

**HMO:** Health maintenance organizations (HMOs) provide health insurance coverage for a monthly or annual fee. An HMO limits member coverage to medical care provided through a network of doctors and other healthcare providers who are under contract to the HMO. These contracts both allow for premiums to be lower than for traditional health insurance since the health providers have the advantage of having patients directed to them, but they also add additional restrictions to the HMO's members.

## I-

**Independence:** Someone who lives on their own and supports themselves

## L-

**Legal responsibilities:** Specific duties imposed upon a person to care or provide for another including liability for personal obligations as granted through a Power of Attorney or Court order. Legal responsibility may be held solely or may be divided or shared.

## M-

**Medicaid:** A public health insurance program in the United States that provides health care coverage to low-income families or individuals. It covers doctor visits, hospital stays, long-term medical care, custodial care, and other health-related costs.



## O-

**Out of pocket costs:** Your expenses for medical care that aren't reimbursed by insurance. Out-of-pocket costs include deductibles, coinsurance, and copayments for covered services plus all costs for services that aren't covered

## P-

**POS:** A type of managed-care health insurance plan that provides different benefits depending on whether the policyholder uses in-network or out-of-network health care providers. A POS combines the features of the two most common types of health insurance plans, the health maintenance organization (HMO) and the preferred provider organization (PPO). Point-of-service plans only represent a small share of the health insurance market; most policyholders have either HMO or PPO plans.

**PPO:** A type of health plan that contracts with medical providers, such as hospitals and doctors, to create a network of participating providers. You pay less if you use providers that belong to the plan's network. You can use doctors, hospitals, and providers outside of the network for an additional cost.

**Premium:** The amount you pay for your health insurance every month. In addition to your premium, you usually have to pay other costs for your health care, including a deductible, copayments, and coinsurance. If you have a Marketplace health plan, you may be able to lower your costs with a premium tax credit.

**Private healthcare plans:** Private health insurance refers to health insurance plans marketed by the private health insurance industry, as opposed to government-run insurance programs. Private health insurance currently dominates the U.S. health care landscape, covering more than half of the US population.

**Public health insurance:** A program run by U.S. federal, state, or local governments in which people have some or all their healthcare costs paid for by the government. The two main types of public health insurance are Medicare and Medicaid. Medicare is a federal health insurance program for people aged 65 years or older and people with certain disabilities. Medicaid is a public health insurance program for some individuals and families with a low income or disabilities.

## R-

**Repetitive behaviors:** Scientists categorize repetitive behaviors into two groups: 1) 'lower-order' repetitive behaviors are movements such as hand-flapping, fidgeting with objects or body rocking, and vocalizations such as grunting or repeating certain phrases; and 2) 'Higher-order' repetitive behaviors include autism traits such as routines and rituals, insistence on sameness and intense interests.

**Restricted interests:** Strong or intense interests in specific topics or objects

## S-

**Social interaction:** Any relationship between two or more individuals

**Social Security Administration:** an independent agency of the U.S. federal government that administers Social Security, a social insurance program consisting of retirement, disability, and survivor benefits

**Social Security Disability Insurance/Disabled Adult Child Benefits (SSDI):** Social Security Disability Insurance is a payroll tax-funded federal insurance program of the United States government. It is managed by the Social Security Administration and designed to provide income supplements to people who are physically restricted in their ability to be employed because of a notable disability

**Spectrum:** refers to the wide range of symptoms and severity

**Supplemental Security Income (SSI):** Supplemental Security Income is a United States means-tested taxpayer funded program that provides cash payments to individuals residing in the United States who have paid into social security and are eligible to retire

# ASD TRANSITION:

Pediatric to Adult Healthcare for Young Adults with ASD



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