

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 education plan (IEP).
- Give the school information

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.

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.
- 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 for healt share their medical information with people they trust. This may be a friend, relative, therapist or teacher.

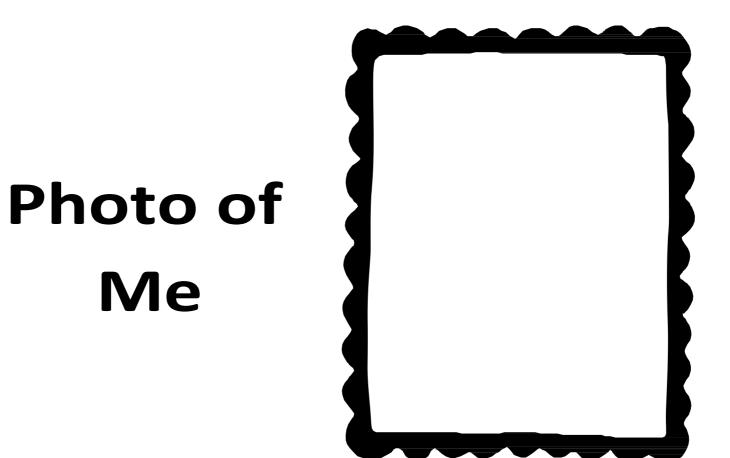
18 and beyond:

- 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 amYears Old	
My Pet's Name is:	

My Favorites

Toys:
Animal:
Games:
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

anguage Spoken at Home :
Other Language(s):
nterpreter Needed: Yes No
⁻ Yes, Interpreter Name:
hone:
mail:

Primary Emergency Contact

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

Preferred Method to be Contacted: _____

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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:

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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

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 Char	nged:

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:

Temperament/Behaviors:

Activity:

Other:

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:

Intermediate Dangerous Behavior:

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:

1			
2.			
3.			

Worsening Symptoms: _____

Acti	ion Plan:		
1			
2			
3.			

Dangerous Symptoms: _____

Action Plan: 1. _____ 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:			
Phone:			
Fax:			
Hours:			

Medical Equipment Supplier

Supplier:	
Contact:	
Address:	
Phone:	
Fax:	
Hours:	
Supplier:	
Contact:	
Address:	
Phone:	
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:	
ervice:	
Contact:	
Address:	
hone:	
ax:	
lours:	

Home Nursing Agencies

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

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

Hours: _____

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

Childcare Provider

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

Respite Care Provider

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

Pharmacy

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

Dentist-Orthodontist

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

Social Worker

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

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Communication Notes

Date:	
ime:	
Communication Type (telephone, meeting, email)	
Name:	
Agency:	
Phone:	
Reason	

_

Notes

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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.

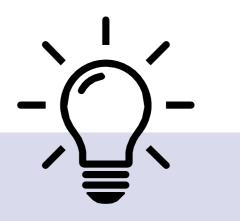
Example: If your son is in the 3oth percentile forweight, this means that 30 percent (or 30 out of 100) boys the same age weigh the same or less. This also means that 70 percent (or 70 out of 100) hours weigh more

out of100) boys weigh more .

Immunizations

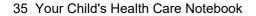
Be sure your child's immunizations are up-to-date.

	Date	Date	Date	Date	Date	Date
Hep B						
Dtap						
Hib						
Polio						
PVC13						
RV						
MMR						
Varicella						
Hep A						
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

i

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

lame of Equipment:	
Drdered by (provider):	
Account #	
erial #/Model:	
Description:	
upplier:	
Product:	
Contact:	
Address:	
hone:	
ax:	
lours:	

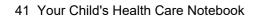
Name of Equipment:	
Ordered by (provider): _	
Account #	

erial #/Model:	
Description:	
upplier:	
Product:	
Contact:	
Address:	
hone:	
ax:	
lours:	



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 change the needleless connector:

How often to do a dressing change:

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

(i)

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:

1) Bronchodilators:

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

Date Purchased:
Type of Device:
Manufacturer:
Mode:
Manual Automatic
Expiratory Pressure:
Inspiratory Pressure:
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: _____

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:

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:
Prism:
Base:
Sphere: Cylinder: AXIS: Prism:

left Eve

Sphere:	
Cylinder: _	
AXIS:	
Prism:	
Base:	

Glasses Contacts Prosthesis History of ROP (Retinopathy of Prematurity) Surgery Lasik Other:

Other Comments or Pertinent Health Information:

Audiology/Hearing

Clinic:
Audiologist:
Date of First Visit:
Medical Record Number:
Address:
Phone Number:
Email:
Website:
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: _			

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	Imp	lants:
--	-----	----	-----	------	----	-----	--------

Purchase Date:	
How are the devices stored: _	

Hearing Aid Information

Brand: Model:
Type of Battery:
Rechargeable?
Yes No
Which Ear?
Right Left Both

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

Yes No

Brand of Microphone:	
Model of Microphone: _	

Purchase Date: _____ How are the devices stored: _____

Bone Conduction Device

•
-

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

Yes No

Brand of Microphone: ______ Model of Microphone: _____

Purchase Date: ______ How are the devices stored: ______

Speech and Communication

Clinic:
peech & language pathologist:
Date of first visit:
Aedical Record#:
Address:
hone:
ax:
mail:
Vebsite:

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
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:

Size of Catheter:

Other Pertinent	Information:
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Catheterization Schedule

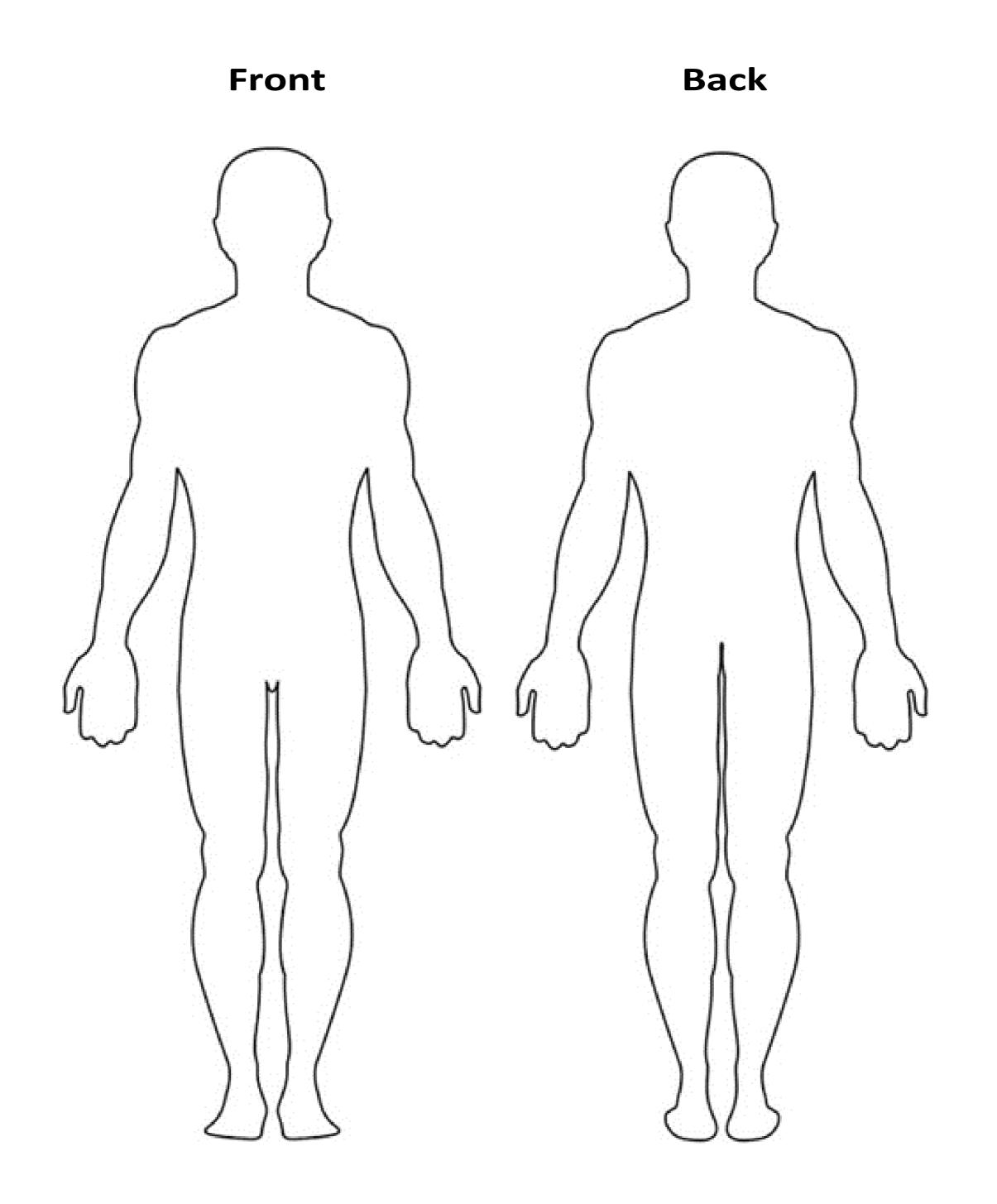
Date	TIme	Amount of Urine	Comment

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.





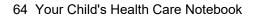
No	Hurts	Hurts	Hurts	Hurts	Hurts
Hurt	Little Bit	Little More	Even More	Whole Lot	Worst

Insurance and Expenses

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Medicaid is always secondary to any other insurance.



Medical Insurance Information

imary Insurance:	
ember ID:	
roup Number:	
roup Name/Employer:	
ubscriber's Name:	
ate of Birth:	
ubscriber's Phone:	
ailing Address:	
econdary Insurance:	
ember ID:	
roup Number:	
roup Name/Employer:	
bscriber's Name:	

Date of Birth:

Subscriber's Phone: _____

Dental 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: _____

Vision Insurance Information

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

Date of Birth:

Subscriber's Phone: _____

Prescription 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: _____

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.

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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:	
Teacher/Aide:	
ST/PT/OT Name:	
ST/PT/OT Phone:: _	

Kindergarten

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

1st Grade

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

2nd Grade

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

3rd Grade

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

4th Grade

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

5th Grade

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

6th Grade

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

7th Grade

School:
Address:
Principal:
hone:
eacher/Aide:
T/PT/OT Name:
T/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:	
ST/PT/OT Phone:: _	

10th Grade

School:
Address:
Principal:
Phone:
eacher/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

zhool:	
ddress:	
rincipal:	
none:	
eacher/Aide:	
/PT/OT Name:	
/PT/OT Phone::	

Transition Year

Transition Year

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

Transition Year

chool:	
ddress:	
rincipal:	
none:	
eacher/Aide:	
r/PT/OT Name:	
<pre>F/PT/OT Phone::</pre>	

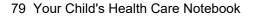
Transition Year



Insert a copy of your child's current IEP.

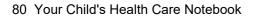
This should include a Transition Plan at the age of 14.

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).



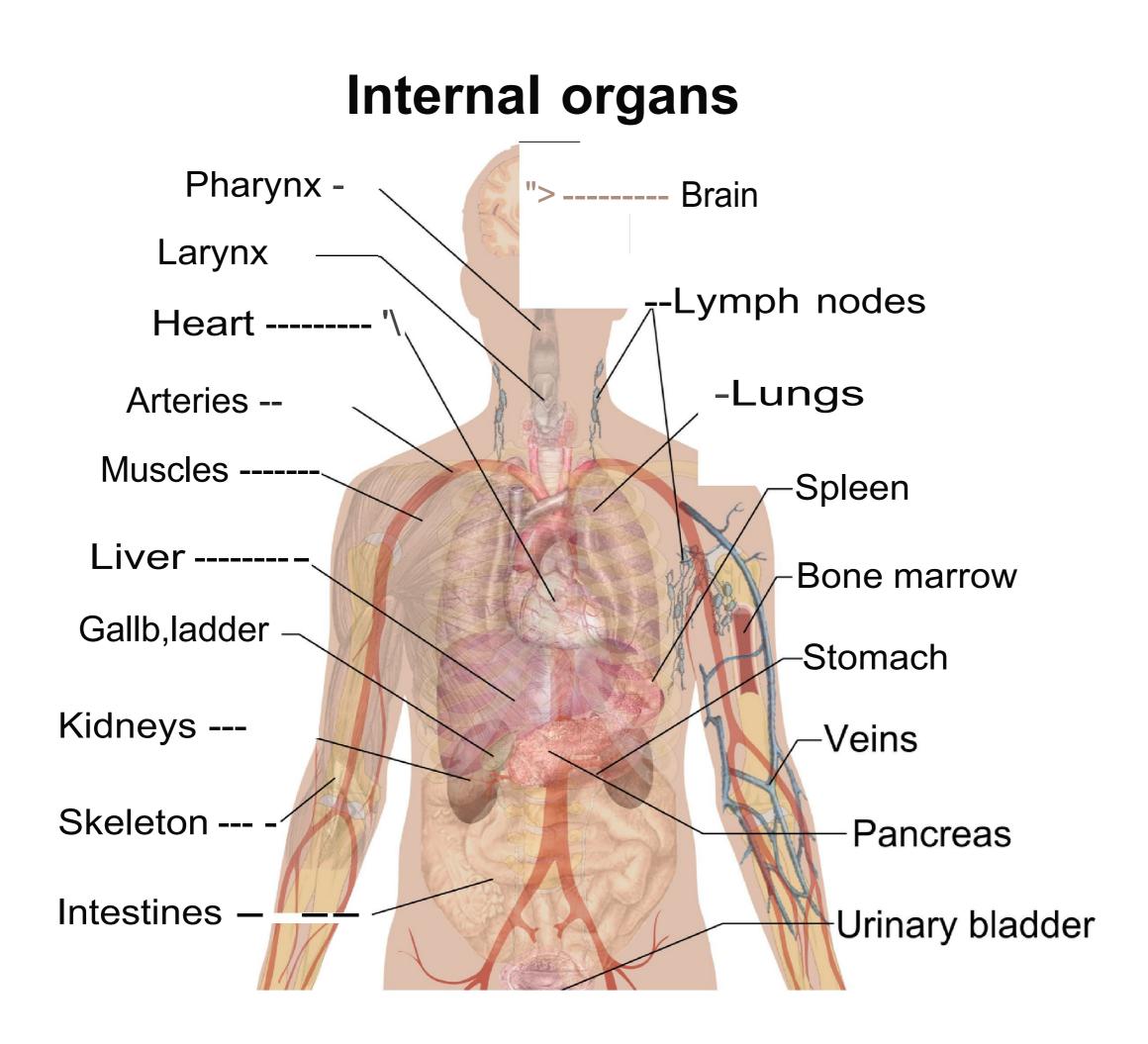
Letter Log

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 copayment 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 specia 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 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 co payments. 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 t11at 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 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 plancovers costs that are left over after the primary insurance pays its share.

Services - Health care that is given by a provider. This includescare 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

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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 HOH	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 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
MCH	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

	Neonatal Intensive Care Unit
	National Association of Rare Disorders
OCR	Office of Civil Rights
OFM	Office of Financial Management
	Orthopedically Impaired
OSEP	Office of Special Education Programs
OSERS	Office of Special Education and Rehabilitation
Services	
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
TRICARE	U.S. Department of Defense Health Care System
TTY	Telecommunication Device for Deaf, Hearing,
	Impaired, and Speech Impaired Persons
VI	Visually Impaired
WIC	Women, Infants and Children Supplemental Food
	Program

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

Attachments

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www.aafa.org/AnaphylaxisInAmerica

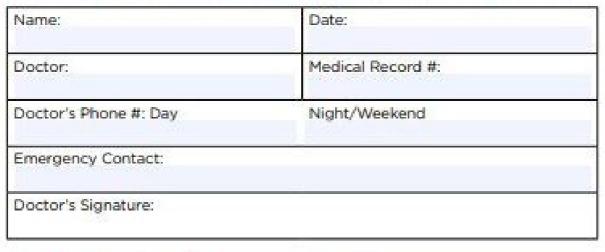
Sample Anaphyla•x s Emergency Ac io Plan

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

ASTHMA ACTION PLAN



aafa Foundation of America

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.

Use these daily controller medicines: GO You have all of these: MEDICINE HOW MUCH HOW OFTEN/WHEN Breathing is good No cough or wheeze Peak flow: Sleep through from the night Can work & play to For asthma with exercise, take: CAUTION Continue with green zone medicine and add: You have any of these: MEDICINE HOW MUCH HOW OFTEN/ WHEN First signs of a cold Exposure to known Peak flow: trigger from · Cough Mild wheeze to Tight chest Coughing at night CALL YOUR ASTHMA CARE PROVIDER.

Personal Best Peak Flow:_

DANGER	Take these medicines and call your doctor 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.

https://aafa.org/asthma/asthma-treatment/asthma-treatment-action-plan/

TODAY'		
	· 20 p 1 7 - 1	are via

COMPLETE BEFORE THE VISIT

IT

ings like illness, check-up, follow-up from previous visit I forms filled out, need medication change or refill, etc
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QUESTIONS I WANT TO ASK TODAY	ANSWERS TO MY QUESTIONS

		THE R PERSON NEW YORK, N. A. CONT. & ADD. NO. 10.	
MY IA	KE-AWAY	INFORMATION	
		all all and the second second second	

Were there any Medication or Diet Changes?

YES / NO If yes:

Medication Name: ____

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

I am to stay on this for _____ days (or specify _____)

Why do I need to take this?

Information about today's treatment plan, recommendations, and/or follow-up

(Things like illness, check-up, follow-up from previous visit, need forms filled out, need medication change or refill, etc.)



<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 I	Long It Lasts	How Often	What Happens
How to respond to a seizure (che		ergency contact a	t
Give rescue therapy according to SA	P Call 911 for	r transport to	
First Aid for any seizure			usness longer than 5 minutes, ed if available
seizure Keep me SAFE - remove harmful object don't restrain, protect head	s, them, no	d seizures longer that of responding to reso of breathing after seized	

- SIDE turn on side if not awake, keep airway clear, don't put objects in mouth
- STAY until recovered from seizure
- Swipe magnet for VNS

- □ Serious injury occurs or suspected, seizure in water

When to call your provider first

- Change in seizure type, number or pattern
- Write down what happens
- □ Other

- Person does not return to usual behavior (i.e., confused for a long period)
- First time seizure that stops on its' own
- Other medical problems or pregnancy need to be checked

When rescue therapy may be needed:

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	
If seizure (cluster, # or length)	
Name of Med/Rx	How much to give (dose)
How to give	
	E2020 Epilepsy Foundation of America, Inc. Revised 03/2023 1505RP/PA81216



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:	
Allergies:	

Epilepsy Surgery (type, date, side effects)				
Device: VNS RNS DBS Date Implanted				
Diet Therapy: Ketogenic Low Glycemic M	Iodified Atkins Other (describe)			
Special Instructions:				
Health care contacts				
Epilepsy Provider:	Phone:			
Primary Care:				
Preferred Hospital:	Phone:			
Pharmacy:	Phone:			
My signature:	Date			
Provider Signature:	Date:			

epilepsy.com

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

6 EPILEPSY

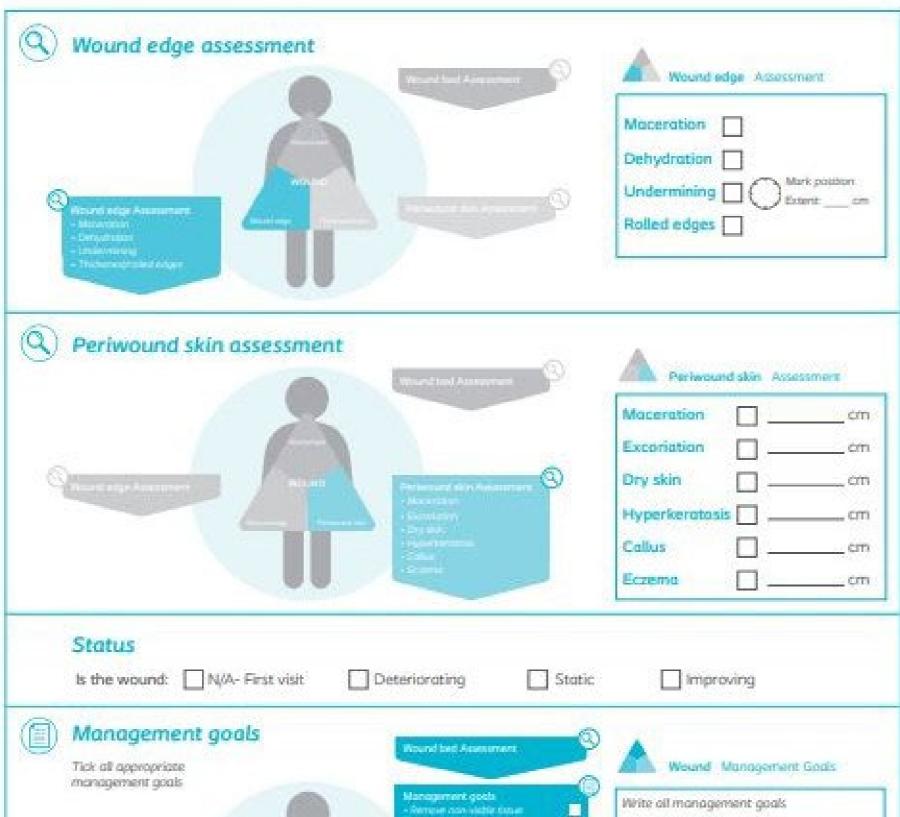
Wound Assessment form

Patient			escription		
Age:years Weight:kgs			wound:		
Gender: Male Female		and a state of the state of the	atments:		
Nutrition status: Well nourished		Size: length_	mmwidth	m	depth
Mobility status: Good mobility	1211201-000	Wound locati	on (please circle w	ound):	
Smoking: Ves		RR	R.R.	IN	21/11
Alcohotunits/week	any/day:	Q1 1 1	01111	IS	50
		4340	A141)A1		1 4
Co-morbidities:)) (())		1210	(R
		Pain level:	00 15	100	
					1 1
Medications:		0 1 2	3 4 5	6 7	8 9
ABPI (if done):	Date:	No pain	Moderate	pain	Wors
	Wound bed Assess	Sk Sk	ssue type contic	Granulating Epithelialisin	0% 20%
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		Ty	Purulent	Coudy Cear	□ Thick □ Pink/red
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<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



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Waresperson years	Manual Annual Annua
Altropy Analogy Annotation Annotation and a second adjust Annotation and a second adjust Annotation and a second adjust	
Treatment choice	Dressing type/name:
Reason for choosing dressing:	
Follow up plan	
Date of next visit:	Main objective at next visit:

Estany Care / Commence Care / Viound & Skin Care / Unology Com-

Complian A/S, Hadestan S, 3050 Hamileback, Denmark down Introductions: The Colophan logic is a registered increment of Colophant A/S -D 2012/D4. All rights reserved Colophant A/S





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	2÷	
Date of initial line placement:		
Date implanted port accessed:		
Date injection caps last changed:		
Date administration set and add-on devices last cha	inged:	
Set used for: Continuous Infusion In	termittent Infusion	
Date dressing last changed:	Dressing type: Ga	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				
Dressing intact and labeled property				
Dressing changed today				
Catheter stabilized/no tension on line				
Administration set replaced and labeled this time?				

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 soiled 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.

http://medicalhomeinfo.org/

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-severeallergic-reaction/

https://www.coloplast.com/products/wound/triangle/

https://aafa.org/asthma/asthma-treatment/asthma-treatmentaction-plan/

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

https://www.epilepsy.com/local/missouri-kansas

<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.



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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.













