



Your child's health care notebook

CookChildren's.



This notebook belongs to:

place
photo
here

This is my story:

Our Promise

**Knowing that every child's life is sacred, it is the
Promise of Cook Children's to improve the health of every child through
the prevention and treatment of illness, disease and injury.**





If you need to print more pages, visit cookchildrens.org/resources/notebook.

How to use this notebook

This notebook can help you keep track of your child's health information.

When your child has special health needs, it's easy to feel overwhelmed. Your child may have lots of appointments with doctors and specialists. You may need special medical equipment and medicines to care for your child. This is a lot to keep up with.

This notebook will help you:

- Stay organized.
- Prepare for appointments.
- Share information with others.
- Be part of health care decisions.
- Be prepared in case of an emergency.

This is **your** notebook. Organize the information in a way that works best for you.

To get started:

Look at the sections and pages in this notebook. Decide what information is most important.

Collect information that you already have:

- Reports from doctor visits.
- Important names and phone numbers.
- Lab and test results.
- Medicines.
- Vaccination (shot) records.
- Receipts for medical expenses.
- Equipment information.



Frequently asked questions

Q: Can I add other pages to this notebook?

A: This is your notebook and it should be useful for you. Feel free to add or remove any sections you want.

Q: What tips do you suggest to keep my child's health information organized?

A: Use your notebook for the most current information.
Update your notebook after appointments.
Move older information to another notebook or box.

Q: Should I bring my notebook to my child's appointments and medical center stays?

A: It's helpful to have your child's current information handy.

Q: What do I do with electronic information?

A: You may receive information from your doctor or specialist (provider) in email or through Cook Children's patient portal. You can print the information to put in this notebook.

Q: When do I need to update information?

A: Write down any changes in your child's care. It's hard to remember things like medicine changes or new providers.

My other questions:



Parents' guide to managing your child's health care

When your child gets a new diagnosis, it is important to learn all you can. You can help teach others who care for your child. Every child is special. They may have different needs and skills. This information reflects typical development.

For all ages:

- Get organized! Use a health care notebook or a smart phone health passport application (app).
- Ask your doctors, nurses, and counselors questions. Write down what you learn.
- Download the patient portal app for your smart phone.
- Use Cook Children's patient portal for online access to your child's records and to keep in touch with your child's health care team.
- Include your child in conversations about their health.
- Buy a medical alert bracelet or necklace for your child.
- Find local and national support groups.
- Join "Parents as Partners" at Cook Children's to meet other families.

Birth to 3 years old:

- Practice talking about your child's condition to your baby and a few people you and your family trust.
- Ask to meet other families who have a child with a similar condition.
- Teach your child the names of their body parts including their private parts.
- Keep a journal or write letters to your child about decisions you are making and what you are learning.

5 to 10 years old:

- Be sure your child's phone has emergency contacts.
- Work with your child's school to create a legal 504 plan or individualized education plan (IEP).
- Give the school information about your child's condition. Teach them signs of an emergency. Have a plan for handling a health emergency at school.
- Teach your child to be aware of signs of pain, discomfort or changes in their body and when to tell an adult.
- Act out situations your child might have at school with classmates, teachers or in gym class. This will help your child practice how to answer questions about their medical condition.

3 to 5 years old:

- Read storybooks about children with differences and special medical needs.
- Teach your child about their health and medicine. Create a daily schedule for medicines, therapies and hygiene.
- Involve your child in their daily care.
- Encourage your child to talk to doctors during appointments.

10 to 14 years old:

- Teach your child about their medicine and what happens if they don't take their medicine.
- Teach your child how to use other supplies needed for their condition.
- Start a list of important words for your child to know about their health and medical condition.
- Let your doctors, nurses and social workers know what you are comfortable talking about with your child.
- Teach your child about puberty and what may be different about their experience. Schools often start education about puberty in 4th to 6th grade.
- Give your child books, websites and videos about their condition so they can read or watch by themselves.
- Encourage questions. Prepare your child to have one question for their doctor or nurse at every appointment.

14 to 18 years old:

- Remind your child of their medical needs, names of conditions, surgical history and allergies.
- Teach your child how to order supplies, manage health insurance, schedule appointments and refill prescriptions.
- Tell your child about medical care and treatments they may need as they become adults.
- Start having your child plan their own schedule to include medicine, therapies and hygiene.
- Encourage your child to share their medical information with people they trust. This may be a friend, relative, therapist or teacher.
- Bring your child to groups where they can meet other kids with their condition.
- Request to meet an older person with your child's condition.
- Sex education usually begins in 6th grade. Talk with your child and your child's health care team about any medical needs that affect puberty, sex and intimacy.
- If your child cannot make their own medical decisions, apply for a medical power of attorney.

18 and beyond:

- Provide support. Help your child become responsible for taking care of their own health needs as an adult.
- Help your child find doctors, therapists and specialists if your child is living away from home, going to college or transferring to a doctor who treats adults.
- Help your child understand and plan for health insurance.

My family and personal information



About my child

Name: _____ Date of birth: _____

Address: _____

City: _____ State: _____ ZIP code: _____

Diagnosis: _____

Blood type: _____

Allergies: _____

Other important information (examples: pain management, comfort preferences, etc.): _____

Parent/guardian: _____ Phone: _____

Parent/guardian: _____ Phone: _____

Parent/guardian: _____ Phone: _____



Diet and nutrition

Normal eating times

Foods to avoid

Food allergies

Special feeding instructions



Emergency contacts

Name:	Relation:	
Phone:	Other phone:	
Address:		
City:	State:	ZIP code:

Name:	Relation:	
Phone:	Other phone:	
Address:		
City:	State:	ZIP code:

Name:	Relation:	
Phone:	Other phone:	
Address:		
City:	State:	ZIP code:

Name:	Relation:	
Phone:	Other phone:	
Address:		
City:	State:	ZIP code:



Medical information



Health care contacts

Primary care provider (PCP):

Address:

City:

State:

ZIP code:

Phone:

Fax:

Email:

Preferred hospital:

Address:

City:

State:

ZIP code:

Phone:

Fax:

Email:

Specialty hospital:

Address:

City:

State:

ZIP code:

Phone:

Fax:

Email:

Lab:

Address:

City:

State:

ZIP code:

Phone:

Fax:

Email:



Specialists

Name:		Specialty:
Clinic/hospital:		
Address:		City:
State:	ZIP code:	Phone:
Fax:	Email:	

Name:		Specialty:
Clinic/hospital:		
Address:		City:
State:	ZIP code:	Phone:
Fax:	Email:	

Name:		Specialty:
Clinic/hospital:		
Address:		City:
State:	ZIP code:	Phone:
Fax:	Email:	



Additional contacts

Dentist:

Address:

City:

State:

ZIP code:

Phone:

Fax:

Email:

Orthodontist:

Address:

City:

State:

ZIP code:

Phone:

Fax:

Email:

Nutritionist/dietician:

Address:

City:

State:

ZIP code:

Phone:

Fax:

Email:

Social worker/case manager:

Address:

City:

State:

ZIP code:

Phone:

Fax:

Email:

Home health agency:

Start date:

End date:

Contact:

Phone:

Address:

City:

State:

ZIP code:

Fax:

Email:

Pharmacy contacts

Pharmacy:	Contact person:
Address:	City:
State: ZIP code:	Phone:
Fax:	Email:

Pharmacy:	Contact person:
Address:	City:
State: ZIP code:	Phone:
Fax:	Email:

Pharmacy:	Contact person:
Address:	City:
State: ZIP code:	Phone:
Fax:	Email:

Compounding pharmacy:	Contact person:
Address:	City:
State: ZIP code:	Phone:
Fax:	Email:

Compounding pharmacy:	Contact person:
Address:	City:
State: ZIP code:	Phone:
Fax:	Email:

Other contacts

Name:		
Address:		City:
State:	ZIP code:	Phone:
Fax:		Email:

Name:		
Address:		City:
State:	ZIP code:	Phone:
Fax:		Email:

Name:		
Address:		City:
State:	ZIP code:	Phone:
Fax:		Email:

Name:		
Address:		City:
State:	ZIP code:	Phone:
Fax:		Email:

Name:		
Address:		City:
State:	ZIP code:	Phone:
Fax:		Email:



Helpful hint: Use this page to write down notes from telephone calls, office visits or any other conversations about your child's health care.

Communication notes

Date: _____ Time: _____

Communication type (telephone, meeting, email, other): _____

Name: _____ Title: _____

Agency: _____ Phone: _____

Address: _____

Reason:

Discussion:

Summary:

Follow-up:

Growth chart

Child's name:

Date of birth:

Date measured	Age	Weight	Height (length)	Percentiles weight/age	Percentiles height/age	Percentiles weight/height	Comments

What is a percentile?

A percentile shows how your child’s height and weight compares to other children of the same age and sex. Height and weight are measured separately.

Example: If your son is in the 30th percentile for weight, this means that 30 percent (or 30 out of 100) boys the same age weigh the same or less. This also means that 70 percent (or 70 out of 100) boys weigh more.





Helpful hint: Ask your child's primary care provider (PCP) for a copy of your child's vaccine (shot) record.

Immunizations (vaccinations)

Be sure your child's immunizations are up to date.

	Date	Date	Date	Date	Date	Date	Date	Date	Provider signature
Hep B (Hepatitis B)									
DTaP (Diphtheria Tetanus and Whooping Cough)									
Haemophilus influenzae type b									
Polio (IPV)									
PVC13 (Pneumococcal Conjugate)									
RV (Rotavirus)									
MMR (Measles Mumps, Rubella)									
Varicella (Chickenpox)									
Hep A (Hepatitis A)									
Flu vaccine (one dose each fall or winter)									
Meningococcal vaccine									
Tetanus									
Human papillomavirus (HPV)									

Surgeries or procedures

Date	Surgery/procedure	Surgeon/specialist	Notes
1/1/2020	Mediport placed	Dr. Port	Anything you feel is important to remember



Patient home medicine list

We will ask to see your medicines or list.

Child's name: _____

Date of birth: _____

It is important to know all of the home medicines your child takes.

- Bring all of your child's home medicines to the hospital.
- Make a list of everything that your child is taking.

Please include:

1. All "scheduled" and "take as needed" prescription medicines, including any "rescue" medications.
2. All over-the-counter (OTC) medicines, vitamins, supplements, herbals and home remedies.
3. All inhalers, breathing treatments, eye drops, ear drops, medicated patches or medicated cream or lotions.

Our nurse or pharmacist will ask to see your medicines or list. This is an example of the information we need.

Medicine name:	Tylenol™ or the generic name "Acetaminophen"
Strength of medicine:	325 mg
Dose you give and how:	One tablet by mouth
How often you take medicine:	Every four hours as needed
Reason you take medicine:	As needed for pain
Time you gave the last dose:	Monday at 8 a.m.



Helpful information:

1. **Bring a current list of your child's medicines:** Each time you go to the doctor, clinic, emergency room, etc.
2. **Use your cell phone to keep track of medicines:** Create a "medicine list" memo. You can take pictures of each medicine bottle. You can also try apps like MyMedSchedule or MediSafe meds and pill reminder for managing medicines.
3. **If your child uses a Cook Children's doctor:** You can track medicines on the Cook Children's patient portal.
4. **If you fill prescriptions at a major pharmacy:** You may be able to view medicine information through the pharmacy's website or mobile app.
5. **Cook Children's Pharmacy:** Located near the Emergency Department. If you would like to use this service, please ask your doctor to send your child's prescriptions to the Cook Children's Pharmacy.

These instructions are only general guidelines. Your doctors may give you special instructions. If you have any questions or concerns, please call your doctor.

801 7th Ave.
Fort Worth, TX 76104
682-885-4000
cookchildrens.org

[illegible]

Address:

Pharmacy hours:

[illegible]



Helpful hint: Keep instruction manuals where you can find them!

Durable medical equipment (DME)/supplies

Name of equipment:

Ordered by (provider):

Phone:

Account or ID #:

Description (brand name, size, etc.):

Serial #/model:

Supplier:

Daytime phone:

After hours phone:

Date ordered:

Date received:

Name of equipment:

Ordered by (provider):

Phone:

Account or ID #:

Description (brand name, size, etc.):

Serial #/model:

Supplier:

Daytime phone:

After hours phone:

Date ordered:

Date received:

Name of equipment:

Ordered by (provider):

Phone:

Account or ID #:

Description (brand name, size, etc.):

Serial #/model:

Supplier:

Daytime phone:

After hours phone:

Date ordered:

Date received:

Insurance and expenses





Helpful hint: Medicaid is always secondary to any other insurance.

Insurance information

Primary insurance:		Member ID:
Group #:	Group name/employer name:	
Subscriber's name:		Date of birth:
Mailing address:		
State:	ZIP code:	Member services phone:

Secondary insurance:		Member ID:
Group #:	Group name/employer name:	
Subscriber's name:		Date of birth:
Mailing address:		
State:	ZIP code:	Member services phone:

Dental insurance:		Member ID:
Group #:	Group name/employer name:	
Subscriber's name:		Date of birth:
Mailing address:		
State:	ZIP code:	Member services phone:

Drug card or prescription insurance:		Member ID:
Group #:	Group name/employer name:	
Subscriber's name:		Date of birth:
Mailing address:		
State:	ZIP code:	Member services phone:



Helpful hint: Call your insurance provider if you have questions about bills.

Medical bill tracking form

Date	Provider	Charges	Deductible	Primary insurance paid	Secondary insurance paid	Amount owed	Date paid

Out-of-pocket expenses

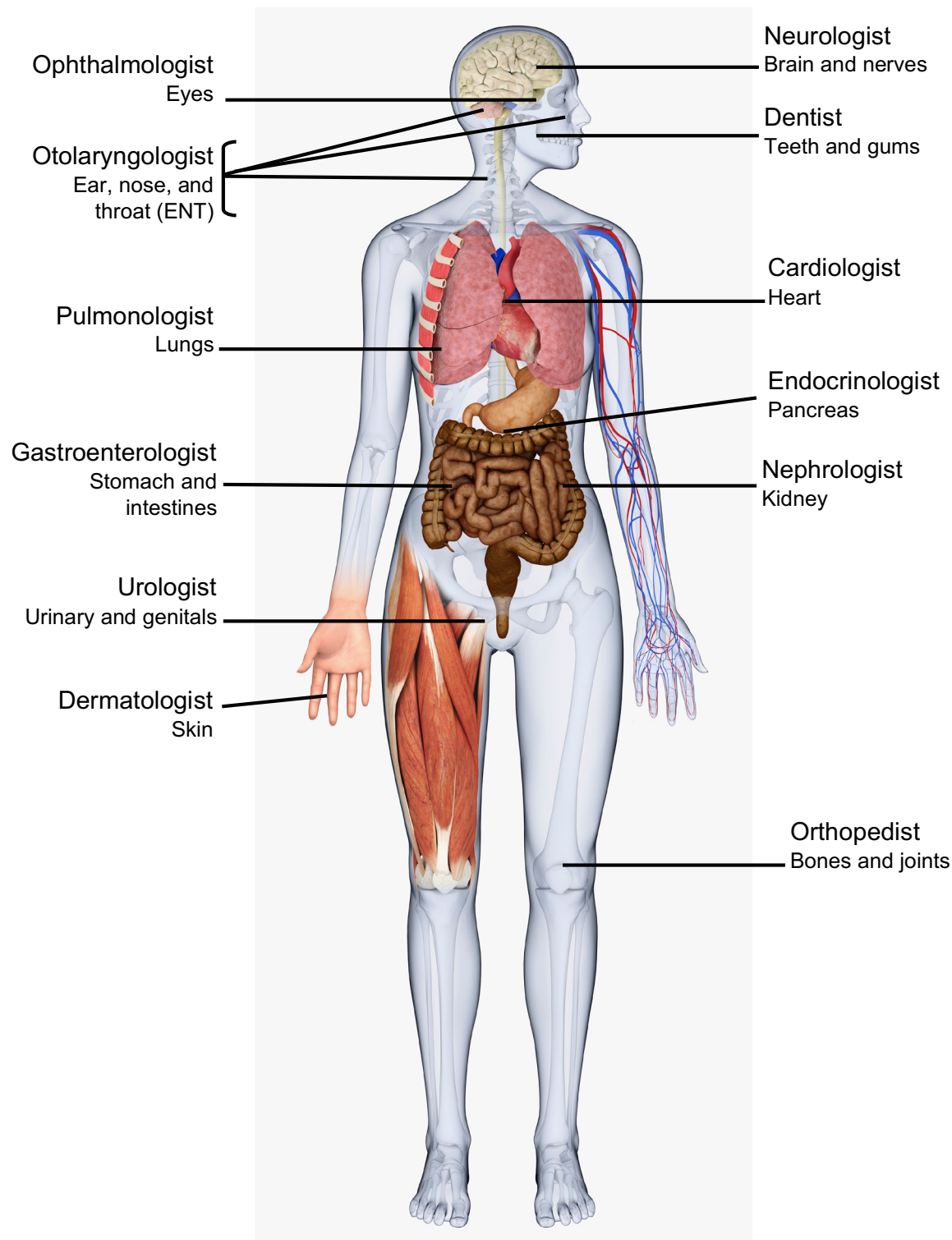
Use this sheet to track expenses not covered by insurance. This sheet may be helpful for income tax purposes.

Date	Activity (travel, mileage, lodging, supplies, etc.)	Amount



Body map and words to know

Body map



Important words to know

Allergist - A doctor who diagnoses and treats allergies.

Anesthesiologist - Gives medicine before and during surgery to help patients relax, fall asleep and stay asleep through the operation.

Benefits - Health care items or services that can be paid for by a health insurance plan. Health insurance providers, Medicaid and CHIP provide information about what benefits are offered by their plans.

CHIP - Children's Health Insurance Program provides no-cost or low-cost health coverage. It may be a choice for families who make too much to qualify for Medicaid. Each state has its own rules about who qualifies for CHIP.

Chronic - A medical condition that may last for a lifetime. There are times when the illness gets worse or better. A chronic illness usually can be managed, but not cured.

Claim - A request to an insurance provider to pay for medical care or supplies.

Clinical therapist - A licensed professional that offers emotional and behavioral support for patients with primary medical conditions.

Coinsurance - An amount that you may have to pay as your share of the cost for services, after you pay any deductibles. It is usually expressed as a percentage. For example: if your coinsurance

is 20 percent, it means that you would have to pay 20 cents for each \$1 of expense.

Co-payment - An amount that you pay as your share of the cost for a medical service or supply, like a doctor's visit or a prescription. A co-payment is usually a set amount like \$10 or \$20. This amount is set by your insurance provider.

Complex care - When your child sees several specialists who work together to treat your child.

Compounding pharmacy - A special pharmacy that has a license to make a medicine just for a certain person. The pharmacy may make a liquid form of a medicine or mix several medicines to make a special strength or dose.

Deductible - The amount of money that you will have to pay out of your own pocket for health care before your health insurance plan will begin to pay any costs.

- Different plans have different deductible amounts.
- There are some costs that your insurance may pay before you have met your deductible.
- There are some costs that may not count toward meeting your deductible.

Dermatologist - A doctor who treats skin, hair and nails.

Developmental pediatrician - A medical doctor who has special training to diagnose and treat children with development or behavior problems.

Diagnostic tests - Tests and procedures ordered by a health care provider to see if a person has a condition or disease.

Durable medical equipment (DME) - Something that is needed because of a medical condition. It is equipment that can be used over and over. It is ordered by your primary care provider. Some examples of durable medical equipment are hospital beds and respirators.

Endocrinologist - A doctor who specializes in diagnosing and treating conditions caused by hormone problems and the glands that make hormones. Diabetes and growth problems are treated by an endocrinologist.

Growth chart - Gives you an idea of how your child is developing. You can see how your child has grown.

Hematologist - A doctor who specializes in blood disorders.

Hospitalist - A doctor who takes care of people when they are in the hospital.

Immunizations - Medicines (shots) that are given to your child to prevent illnesses. Primary care providers usually give these shots to your child is at certain ages. These are also called vaccinations.

Immunologist - A doctor who diagnoses and manages disorders of the immune system.

Infectious disease specialist - A doctor or specialist who diagnoses and treats infections.

In-network - A provider who works with your health insurance or plan and offers services at a discounted rate.

Neonatologist - A doctor who takes care of premature and critically ill newborn babies.

Neuropsychologist - A doctor who understands how the brain works and assesses and treats patients with brain injury or disease.

Nurse practitioners (NP, CPNP) - Work with doctors and the health care team to diagnose and treat your child. Nurse practitioners have special medical training in order to get certified and licensed. They can give a diagnosis and write prescriptions for medicines and other treatments.

Occupational therapist (OT) - An occupational therapist works with patients to improve coordination, motor skills and skills needed to play, function in school and perform routine activities (like hand-eye coordination).

Oncologist - A doctor who specializes in diagnosing and treating cancer.

Out of network - A provider who does NOT work with your health insurance or plan. If you choose an out-of-network provider, your insurance may not pay as much or may not pay at all for those services.



Out-of-pocket costs - Costs that you will have to pay for yourself because they are not covered by your insurance. Out-of-pocket costs include deductibles, coinsurance and copayments. Sometimes you can deduct these expenses from your taxes.

Over-the-counter - Drugs and supplies that can be bought without a prescription.

Pain management specialist - A pain management specialist is a doctor with knowledge and training in diagnosing and treating pain.

Pathologist - A doctor who studies body fluids and tissues to help find a diagnosis.

Pediatrician - A doctor who takes care of babies, children and teens.

Pharmacist - Provides medicines for patients, checks for any interactions between drugs and works with the medical team to choose the best medicine.

Physical therapist (PT) - A physical therapist uses exercises, stretches and other techniques to improve mobility, decrease pain and reduce any disability related to illness or injury.

Physician assistant (PA) - A nationally certified and state-licensed medical professional. They practice medicine on health care teams with doctors and other providers.

Primary care provider (PCP) - The health care provider your child goes to for medical care like checkups, vaccinations and minor illnesses. This person can also refer your child to a specialist when necessary.

Primary insurance - Also called primary coverage. If you have more than one health insurance plan, this is the insurance plan that pays any claims first.

Procedure - A medical treatment or operation done to diagnose, measure or treat a problem such as a disease or injury.

Provider - A doctor, hospital health care professional or health care facility.

Psychiatrist - A medical doctor who specializes in treating emotional and behavioral problems through psychotherapy, prescribing medications and performing some medical procedures.

Psychologist - A psychologist specializes in treating emotional and behavioral problems through psychological consultation, assessment, testing and therapy.

Qualify - An event or condition that allows you to get a benefit or service.

Radiologist - A specialist who diagnoses and treats diseases and injuries using medical imaging techniques, such as X-rays, computed tomography (CT) and magnetic resonance imaging (MRI).

Referral - An order from your primary care provider for your child to see a specialist. Some insurance plans will not pay for services from a specialist unless you get a referral first.

Respiratory therapist (RT) - Evaluates, treats and cares for breathing problems and heart problems that can also affect the lungs.

Rheumatologist - A doctor who treats problems involving the joints, muscles, and bones, as well as autoimmune diseases. Rheumatologists treat conditions such as arthritis and lupus.

Secondary insurance - If you have more than one health insurance plan, this plan covers costs that are left over after the primary insurance pays its share.

Services - Health care that is given by a provider. This includes care for keeping your child healthy, as well as treating an illness, injury or condition.

Sleep specialist - A doctor who specializes in diagnosing and treating sleep disorders.

Specialist - A health care provider who is trained to provide care in a special medical field. For example, a cardiologist is a person who has extra training in caring for heart problems.

Speech-language pathologist (SLP)- Specially trained and certified to treat many types of communication, swallowing and feeding problems.

Surgeon - A doctor who performs operations.

Therapist - Someone who works with a patient who has special needs because of an illness or injury. There are different kinds of therapists including speech, occupational, physical and respiratory.

Urologist - A doctor who treats the urinary system including conditions of the urethra, bladder, ureters, kidneys and genitals.

Vaccinations - See Immunizations.

Other important words:

