

This notebook belongs to:

This is my story:

Our Promise

Promote the medical home approach to improve care outcomes.



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. 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 (app).
- Ask your doctors, nurses, and counselors questions.
 Write down what you learn.
- Download the patient portal app for your smart phone.
- Include your child in conversations about their health.
- Buy a medical alert bracelet or necklace for your child.
- Find local and national support groups.

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

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.

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.

- 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.

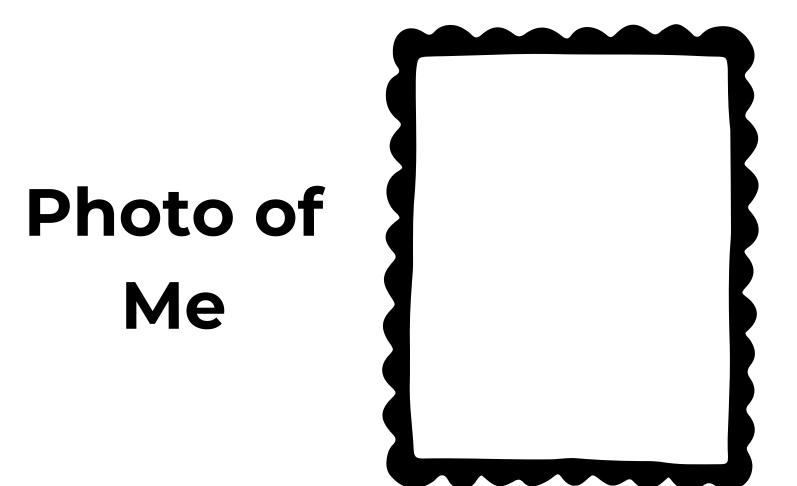
18 and beyond:

- 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.

- 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

My Family and

Personal Information



Date:

My Name is: _____

My Nickname is: _____

I am _____ Years Old

My Pet's Name is: _____

My Favorites

Toys: _____ Animal: _____ Comoc

Hobbies:
Music:
TV Shows:
Other:
My Favorite Foods are:
My Least Favorite Foods are:
My Friends Name are:
When I am happy, I:
When I am sad, I:
When I feel pain, I:
Things I need help with (like washing, dressing, or brushing
teeth):
Things I can do for myself (but thanks for asking):
If you need to know something else, ask me or ask:
Reach them by calling:

Legal Guardian:	
Address:	
Phone:	
Mother's Name:	
Address:	
Phone:	
Email:	
Father's Name:	
Address:	
Phone:	

Family Members

Sibling's Name:	Age:
Sibling's Name:	Age:
Sibling's Name:	Age:
Sibling's Name:	Age:
Name:	Age:
Name:	Age:
Name:	Age:
Name:	Age:

Other Household Members

Name:	Age:
Name:	Age:
Name:	Age:
Name:	Age:

Important Family Information

Language Spoken at Hom	e:
Other Language(s):	
Interpreter Needed: Yes	No
If Yes, Interpreter Name:	
Phone:	
Email:	

Primary Emergency Contact

Name:
Relation:
Address:
Daytime Phone:
Evening Phone:
Cell Phone:
Email:

Preferred Method to be Contacted: _____

12 Your Child's Health Care Notebook

Emergency Contact

Name:
Relation:
Address:
Daytime Phone:
Evening Phone:
Cell Phone:
Email:
Preferred Method to be Contacted:

Name:		
Relation:		
Address:		

Daytime Phone: _____

Evening Phone:	
Cell Phone:	
Email:	
Preferred Method to be Contacted:	

Name:
Relation:
Address:
Daytime Phone:
Evening Phone:
Cell Phone:
Email:
Preferred Method to be Contacted:

Diagnosis and Conditions

This page helps you document your child's official and suspected diagnoses, along with the dates and other notes you may take about them.

Blood Type:

Diagnosis or Suspected Diagnosis	Provider Who Gave Diagnosis or Working on it	Date	Notes

Service Animal Information

Type of Service:

Psychiatric Service Medical Alert and Response Service Mobile/Physical Assistance Service Emotional Support Therapy

Type of Animal: _____

Animal's Name: _____

Support Animal Provides:

15 Your Child's Health Care Notebook

Diet and Nutrition

Dlet:

Special Feeding Instructions:

Normal Eating Times:

Foods to		
Avoid:		

Food Allergies:

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							

Tube Feeding Information

Type of Tube:

NG Naso-intestinal G-tube J-tube GJ-Tube

Delivery Method:

Syringe Gravity Feeding Pump

Tube Feedings:

Bolus or Intermittent

Continuous	
Mix of two methods	

Tube Size:	
Pump Type: Infinity Pump	Kangaroo Joey
How Often Fed:	
Type of Formula:	
Feed Rate mL/HR:	
Amount of Feed (mL):	
Date of Last Tube Change:	
Next Time Tube Needs Chan	ged:

Allergic Reaction Tracking Form

Date	Allergen	Reaction	Anecdote (w/Dosage)

Medical Information

Baseline Information

Blood Pressure:
Pulse/Heart Rate:
Respiratory Rate:
Respiratory Pattern:
Oxygen Saturation:
Temperature:

Appetite:	
1 1	

Temperament/Behaviors:

Activity:

Care Plan for Behavioral Disorders

Crisis Hotline:
Case Manager Phone:
Family Contact Person:
Phone:

What behavior pattern is typical for this individual? Include affect, seasonal changes etc.

Worrisome Behavior to Watch for: _____

Action Plan:

- 1.

 2.

 7
- 3. _____

. . . .

Intermed	liate Dange	erous Behavio	or:	
	<u> </u>			

Action Plan:	
1	_
2	_
3	
Dangerous Behavior:	
Action Plan:	
1	
2	
3	

Extremely Dangerous Behavior: CALL 911

Care Plan for Medical Disorders

Physician Call Center Number:
Case Manager Phone:
Family Contact Person:
Phone:

What medical symptoms are typical for this individual? Include affect, behavioral problems, physical symptoms etc. of frequently occurring illnesses.

Worrisome Symptoms to Watch for: _____

Action Plan:

٦.	
2.	
3.	

Marconing Symptome

vvorsening symptoms.	

Action Plan: 1. ______ 2. _____ 3. _____

Dangerous Symptoms: _____

Action Plan:

٦.	
2.	
3.	

Life Threatening Situations: CALL 911

Important Contact Information

Life-Threatening Emergency: Call 911

Primary Care Doctor- Medical Home

Name:		
Address:		
Phone:		
Fax:		
Care Coordinator:		
Email:		

Urgent Care- After Hours - Advice Nurse

Name: _____

Address: _____

Phone:		
Fax:		
Email:		
Hours:		

Primary Hospital

Name:		
Address:		
Phone:		
ER Phone:		

Specialist Doctors-Therapists- Other Care Providers

Provider:		
Specialty:		
 Clinic:		
Address:		
Phone:		
Fax:		
Hours:		

Provider:			
Specialty:			
Clinic:			
Address:			
Phone:			
Fax:			
Hours:			
Provider:			
Specialty:			
Clinic:			

Address: _____

Fax: _____

Phone: _____

Hours: _____

Medical Equipment Supplier

Supplier:		
Product:		
Contact:		
Address:		
Phone:		
Fax:		
Hours:		
Supplier:		
Product:		
Contact:		
Address:		
Phone:		
Fax:		
Hours:		
Supplier:		
Product:		
Contact:		
Address:		
Phone:		
Fax:		
Hours:		

Community Agencies

Agency:			
Service:			
Contact:			
Address:			
Phone:			
Fax:			
Hours:			

Agency:		
Service:		
Contact:		
Address:		
Phone:		
Fax:		
Hours:		
Agency:		
Service:		
Contact:		

Address: _____

Phone: _____

Fax: _____

Hours: _____

Home Nursing Agencies

Agency:			
Service:			_
Contact:			
Address:			
Phone:			
Fax:			
Hours:			

Agency:		
Service:		
Contact:		
Address:		
Phone:		
Fax:		
Hours:		
Agency:		
Service:		
Contact:		

Address: _____

Fax: _____

Phone: _____

Hours: _____

Childcare Provider

Name:		
Address:		
Phone:		
Fax:		
Email:		
Hours:		

Respite Care Provider

Name:		
Address:		
Phone:		
Fax:		
Email:		

Hours: _____

<u>Pharmacy</u>

Name:		
Address:		
Phone:		
Fax:		
Email:		
Hours:		

Dentist-Orthodontist

Name:		
Address:		
Phone:		
Fax:		
Email:		
Hours:		

Social Worker

Name:		
Address:		
Phone:		
Fax:		
Email:		

Hours: _____

Communication Notes

Date:	
Time:	
Communication Type (telephone, meeting, emai	l)
Name:	
Agency:	
Phone:	
Reason	

Notes

Growth Chart

Child's Name: ______ Date of Birth: _____

Date	Age	Weight	Height	% Weight	% Height	% Ratio



What is a percentile?

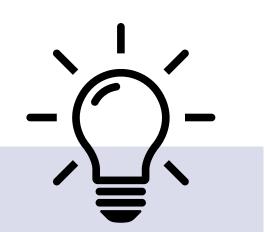
A percentile shows how your child's height and weight compares to other children of the same age and sex. Height and weight are measured separately.

Example: If your son is in the 3oth percentile forweight, 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 of100) boys weigh more .

Immunizations

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

	Date	Date	Date	Date	Date	Date
Нер В						
Dtap						
Hib						
Polio						
PVC13						
RV						
MMR						
Varicella						
Нер А						
Flu						
Meningo coccal						
HPV						



Helpful Hint:

Ask your child's primary care provider (PCP) for a copy of your

child's vaccine (shot) record.

Surgeries or Procedures

Date	Surgery/ Procedure	Surgeon/Specialist	Notes

Hospital Stays

Date	Reason	Doctor/s	Changes/Notes



Home Medicine List

- 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 you fill prescriptions at a major pharmacy: You may be able to view medicine information through the pharmacy's website or mobile app.

Home Medicine List

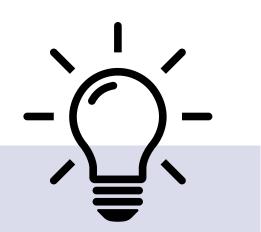
Medicine	Stren gth	Dose	Route	Time	Reason	Last Taken

Durable Medical Equipment (DME)/Supplies

Name of Equipment:
Ordered by (provider):
Account #
Serial #/Model:
Description:
Supplier:
Product:
Contact:
Address:
Phone:
Fax:
Hours:

Name of Equipment:

ordered by (provider):
ccount #
erial #/Model:
escription:
upplier:
roduct:
ontact:
ddress:
hone:
ax:
ours:



Helpful Hint:

Keep instruction manuals where you can find them.



Assistive Technology/Specialist Support Equipment/ Adaptive Devices

Assistive Device: _____

How to Use :

When to Use:

Manufacturer:

Contact Person:		
Phone Number:		
Address:		
Date Purchased:		

Port Line Information

Type of Implanted Port:

Single Lumen Port Double Lumen Port Power-Injectable Port

Date of Placement :

Flush the Port with:

Does the patient need numbing medication before access

Yes

No:

Size of Needle Used to Access:

Use the Port for (blood draws, medication, etc.):

PICC Line Information

Type of PICC Line:

Single Lumen Double Lumen Triple Lumen

Date of Placement :

Flush the PICC with:

How often to do a dressing change:

Use the line for (blood draws, medication, etc.):



PICC Line

Do not have any of the following on the arm where your PICC was placed:

- -Needle sticks (such as for blood draws or an IV line).
- -Blood pressure measurements.
- -Tight clothing or tourniquets.

At least once a week, your:

-Tegaderm dressing, needleless connectors, and disinfection caps must be changed.

-PICC must be flushed.

Nebulizer and Vest Treatments

Date	TIme	Neb Given	Vest Given	02 Sat Pre	02 Sat Post	Intitals

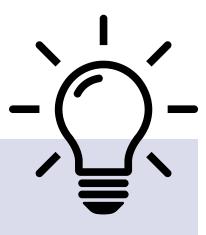
Vest Settings and Treatment

Date Purchased:
Type of Vest:
Full Vest
Wrap Vest
Vest Size:
Frequency Settings:
Pressure Settings:
Minutes in Each Frequency:
Manufacturer of Vest:

Medications Used with Vest Treatment:

2) Mucolytics:

3) Antibiotics:



Helpful Hint:

- To avoid problems with your child's stomach, try to do vest treatments before meals or no sooner than one hour after meals.

- Some patients find it helpful to moisten their airway secretions. This is done by taking nebulizer treatments with normal or hypertonic saline after other medicines are complete.

-If itching occurs, try a couple of cotton T-shirts between the skin and the vest.

- Have the vest machine and inflatable vest checked each year. This is needed to ensure it is working properly and that your child has the correct vest size.

Cough Assist Settings

Flow Rate: _____

Cycle Timing: _____

Suction Settings

Type of Suction:

Oropharyngeal Nasopharyngeal

Type of Unit:

Wall Suction Portable Suction

Suctioning Device:

Yankauer Sterile Suction Catheter

Size of Sterile Suction Catheter: ____

Pressure Settings: _____

How long to Suction: _____

When to use Suction:

Ventilator Settings

Mode: A/C SIMV CPAP PSV VS CMV APRV MMV IRV HFOV

Tidal Volume: _____

Frequency (Respiratory Rate): _____

FiO2: _

Inspiratory Flow Rate:
I:E Ratio:
Positive End Expiratory Pressure (PEEP):
Sensitivity:

Summary of Care Sensory and Communication

Vision

Clinic:
Ophthalmologist/Optometrist:
Date of First Visit:
Medical Record Number:
Address:
Phone Number:
Email:
Website:
Date of Last Visit:
Results, if known:
Right Eye
Sphere:
Cylinder:
AXIS:
Prism:
Base:

Left Eye	
Sphere:	
Cylinder:	
AXIS:	
Prism:	_
Base:	_
Glasses	
Contacts	
Prosthesis	
Listow (of DOD (Dationanat	h h

History of ROP (Retinopathy of Prematurity)

Surgery

Lasik

Other:

Other Comments or Pertinent Health Information:

Summary of Care Sensory and Communication

Audiology/Hearing

Clinic:	
Address:	
Date of Hearing Exam:	
Results, if known:	
Hearing Devices:	
Cochlear Implant	
Hearing Aids	
Bone Conductive Device	
Baha Band	

Wears in: Right Ear Left Ear Both Ears

Do they have a microphone that connects to hearing technology (DM/FM)?

Yes No

Summary of Care Sensory and Communication Cochlear Implant Information

External Unit of Cochlear Implant and Charger Behind-the-ear external unit of Cochlear Implant

Brand:		
Model:		

Type of Battery: _____ MRI Compatibility/Limitations: _____

Do they have a microphone that connects to hearing technology (DM/FM)?

Yes

No

Brand of Microphone: _____

Model of Microphone: _____

Which Ear?

Right Left Both

Age at the time of Hearing Loss: Cause of Hearing Loss:
Age at the time of Implants:
Purchase Date:
How are the devices stored:

Summary of Care Sensory and Communication Hearing Aid Information

Brand:
Model:
Type of Battery:
Rechargeable?
Yes
Νο
Which Ear?
Right
Left
Both

Do they have a microphone that connects to hearing technology



Yes No

Brand of Microphone: _	
Model of Microphone: _	

Purchase Date:	
How are the devices stored: _	

Summary of Care Sensory and Communication Bone Conduction Device

Brand:
Model:
Type of Battery:
Rechargeable?
Yes
No
If it is implanted, what are the MRI compatibilities/limitations?

Do they have a microphone that connects to hearing technology (DM/FM)?



Brand of Microphone:	
Model of Microphone:	

Purchase Date: _____

How are the devices stored: _____

Summary of Care Sensory and Communication

Speech and Communication

Clinic:
Speech & language pathologist:
Date of first visit:
Medical Record#:
Address:
Phone:
Fax:
Email:
Website:
Fax: Email:

Results of Evaluations:

Child uses following devices to meet communication needs:

Computer

Sign Language (ASL)

Communication Board

Interpreter Services

Lip Reads

Communication Book

Sign Language

D Other:

Other comments or helpful information:

Summary of Care Sensory and Communication Catheterization Protocol

Type of Catheter:

Suprapubic Intermittent Indwelling (Urethra)

How Often to Cath:

When to Cath:

Date	Catheter	was Ch	anded:

Other Pertinent Information:

Catheterization Schedule

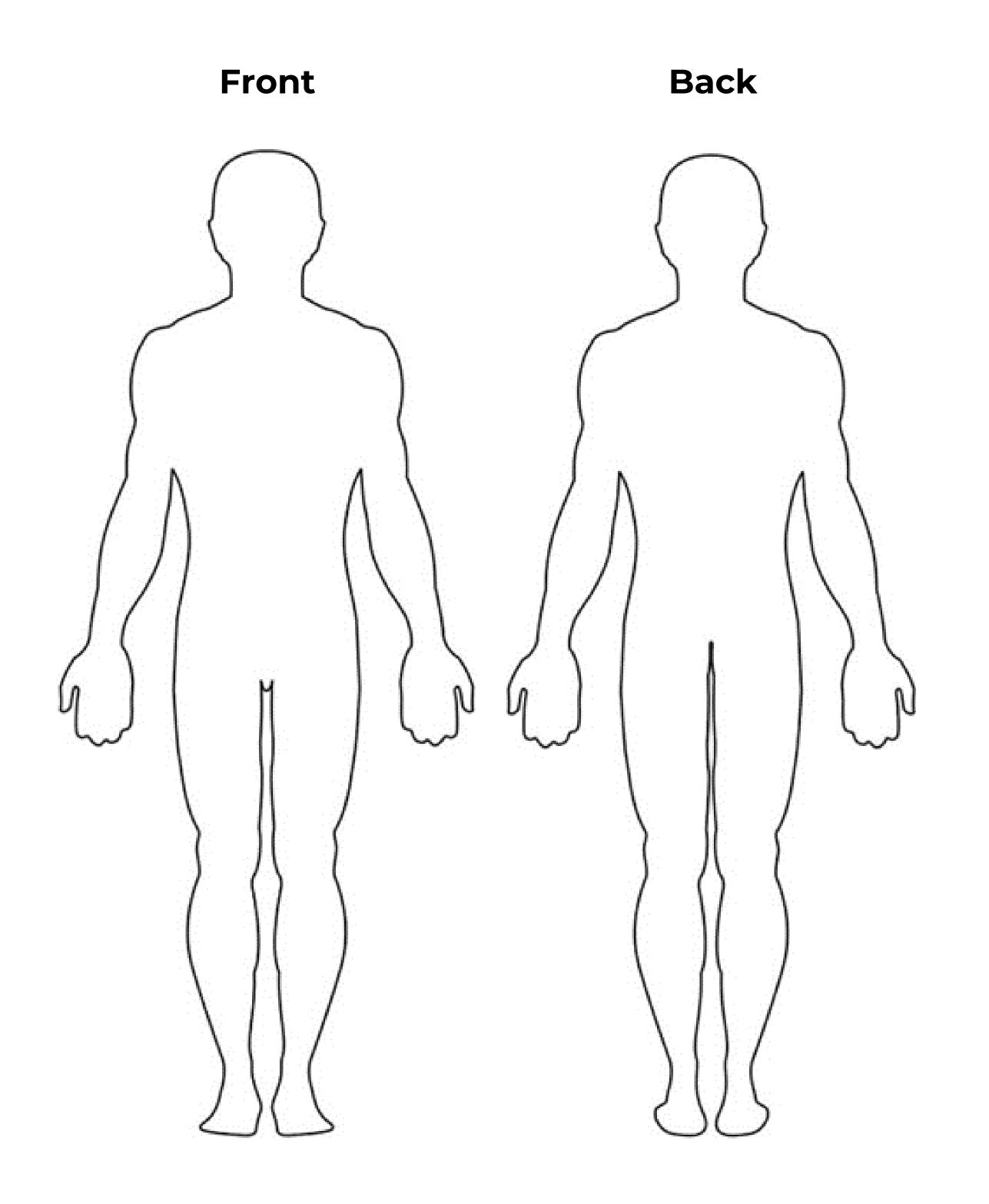
Date	TIme	Amount of Urine	Comments

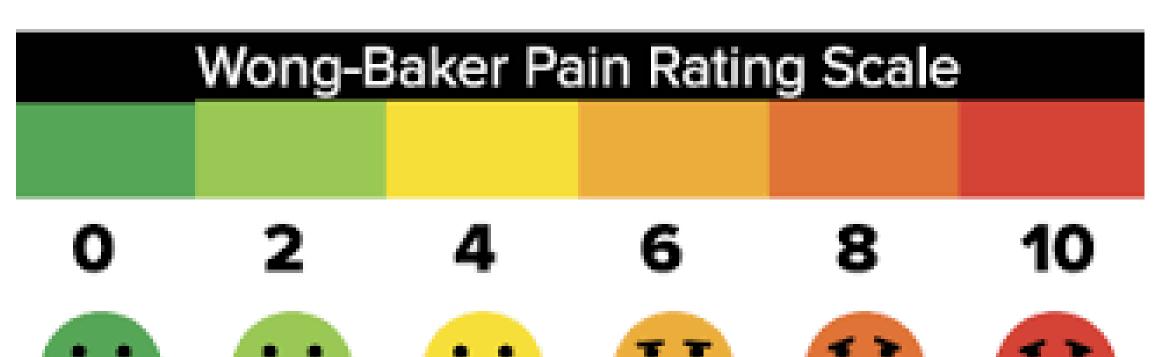
Seizure/Behavior Log

Date	Duration of Seizure	Description of Seizure or Behavior

Where Does it Hurt?

Mark each spot where you have an ache, pain, or discomfort, on the front and back.













Medicaid is always secondary to any other insurance.



Medical Insurance Information

Primary Insurance:
Member ID:
Group Number:
Group Name/Employer:
Subscriber's Name:
Date of Birth:
Subscriber's Phone:
Mailing Address:

Secondary Insurance:	
Member ID:	
Group Number:	
Group Name/Employer:	

Subscriber's Name:	
Date of Birth:	
Subscriber's Phone:	
Mailing Address:	

Dental Insurance Information

Primary Insurance:	
1ember ID:	
Group Number:	
Group Name/Employer:	
ubscriber's Name: Date of Birth: Dubscriber's Phone: Nailing Address:	

Secondary Insurance:	
Member ID:	
Group Number:	
Group Name/Employer:	

Subscriber's Name: _	
Date of Birth:	
Subscriber's Phone: _	
Mailing Address:	

Vision Insurance Information

Secondary Insurance:	
Member ID:	
Group Number:	
Group Name/Employer:	

Subscriber's Name:	
Date of Birth:	
Subscriber's Phone:	
Mailing Address:	

Prescription Insurance Information

Primary Insurance:
Aember ID:
Group Number:
Group Name/Employer:
Subscriber's Name:
Date of Birth:
Subscriber's Phone:
Aailing Address:

Secondary Insurance:	
Member ID:	
Group Number:	
Group Name/Employer:	
Jioup Name/Employer	

Subscriber's Name: _	
Date of Birth:	
Subscriber's Phone: _	
Mailing Address:	

Medical Bill Tracking Form

Date	Provider	Charges	Deductible	Primary Insurance Paid	Secondary Insurance Paid	Amount Owed /Date Paid



Helpful Hint:

Call your insurance provider if you have

questions about bills.

70 Your Child's Health Care Notebook

Medical Bill Communication Log

Date	Provider	Date of Service	Service Provided	Date of Contact	Time/Name	Notes

Out of Pocket Expenses

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

Preschool

School:		
Address:		
Principal:		
Phone:		
Teacher/Aide:		
ST/PT/OT Name:		
ST/PT/OT Phone::		

Kindergarten

School:		
Address:		
Principal:		
Phone:		
Teacher/Aide:		
ST/PT/OT Name:		
ST/PT/OT Phone::		

1st Grade

School:		
Address:		
Principal:		
Phone:		
Teacher/Aide:		
ST/PT/OT Name:		
ST/PT/OT Phone::		

2nd Grade

School:		
Address:		
Principal:		
Phone:		
Teacher/Aide:		
ST/PT/OT Name:		
ST/PT/OT Phone::		

3rd Grade

School:	
Address:	
Principal:	
Phone:	
Teacher/Aide:	
ST/PT/OT Name:	
ST/PT/OT Phone::	

4th Grade

School:	
Address:	
Principal:	
Phone:	
Teacher/Aide:	
ST/PT/OT Name:	
ST/PT/OT Phone::	

5th Grade

School:		
Address:		
Principal:		
Phone:		
Teacher/Aide:		
ST/PT/OT Name:		
ST/PT/OT Phone::		

6th Grade

chool:
ddress:
rincipal:
hone:
eacher/Aide:
T/PT/OT Name:
T/PT/OT Phone::

7th Grade

School:	
Address:	
Principal:	
Phone:	
Teacher/Aide:	
ST/PT/OT Name:	
ST/PT/OT Phone::	

8th Grade

School:		
Address:		
Principal:		
Phone:		
Teacher/Aide:		
ST/PT/OT Name:		
ST/PT/OT Phone::		

9th Grade

School:	
Address:	
Principal:	
Phone:	
Teacher/Aide:	
ST/PT/OT Name:	
ST/PT/OT Phone::	

10th Grade

School:	
Address:	
Principal:	
Phone:	
Teacher/Aide:	
ST/PT/OT Name:	
ST/PT/OT Phone::	

11th Grade

School:		
Address:		
Principal:		
Phone:		
Teacher/Aide:		
ST/PT/OT Name:		
ST/PT/OT Phone::		

12th Grade

School:	
Address:	
Principal:	
Phone:	
Teacher/Aide:	
ST/PT/OT Name:	
ST/PT/OT Phone::	

Transition Year

School:	
Address:	
Principal:	
Phone:	
Teacher/Aide:	
ST/PT/OT Name:	
ST/PT/OT Phone::	

Transition Year

School:		
Address:		
Principal:		
Phone:		
Teacher/Aide:		
ST/PT/OT Name:		
ST/PT/OT Phone::		

Transition Year

School:		
Address:		
Principal:		
Phone:		
Teacher/Aide:		
ST/PT/OT Name:		
ST/PT/OT Phone::		

Transition Year

School:	
Address:	
Principal:	
Phone:	
Teacher/Aide:	
ST/PT/OT Name:	
ST/PT/OT Phone::	



Insert a copy of your child's current IEP.

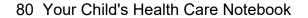
This should include a Transition Plan at the age of 14.

If you do not use an IEP then add your Section 504 and/or Individualized Health Plan (IHP) plan to this

section.



Insert a copy of legal papers (custody, guardianship, or advanced directive forms).



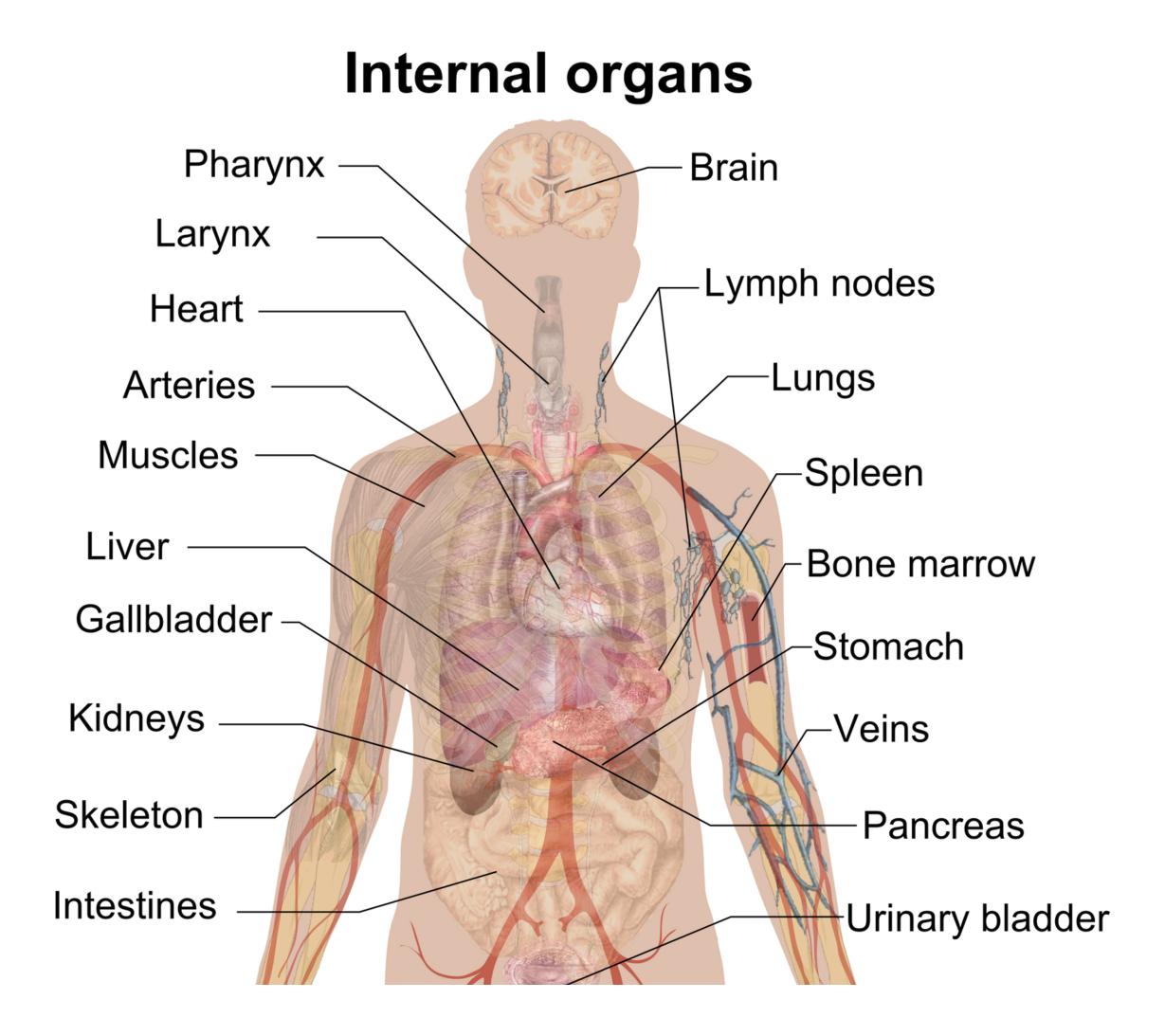
Letter Log

Date	To Whom	From Whom	Reason for Letter	Reply

Telephone Log

Date	Time	Person Called	Reason	Follow-Up

Body Map and 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.

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.

Complete 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 servicesat a discounted rate.

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

Neuropsychologist - A doctor who understands how thebrain works and assesses and treats patientswith 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 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 neededto play, function in school, and perform routineactivities (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 statelicensed medical professional. They practice medicine on healthcare 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 tllat pays any claims first.

Procedure - A medical treatment or operation done to diagnose, measure or treata 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 usingmedical imaging techniques, such as Xrays, 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

92 Your Child's Health Care Notebook

Acronym Index

ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AIDS	Acquired Immune Deficiency Syndrome
ARC	The ARC: Advocates for the Rights of Citizens with
	Developmental Disabilities and their Families
ARNP	Advanced Registered Nurse
BIA	Bureau of Indian Affairs
BD	Behaviorally Disabled
CAP-C	Community Alternatives Program for Children
CAP-MR/DD	Community Alternatives Program for Mentally
	Retarded/Developmentally Disabled Individuals
CD	Communication Disorders
CDS	Communication Disorders Specialist
CFR	Code of Federal Regulations
CHRMC	Children's Hospital and Regional Medical Center
CP	Cerebral Palsy
CPS	Child Protective Services
CSHCN	Children with Special Health Care Needs
CSO	Community Service Office, DSHS

DCFS	Division of Children and Family Services
DD	Developmentally Disabled
DDD	Division of Developmental Disabilities
DSHS DDPC	Developmental Disabilities Planning Council
DH	Developmentally Handicapped
DMH	Division of Mental Health
DH	Department of Health
DSB	Department of Services for the Blind
DSHS	Department of Social and Health Services
DVR	Division of Vocational Rehabilitation
ECDAW	Early Childhood Education and Assistance Program
ED	Emotionally Disturbed
EEG	Electroencephalogram
EFMP	Experimental Education Unit, CHDD Exceptional
	Family Member Program (helps military families
	locate to areas with services)

Acronym Index

EKG EPSDT ESD FAPE FRC HHS HI HMO HO	Electrocardiogram Early Periodic Screening, Diagnosis, and Treatment Educational Service District Free Appropriate Public Education Family Resources Coordinator Health and Human Services Health Impaired or Hearing Impaired Health Maintenance Organization Healthy Options, DSHS, Medicaid Managed Care
НОН	Hard of Hearing
ICC	Interagency Coordinating Council; county ICC and
state ICC.	
IDD	Intellectual Developmentally Disability
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
IFSP	Individual Family Service Plan
1& R	Information and Referral
ISP	Individual Service Plan
LD	Learning Disabled
LDA	Learning Disabilities Association
LEA	Local Education Agency
LICWAC	Local Indian Child Welfare Advocacy Board
LRE	Least Restrictive Environment
МСН	Maternal and Child Health
MD	Medical Doctor
MDT	Multi-Disciplinary Team
MH	Multiply Handicapped
MR	Mentally Retarded
MR/DD	Mentally Retarded/Developmentally Disabled
MS	Multiple Sclerosis

Acronym Index

NICU NORD	Neonatal Intensive Care Unit National Association of Rare Disorders
OCR	Office of Civil Rights
OCR	Office of Financial Management
	S S
OSEP	Orthopedically Impaired Office of Special Education Programs
OSERS	Office of Special Education and Rehabilitation
Services	Once of Special Education and Rehabilitation
OSPI	Office of Superintendent of Public Instruction
OT	Occupational Therapy/Therapist
OTR	Licensed and Registered Occupational Therapist
PAVE	Parents Are Vital in Education
P&A	Protection and Advocacy
PHN	Public Health Nurse
PL	Public Law
PT	Physical Therapy/Therapist
PTA	Parent Teacher Association
RN	Registered Nurse
RPR	Registered Physical Therapist
SBD	Seriously Behaviorally Disabled
SEA	State Education Agency
SEAC	Special Education Advisory Council
SEPAC	Special Education Parent/Professional Advisory
Council	
SLD	Specific Learning Disability
SSA	Social Security Administration
SSI	Social Security Income
STOMP	Specialized Training of Military Parents
SW	Social Work/Worker
TANF	Temporary Assistance to Needy Families
TAPP	Technical Assistance for Parents and Professionals
TASH	The Association for Persons with Severe Handicaps
TBI	Traumatic Brain Injury
TDD	Telecommunication Device for the Deaf
	U.S. Department of Defense Health Care System
TTY	Telecommunication Device for Deaf, Hearing,
\ /1	Impaired, and Speech Impaired Persons
V	Visually Impaired
WIC	Women, Infants and Children Supplemental Food
	Program

This list was adapted from and used with permission of PAVE.

Attachments

96 Your Child's Health Care Notebook



Asthma and Allergy Foundation of America

www.aafa.org/AnaphylaxisInAmerica

Sample Anaphylaxis Emergency Action Plan

NAME:		AGE:
ALLERGY TO:		
Asthma:	Yes (high risk for severe reaction)	🖵 No
Other health	problems besides anaphylaxis:	
Current medi	cations, if any:	

Wear medical identification jewelry that identifies the anaphylaxis potential and the food allergen triggers.

SYMPTOMS OF ANAPHYLAXIS INCLUDE:

- MOUTH—itching, swelling of lips and/or tongue
- THROAT*—itching, tightness/closure, hoarseness
- SKIN—itching, hives, redness, swelling
- GUT—vomiting, diarrhea, cramps
- LUNG*—shortness of breath, cough, wheeze
- HEART*—weak pulse, dizziness, passing out

Only a few symptoms may be present. Severity of symptoms can change quickly.

* Some symptoms can be life-threatening! ACT FAST!

WHAT TO DO:

1. INJECT EPINEPHRINE IN THIGH USING (check one):

Adrenaclick (0.15 mg) Adrenaclick (0.30 mg)	Auvi-Q (0.15 mg)	EpiPen Jr (0.15 mg) EpiPen (0.30 mg)
"Note: Patients should be allowed make sure a doctor has provided a and always keep this medication w	to self-carry and self-administer epil prescription for the right medication	nephrine; medications shown in alpha order; n for this patient, that it is current/not expired;
Other medication/dose/route:		
IMPORTANT: Asthma inhalers an	d/or antihistamines can't be de	epended on in anaphylaxis!
2. CALL 9-1-1 or RESCUE SQUAD) (before calling contacts)!	
3. EMERGENCY CONTACTS		
#1: home	workce	II
#2: home	_workce	
#3: home	work ce	II and the second s

DO NOT HESITATE TO GIVE EPINEPHRINE!

COMMENTS:

Doctor's Signature/Date

Parent's Signature (for individuals under age 18 years)/Date

†Adapted from J Allergy Clin Immunol 1998;102:173–176 and J Allergy Clin Immunol 2006;117:367–377.

<u>https://aafa.org/allergies/allergy-symptoms/anaphylaxis-severe-allergic-reaction/</u>

ASTHMA ACTION PLAN

Name:	Date:	
Doctor:	Medical Record #:	
Doctor's Phone #: Day	Night/Weekend	
Emergency Contact:		
Doctor's Signature:		





Asthma and Allergy Foundation of America aafa.org.

The colors of a traffic light will help you use your asthma medicines.



GREEN means Go Zone! Use preventive medicine.

YELLOW means Caution Zone! Add quick-relief medicine.

RED means Danger Zone! Get help from a doctor.

GO		Jse these daily contr	oller medicines:	
You have all of these: • Breathing is good • No cough or wheeze • Sleep through the night • Can work & play	to	MEDICINE	HOW MUCH	HOW OFTEN/WHEN
	F	For asthma with exercise,	take:	
CAUTION	(Continue with green	zone medicine and	add:
You have any of these: • First signs of a cold • Exposure to known trigger • Cough • Mild wheeze • Tight chest		MEDICINE	HOW MUCH	HOW OFTEN/ WHEN
DANGER		CALL YOUR ASTHMA CAR		or now.
 Your asthma is getting worse fast: Medicine is not helping Breathing is hard & fast Nose opens wide Trouble speaking Ribs show (in children) 		MEDICINE	HOW MUCH	HOW OFTEN/WHEN

GET HELP FROM A DOCTOR NOW! Your doctor will want to see you right away. It's important! If you cannot contact your doctor, go directly to the emergency room. DO NOT WAIT.

Make an appointment with your asthma care provider within two days of an ER visit or hospitalization.

<u>https://aafa.org/asthma/asthma-treatment/asthma-treatment-action-plan/</u>

1		
	•	
		<u> </u>

TODAY'S HEALTH CARE VISIT

I am to take this _____ times per day, at _____

COMPLETE BEFORE THE VISIT т

My Name: Today's Date: Who is with me today?	Why am I at the doctor's or clinic today? (Things like illness, check-up, follow-up from previous visit, need forms filled out, need medication change or refill, etc.)
Current list of my medications, pills, and vitamins (attach it for the doctor or nurse)	
Do I have a plan or card that pays for my medicine? Yes / No (list)	
Did I recently go see any other doctor or dentist? Yes / No (who?)	
What was the reason?	

QUESTIONS I WANT TO ASK TODAY	ANSWERS TO MY QUESTIONS
MY TAKE-AWAY	(INFORMATION
Were there any Medication or Diet Changes? YES / NO If yes:	Information about today's treatment plan, recommendations, and/or follow-up
Medication Name:	(Things like illness, check-up, follow-up from previous visit, need forms filled out, need medication change or refill, etc.)

Medication Name:	Contraction of the second s	
I am to take this times per day, a I am to stay on this for days (or s		
Why do I need to take this?		
and a second state when the second state second state second		
	and a second second	
Are there medications I don't need to	take	
Are there medications I don't need to anymore, or anything else I should kno	take	
Are there medications I don't need to	take	

<u>https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/healthy-living/</u>

SEIZURE ACTION PLAN (SAP)



Name:	Birth Date:	
Address:	Phone:	
Emergency Contact/Relationship:	Phone:	

Seizure Information

Seizure Type	How Long It Lasts	How Often	What Happens
-			

How to respond to	o a seizure (check	all that apply)
-------------------	--------------------	-----------------

First aid - Stay. Safe. Side. Call 911 for transport to ____

Notify emergency contact at _____

Give rescue therapy according to SAP

Notify emergency contact

Other_

First Aid for any seizure

- STAY calm, keep calm, begin timing seizure
- Keep me SAFE remove harmful objects, don't restrain, protect head
- SIDE turn on side if not awake, keep airway clear, don't put objects in mouth

When to call 911

- Seizure with loss of consciousness longer than 5 minutes, not responding to rescue med if available
- Repeated seizures longer than 10 minutes, no recovery between them, not responding to rescue med if available
- D Difficulty breathing after seizure
- Serious injury occurs or suspected, seizure in water

STAY until recovered from seizure	When to call your provider first
Swipe magnet for VNS	Change in seizure type, number or pattern
Write down what happens	Person does not return to usual behavior (i.e., confused for a long period)
D Other	First time seizure that stops on its' own
	Other medical problems or pregnancy need to be checked
When rescue therapy may be nee	eded:
When and What to do	
If seizure (cluster, # or length)	
Name of Med/Rx	How much to give (dose)
How to give	
If seizure (cluster, # or length)	
Name of Med/Rx	How much to give (dose)
How to give	
f seizure (cluster, # or length)	
	How much to give (dose)
How to give	
	epilepsy.

#2020 Epilepsy Foundation of America, Inc. Revised 03/2023 1305RP/PABI216



https://www.epilepsy.com/sites/default/files/2023-08/SeizureActionPlan2023ACCE.pdf

Seizure Action Plan continued

Care after seizure

What type of help is needed? (describe)

When is person able to resume usual activity?

Special instructions

First Responders:		
Emergency Department:		

Daily seizure medicine

Medicine Name	Total Daily Amount	Amount of Tab/Liquid	How Taken (time of each dose and how much)

Other information

Triggers:

Important Medical History

Health care contacts

Epilepsy Provider:	Phone:	
Primary Care:	Phone:	
Preferred Hospital:	Phone:	
Pharmacy:	Phone:	
My signature:	Date	
Provider Signature:	Date:	

epilepsy.com

#2020 Epilepsy Foundation of America, Inc. Revised 03/2023 1305RP/PABt216





<u>https://www.epilepsy.com/sites/default/files/2023-08/SeizureActionPlan2023ACCE.pdf</u>

Wound Assessment form

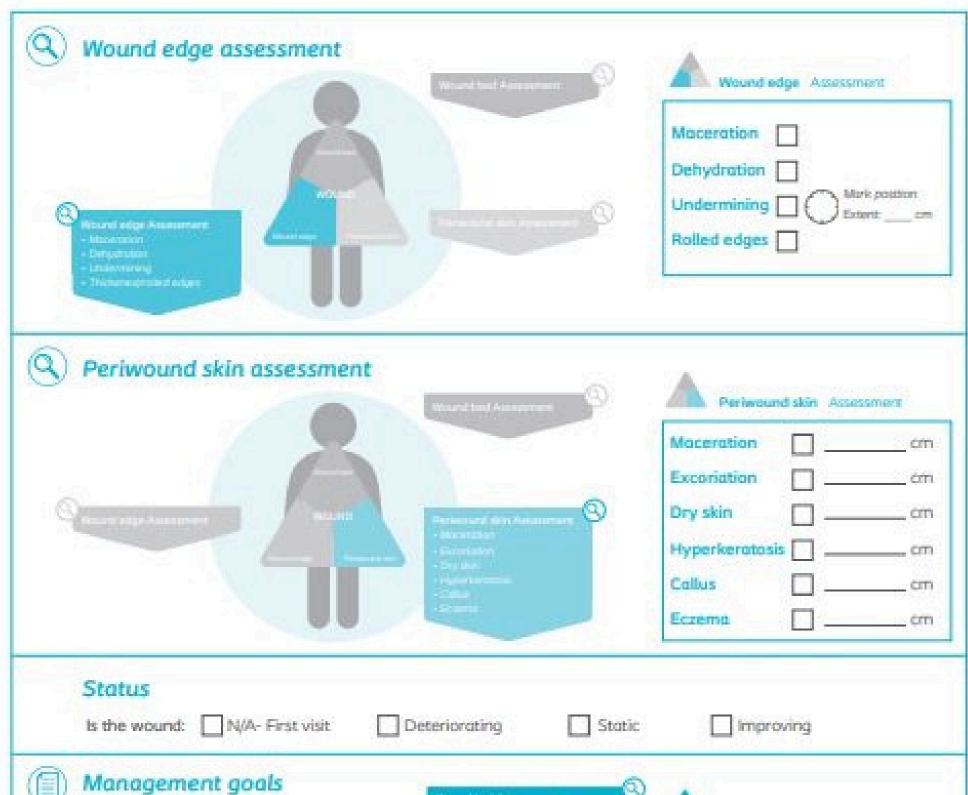
Date: Patient Name: . Patient ID: _

Patient	Wound description
Age:years	Wound type:
Weight:kgs	Duration of wound:
Gender: 🗌 Male 🗌 Female	Previous treatments:
Nutrition status: Well nourished Malnourished	Size: lengthmm widthmm depthm
Mobility status: Good mobility Bad Mobility	and the second
Smoking: Yes No	Wound location (please circle wound):
	SX RR NUM
If yes, how many/day:	0/11/11/11/2015
Alcohol: units/week	MANANN -
Co-morbidities:	1 1 1 1 1 1 1 BC
	J/ W/ W/ W/ 11 177
	Pain level:
Medications:	
Medications:	0 1 2 3 4 5 6 7 8 9
ABPI (if done): Date:	
	No pain Moderate pain Worst
Wound bed assessment	Wound bed Assessment Tissue type Necrotic - % Sloughy - %
Wound bed assessment	Wound bed Assessment Tissue type Necrotic - % Skughy - %
Wound bed assessment	Wound bed Assessment Tissue type Necrotic% Granulating% Sloughy% Epithelialising%
Wound bed assessment	Wound bed Assessment Viewer Necrotic % Sloughy % Exudate Level Dry Low Medium High Type Theywatery Cloudy
Wound bed assessment	Wound bed Assessment Vound bed Assessment Tissue type Necrotic % Soughy % Soughy % Exudate Level Dry Low Medium High Type Theywatery Cloudy Thick Purulent
Wound bed assessment	Image: Second and Seco
Wound bed assessment	Image: Second Secon
Wound bed assessment	Wound bed Assessment Tissue type Necrotic % Sloughy % Exudate Level Dry Low Medum High Type Theywatery Clear Purulent Dry Clear Preview Infection Local Spreading/systemic Erythema Pyresia
Wound bed assessment	Wound bed Assessment Tissue type Necrotic% Soughy% Soughy% Exudate LevelDryLowMediumHigh TypeThis/wateryCloudyThick PurulentClearPrevined Infection Local Erythema Erythema Octema
Wound bed assessment	Wound bed Assessment Tissue type Necrotic % Soughy % Exudate Level Dry Low Mechum Purulent Clear Prevident Infection Local Dry clear Dry clear Dry clear Mechum
Wound bed assessment	Image: Second
Wound bed assessment	Image: Second





<u>https://www.coloplast.com/Global/1_Corporate_website/Products/</u> Woundcare/TOWA/CPWSC_EWMA%202017_TOWA_Wound%20a ssesment_Onepager%20A4_no%20marks.pdf



ma	inagement goals		Monopiment gools - Remote non-victie toue - Monopi evictore	-	Pite all management goals
		À	Monage bacterial burden Antydrate waand ded Protect granulation/epitte		
wind red	Lab Assessment		Participant data Assessment	. 0	
	ers grade		Manual Install grants	0	
	er mannet måget norst vikkeler forsket norskelskonstygeter forsket		- Providence Reference and Providence and		
1	eatment choice		Dress	ing type/name	
Re	eason for choosing dress	ing:			
Fo	ollow up plan				
	te of next visit:	Main obj	ective at next visit:		



https://www.coloplast.com/Global/1_Corporate_website/Produc ts/Woundcare/TOWA/CPWSC_EWMA%202017_TOWA_Wound %20assesment_Onepager%20A4_no%20marks.pdf

Daily Central Line Maintenance Checklist - Template

Patient Name/ID#:	Unit:	Room/Bed:
Date:		
Person Completing Form: Name		
Date of initial line placement:		
Date implanted port accessed:		
Date injection caps last changed:		
Date administration set and add-on devices last	changed:	
Set used for: Continuous Infusion	Intermittent Infusion	
Date dressing last changed:	Dressing type: G	auze Clear

Critical Steps	Yes	No	N/A	Notes/Comments
Necessity assessed If no longer necessary, remove, indicating details of removal in the records (including date, location, and signature and name of operator undertaking removal).				
Injection sites are covered by caps or valved connectors				
Caps changed today				
Implanted ports newly accessed today				
Accessed with (indicate type and size of needle)				
Insertion site without evidence of infection		ľ		
Dressing intact and labeled property				
Dressing changed today				
Catheter stabilized/no tension on line				
Administration set replaced and labeled this time?				

Procedural Reminders

Suspected Infection

If central venous catheter infection is strongly suspected, replace catheter and all intravenous fluids, tubing, and caps.

Hand Hygiene

 Clean hands immediately before and after each episode of patient contact using the correct hand hygiene technique. (Use World Health Organization "My 5 Moments for Hand Hygiene".)

Cap Changes

- Sanitize caps with 2%chlorhexidine gluconate in 70% isopropyl alcohol before and after each use ("Scrub the Hub").
- Change caps when necessary using sterile gloves and mask, that is, after administering blood and if there is visual observation of blood in the caps.
- Change caps no more often than 72 hours (or according to the manufacturer's recommendations and whenever the administration set is changed).

Tubing Changes

- Replace administration sets and add-on devices no more frequently than every 96 hours, and at least every 7 days, after initiation of use, unless contamination occurs.
- Replace set and add-on devices within 24 hours of start of infusion if fluids that enhance microbial growth are infused (for example, fat emulsions combined with amino acids and glucose in three-in-one admixture or blood products infused separately).
- Change needleless components as often as the administration set and no more often than 72 hours.

Dressing Changes

- Change gauze dressing every 2 days, clear dressings every 7 days, unless dressing becomes damp, loosened, or visibly solled then change.
- Use sterile gauze or sterile, transparent, semipermeable dressings.
- Perform catheter site care using 2% chlorhexidine gluconate in 70% isopropyl alcohol to clean the insertion site during dressing changes.

© The Joint Commission. May be adapted for internal use. Suggested citation: The Joint Commission. Preventing Central Line-Associated Bloodstream Infections: Useful Tools, An International Perspective. Nov 20, 2013. Accessed [user please fill in access date]. http://www.jointcommission.org/CLABSIToolkit



https://www.jointcommission.org/-/media/tjc/documents/resources/health -services-research/clabsi-toolkit/clabsi_toolkit_tool_3-23_daily_central_line_maintenance_checklist_-_templatepdf.pdf

Helpful Websites

http://www.aap.org/ American Academy of Pediatrics

www.HealthyTransitionsNY.org

For youth with developmental disabilities ages 14-25, family caregivers, service coordinators, and health care providers. It teaches skills and provides tools for care coordination, keeping a health summary, and setting priorities during the transition process. It features video vignettes that demonstrate health transition skills and interactive tools that foster self-determination and collaboration.

<u>http://medicalhomeinfo.org/</u>

Provides resources for health professionals, families, and everyone interested in creating a family-centered medical home for all children and youth.

Other versions of care notebooks and helpful forms can be downloaded at: www.cshcn.org

Information on care notebooks & emergency preparedness www.FullLifeAhead.org

Citations

https://aafa.org/allergies/allergy-symptoms/anaphylaxis-severe-<u>allergic-reaction/</u>

<u>https://www.coloplast.com/products/wound/triangle/</u>

https://aafa.org/asthma/asthma-treatment/asthma-treatment-<u>action-plan/</u>

https://www.lifecoursetools.com/lifecourse-library/exploring-the-<u>life-domains/healthy-living/</u>

<u>https://www.epilepsy.com/local/missouri-kansas</u>

<u>https://www.jointcommission.org/-/media/tjc/documents/resourc</u> es/health-services-research/clabsi-toolkit/clabsi_toolkit_tool_3-<u>23_daily_central_line_maintenance_checklist_-_templatepdf.pdf</u>

Thank you to the following groups for creating pages that I was able to incorporate into the use of a Care Notebook in the State of Missouri:

- Asthma and Allergy Foundation of America
- Coloplast
- Epilepsy Foundation
- Life Course Nexus, UMKC, IHD

The creation of this Care Notebook would not have been possible without the tools they have provided.



Stanberry: 302 N Park Street Stanberry, MO 64489 Phone: 660-783-2707 Fax: 660-783-2775

Maysville: 302 S Washington Street Maysville, MO 64469 Phone: 816-449-5706 Fax: 816-449-2221

Stewartsville: 1307Main Street Stewartsville, MO 64490 Phone: 660-254-0021

Grant City

16 West 4th Street Grant City, MO 64456 Phone: 660-564-8070 Fax: 660-300-4010



Developed through collaboration of the Tri-County Health Department and the Missouri Department of Health and Senior Services, Bureau of Special Health Care Needs and Family Partnership.

This project is/was funded in part by the Missouri Department of Health and Senior Services Maternal Child Health Services Program Contract #DH220051154 and is/was supported by the Health Resources Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant#B04MC47428, Maternal and Child Health Services for \$12,834,718, of which \$0 is from nongovernmental sources. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.











