



Your Child's



Health Care

Notebook



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:

[illegible]

Parent's guide to managing your child's health care

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

For all ages:

Get organized Use a health care notebook or a smart phone health passport application (app).
Ask your doctors, nurses, and counselors questions. Write down what you learn.
Download the patient portal app for your smart phone.
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 about your child's condition. Teach them signs of an emergency.

Have a plan for handling a health emergency at school.

Teach your child to be aware of signs of pain, discomfort or changes in their body and when to tell an adult.

Act out situations your child might have at school with classmates, teachers or in gym class. This will help your child practice how to answer questions about their medical condition.

3 to 5 years old:

Read storybooks about children with differences and special medical needs.

Teach your child about their health and medicine. Create a daily schedule for medicines, therapies and hygiene. Involve your child in their daily care. Encourage your child to talk to doctors during appointments.

10 to 14 years old:

Teach your child about their medicine and what happens if they don't take their medicine.

Teach your child how to use other supplies needed for their condition.

Start a list of important words for your child to know about their health and medical condition.

Let your doctors, nurses and social workers know what you are comfortable talking about with your child.

Teach your child about puberty and what may be different about their experience. Schools often start education about puberty in 4th to 6th grade. Give your child books, websites and videos about their condition so they can read or watch by themselves.

Encourage questions. Prepare your child to have one question for their doctor or nurse at every appointment.

14 to 18 years old:

Remind your child of their medical needs, names of conditions, surgical history and allergies.

Teach your child how to order supplies, manage health insurance, schedule appointments and refill prescriptions.

Tell your child about medical care and treatments they may need as they become adults.

Start having your child plan their own schedule to include medicine, therapies and hygiene.

Encourage your child to share their medical information with people they trust. This may be a friend, relative, therapist or teacher. Bring your child to groups where they can meet other kids with their condition. Request to meet an older person with your child's condition.

Sex education usually begins in 6th grade. Talk with your child and your child's health care team about any medical needs that affect puberty, sex and intimacy.

If your child cannot make their own medical decisions, apply for a medical power of attorney.

18 and beyond:

Provide support. Help your child become responsible for taking care of their own health needs as an adult.

Help your child find doctors, therapists and specialists if your child is living away from home, going to college or transferring to a doctor who treats adults.

Help your child understand and plan for health insurance.

My family and Personal Information

Photo of Me!

Date:

My Name Is:

My Nickname Is:

I am Years Old:

My Pet Is A:

My Pet's Name Is:

"My Favorites"

Toys:

Animal:

Games:

Hobbies:

Music:

T.V. Shows:

Other:

My Favorite Foods Are:

My Least Favorite Foods Are:

My Friends Names 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

Who Can Be Reached 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 Home: _____

Other Languages: _____

Interpreter Needed: Yes No

Interpreter Name: _____

Phone: _____

Email: _____

Primary Emergency Contact

Name: _____

Relation: _____

Address: _____

Daytime Phone: _____

Evening Phone: _____

Cell Phone: _____

Email: _____

Preferred Method to Be Contacted: _____

Emergency contacts

Name:	Relation:	
Phone:	Other Phone:	
Address:		
City:	State:	Zip Code:

Name:	Relation:	
Phone:	Other Phone:	
Address:		
City:	State:	Zip Code:

Name:	Relation:	
Phone:	Other Phone:	
Address:		
City:	State:	Zip Code:

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:

[illegible]

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: _____

Diet and Nutrition

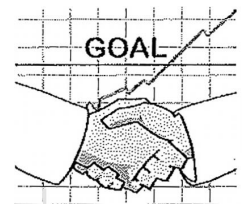
Diet: _____

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 Nasointestinal 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 of Feed: _____

Type of Formula: _____

Feed Rate mL/hr: _____

Amount of Feed (mL): _____

Date of Last Tube Change: _____

Next Time Tube Needs Changed: _____

Allergic Reaction Tracking Form



DATE	ALLERGEN	REACTION	ANECDOTE (w/Dosage)



Sample Anaphylaxis Emergency Action Plan

NAME: _____ AGE: _____

ALLERGY TO: _____

Asthma: ☐ Yes (high risk for severe reaction) ☐ No

Other health problems besides anaphylaxis: _____

Current medications, 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)

☐ Auvi-Q (0.15 mg)

☐ EpiPen Jr (0.15 mg)

☐ Adrenaclick (0.30 mg)

☐ Auvi-Q (0.30 mg)

☐ EpiPen (0.30 mg)

**Note: Patients should be allowed to self-carry and self-administer epinephrine; medications shown in alpha order; make sure a doctor has provided a prescription for the right medication for this patient, that it is current/not expired; and always keep this medication within reach of the patient.*

Other medication/dose/route: _____

IMPORTANT: Asthma inhalers and/or antihistamines can't be depended on in anaphylaxis!

2. CALL 9-1-1 or RESCUE SQUAD (before calling contacts)!

3. EMERGENCY CONTACTS

#1: home _____ work _____ cell _____

#2: home _____ work _____ cell _____

#3: home _____ work _____ cell _____

DO NOT HESITATE TO GIVE EPINEPHRINE!

COMMENTS:

Doctor's Signature/Date

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

Medical Information

Baseline Information:

Blood Pressure: _____

Pulse Rate/Heart Rate: _____

Respiratory Rate: _____

Respiratory Pattern: _____

Oxygen Saturation: _____

Temperature: _____

Appetite: _____

Temperament/Behaviors: _____

Activity Level:

Other (skin/pigmentation, bowel, bladder, etc.): _____

Care Plan for Behavior 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. _____
3. _____

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:

Action 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: _____

City: _____ Zip: _____

Care Coordinator: Phone: _____

Hours: _____ Fax: _____

Email: _____

Urgent Care - After Hours - Advice Nurse

Name: _____

Address: _____

City: _____ Zip: _____

Phone: _____ Fax: _____

Hours: _____ Email: _____

Primary Hospital

Hospital: _____

Information Phone Number: _____

Address: _____

Emergency Room Phone Number: _____

Special Transportation

Transportation Agency: _____

Contact Name: _____ Phone: _____

Address: _____

Transportation Agency: _____

Contact Name: _____ Phone: _____

Address: _____

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:	

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

Medical Equipment Supplier

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

Community Agencies

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

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

Home Nursing Agencies

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

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

Child Care Provider

Name:	Phone:
Address:	Email:
Notes:	
Name:	Phone:
Address:	Email:
Notes:	

Respite Care Provider

Name: _____ Phone: _____

Address: _____ Email: _____

Notes: _____

Name: _____ Phone: _____

Address: _____ Email: _____

Notes: _____

Name: _____ Phone: _____

Address: _____ Email: _____

Notes: _____

Pharmacy Used for Prescriptions

Pharmacy: _____ Pharmacist: _____

Phone: _____ Fax: _____

Address: _____ Hours: _____

Notes: _____

Pharmacy: _____ Pharmacist: _____

Phone: _____ Fax: _____

Address: _____ Hours: _____

Notes: _____

Pharmacy: _____ Pharmacist: _____

Phone: _____ Fax: _____

Address: _____ Hours: _____

Notes: _____

Dentist - Orthodontist

Name: _____ Phone: _____

Address: _____ Fax: _____

Hours: _____ Notes _____

Name: _____ Phone: _____

Address: _____ Fax: _____

Hours: _____ Notes _____

Social Worker

Name: _____ Phone: _____

Email: _____ Address: _____

Notes: _____



TODAY'S HEALTH CARE VISIT

COMPLETE BEFORE THE VISIT

My Name: _____

Today's Date: _____

Who is with me today? _____

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? _____

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.)

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:*

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? _____

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? _____

Are there medications I don't need to take
anymore, or anything else I should know?

**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.)

medical professional signature

date

staff or provider signature

date



Communication notes

Date: _____ Time: _____

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

Name: _____ Title: _____

Agency: _____ Phone: _____

Address: _____

Reason: _____

Discussion: _____

Summary: _____

Follow Up: _____

Growth chart

Child's name:

Date of birth:

Date Measured	Age	Weight	Height (length)	Percentiles Weight/Age	Percentiles Height/Age	Percentiles Weight/Height	Comments

What is a percentile?

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

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

Immunizations (vaccinations)

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

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



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

Surgeries or procedures

[illegible]

Hospitalization Stays

Date	Reason	Doctor/s	Changes	Notes



Patient home medicine list

We will ask to see your medicines or list.

Child's Name:

Date of birth:

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

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

Please include:

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

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

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

Tylenol tablets 325 mg
Take one tablet by mouth
Every four hours as needed for pain



Helpful information:

1. **Bring a current list of your child's medicines:** Each time you go to the doctor, clinic, emergency room, etc.
2. **Use your cell phone to keep track of medicines:** Create a "medicine list" memo. You can take pictures of each medicine bottle. You can also try apps like MyMedSchedule or MediSafe meds and pill reminder for managing medicines.
3. **If you fill prescriptions at a major pharmacy:** You may be able to view medicine information through the pharmacy's website or mobile app.

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

My child's home medicine list

List all of your child's prescriptions and over-the-counter medicines, vitamins, herbs, food supplements, and natural or home remedies. It is important to include all of this information in case of an emergency. Carry this list with you or on your cell phone. Show this list to all of your doctors, pharmacists or other caregivers.

[illegible]

Durable Medical Equipment (DME)/supplies

Name of Equipment: _____

Ordered by (provider): _____

Phone: _____ **Account or ID#:** _____

Description (Brand Name, Size, etc.): _____

Serial#/Model: _____

Supplier: _____

Daytime Phone: _____ **After Hours Phone:** _____

Date Ordered: _____ **Date Received:** _____

Name of Equipment: _____

Ordered by (provider): _____

Phone: _____ **Account or ID#:** _____

Description (Brand Name, Size, etc.): _____

Serial#/Model: _____

Supplier: _____

Daytime Phone: _____ **After Hours Phone:** _____

Date Ordered: _____ **Date Received:** _____



Helpful hint: Keep instruction manuals where you can find them

Assistive Technology/Specialized 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
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Placement: _____

Date of Placement: _____

Flush the Port With: _____

Does the Patient Need Numbing Medication before Access:	Yes	No	Unknown
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Size of Needle Used to Access: _____

Use the Port For (blood draws, medications, etc.): _____

PICC Line Information

Type of PICC Line: Single Lumen Double Lumen Triple Lumen

Placement:_____

Date of Placement:_____

Flush the PICC With:_____

How Often to Change the Needleless Connector:_____

How Often to Do a Dressing Change:_____

Use the Port For (blood draws, medications, etc.):_____

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.

Daily Central Line Maintenance Checklist

Date: _____

Person Completing Form: _____

Date implanted port accessed: _____

Date injection caps last changed: _____

Date dressing last changed: _____

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 properly				
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.

Cap Changes

- Sanitize caps with 2%chlorhexidine gluconate in 70% isopropyl alcohol before and after each use.
- 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.

ASTHMA ACTION PLAN



Asthma and Allergy
Foundation of America
aafa.org

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

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.

Personal Best Peak Flow: _____

GO		Use these daily controller medicines:		
You have <i>all</i> of these: <ul style="list-style-type: none"> Breathing is good No cough or wheeze Sleep through the night Can work & play 	Peak flow: <div>from _____</div> <div>to _____</div>	MEDICINE	HOW MUCH	HOW OFTEN/WHEN
		For asthma with exercise, take:		
CAUTION		Continue with green zone medicine and add:		
You have <i>any</i> of these: <ul style="list-style-type: none"> First signs of a cold Exposure to known trigger Cough Mild wheeze Tight chest Coughing at night 	Peak flow: <div>from _____</div> <div>to _____</div>	MEDICINE	HOW MUCH	HOW OFTEN/ WHEN
		CALL YOUR ASTHMA CARE PROVIDER.		
DANGER		Take these medicines and call your doctor now.		
Your asthma is getting worse fast: <ul style="list-style-type: none"> Medicine is not helping Breathing is hard & fast Nose opens wide Trouble speaking Ribs show (in children) 	Peak flow: <div>reading below _____</div>	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.

Nebulizer Treatments and Vest Treatments

Keeping track of how many breathing treatments you do can seem impossible. This page was created to help families keep track of what treatments are being given, who gave them, what time, and oxygen usage.

[illegible]

Vest Settings 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:** _____

Tips

- 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:_____

Suctioning 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/Optometrists:

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:
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Left Eye:	Sphere:	Cylinder:	AXIS:	Prism:	Base:
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Glasses	Contacts	Prosthesis	History of ROP (Retinopathy of Prematurity)
Surgery	Lasik	Other:	

Other Comments or Pertinent Health Information:

SUMMARY OF CARE SENSORY AND COMMUNICATION

Audiology/Hearing

Clinic: _____ Audiologist: _____

Date of First Visit: _____ Medical Record Number: _____

Address: _____

Phone Number: _____ Email: _____

Website: _____

Date of Last Hearing Exam: _____

Additional Tests: _____

Results: _____

Additional Tests: _____

Results: _____

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

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: _____

Any other Health Problems or Learning Disability: _____

Purchase Date:

How are the devices stored:

Any Other Pertinent Information:

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:_____

Any other Health Problems or Learning Disability:

Purchase Date:

How are the devices stored:

Any Other Pertinent Information:

Bone Conduction Device:

External or Internal

Brand:

Model:

Type of Battery:

Is it 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)? Yes No

Brand of Microphone: _____

Model of Microphone: _____

Any other Health Problems or Learning Disabilities?

Purchase Date:

How are the devices stored:

Any other pertinent information?

Speech and Communication:

Clinic: _____ Speech & language pathologist: _____

Date of first visit: _____ Medical Record #: _____

Address: _____

Phone: _____ Fax: _____

Email: _____ Website: _____

Results of Evaluations: _____

Child uses following devices to meet communication needs:

- | | | | |
|------------------------------------|--|--|---|
| <input type="checkbox"/> Computer | <input type="checkbox"/> Sign Language (ASL) | <input type="checkbox"/> Communication Board | <input type="checkbox"/> Interpreter Services |
| <input type="checkbox"/> Lip Reads | <input type="checkbox"/> Communication Book | <input type="checkbox"/> Sign Language | <input type="checkbox"/> Other: _____ |

Other comments or helpful information:

Catheterization Protocol

Type of Catheter: Suprapubic Intermittent Indwelling (Urethra)

How Often to Cath: _____

When to Cath: _____

Size of Catheter: _____

Date Catheter was Changed: _____

Other Pertinent Information: _____

Catheterization Schedule

A catheterization schedule can help anytime, but especially if the doctor needs information about it. This page will help you keep track of cath times and urine output.

[illegible]

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 a seizure (check all that apply)

- ☐ First aid – **Stay. Safe. Side.**
- ☐ Give rescue therapy according to SAP
- ☐ Notify emergency contact
- ☐ Notify emergency contact at _____
- ☐ Call 911 for transport to _____
- ☐ 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
- ☐ **STAY** until recovered from seizure
- ☐ Swipe magnet for VNS
- ☐ Write down what happens

- ☐ Other

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
- ☐ Difficulty breathing after seizure
- ☐ Serious injury occurs or suspected, seizure in water

When to call your provider first

- ☐ Change in seizure type, number or pattern
- ☐ 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 _____

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 ☐ Modified Atkins ☐ Other (describe) _____

Special Instructions: _____

Health care contacts

Epilepsy Provider: _____ Phone: _____

Primary Care: _____ Phone: _____

Preferred Hospital: _____ Phone: _____

Pharmacy: _____ Phone: _____

My signature: _____ Date _____

Provider Signature: _____ Date: _____

Seizure/Behavior Log

Use this page to track seizures, possible seizures, or concerning behaviors. It is important to know the time between seizures and what they looked like when talking to the neurologist.

[illegible]

Wound Assessment form

Date: _____ Patient Name: _____ Patient ID: _____

Patient

Age: _____ years

Weight: _____ kgs

Gender: ☐ Male ☐ Female



Nutrition status: ☐ Well nourished ☐ Malnourished

Mobility status: ☐ Good mobility ☐ Bad Mobility

Smoking: ☐ Yes ☐ No
If yes, how many/day: _____

Alcohol: _____ units/week

Co-morbidities: _____

Medications: _____

ABPI (if done): _____ Date: _____

Wound description

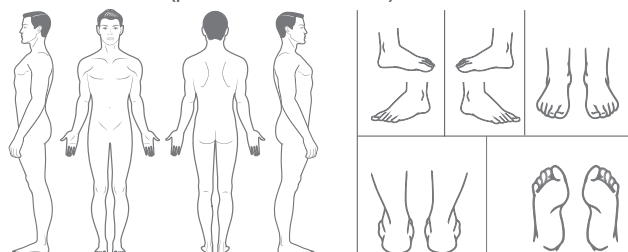
Wound type: _____

Duration of wound: _____

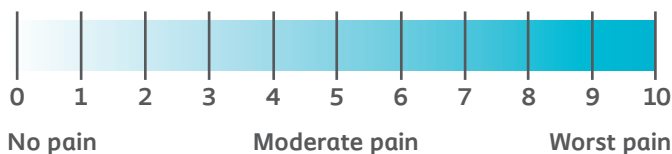
Previous treatments: _____

Size: length _____ mm width _____ mm depth _____ mm

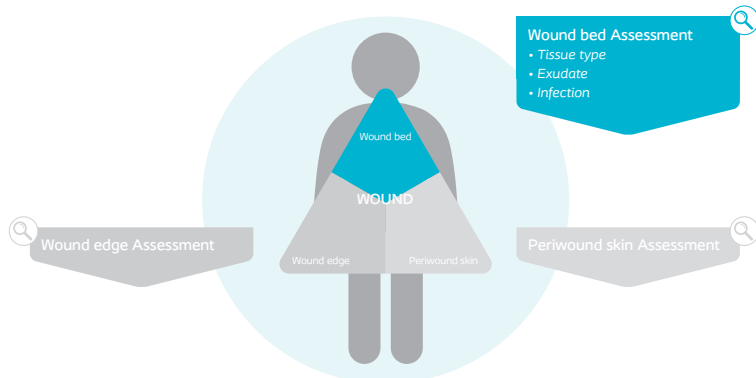
Wound location (please circle wound):



Pain level:



Wound bed assessment



Wound bed Assessment
• Tissue type
• Exudate
• Infection

Wound edge Assessment

Peri-wound skin Assessment



Wound bed Assessment

Tissue type

Necrotic ☐ _____ % Granulating ☐ _____ %
Sloughy ☐ _____ % Epithelialising ☐ _____ %

Exudate

Level ☐ Dry ☐ Low ☐ Medium ☐ High

Type ☐ Thin/watery ☐ Cloudy ☐ Thick
☐ Purulent ☐ Clear ☐ Pink/red

Infection

Local

☐ Increased pain
☐ Erythema
☐ Oedema
☐ Local warmth
☐ Increased exudate
☐ Delayed healing
☐ Friable granulation tissue
☐ Malodour
☐ Pocketing

Spreading/systemic

☐ Increased erythema
☐ Pyrexia
☐ Abscess/pus
☐ Wound breakdown
☐ Cellulitis
☐ General malaise
☐ Raised WBC count
☐ Lymphangitis



Coloplast

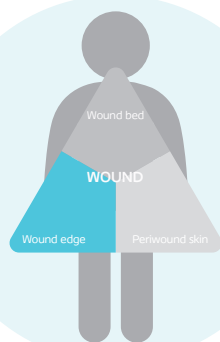


Wound edge assessment



Wound edge Assessment

- Maceration
- Dehydration
- Undermining
- Thickened/rolled edges



Wound bed Assessment

Periwound skin Assessment



Wound edge Assessment

Maceration ☐

Dehydration ☐

Undermining ☐

Rolled edges ☐

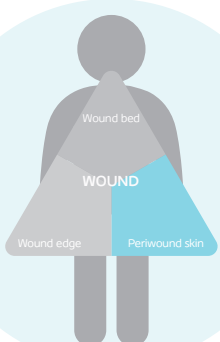
Mark position
Extent: ____ cm



Periwound skin assessment



Wound edge Assessment



Wound bed Assessment

Periwound skin Assessment

- Maceration
- Excoriation
- Dry skin
- Hyperkeratosis
- Callus
- Eczema



Periwound skin Assessment

Maceration ☐ ____ cm

Excoriation ☐ ____ cm

Dry skin ☐ ____ cm

Hyperkeratosis ☐ ____ cm

Callus ☐ ____ cm

Eczema ☐ ____ cm

Status

Is the wound: ☐ N/A- First visit

☐ Deteriorating

☐ Static

☐ Improving



Management goals

Tick all appropriate management goals

Wound bed Assessment

Management goals

- Remove non-viable tissue ☐
- Manage exudate ☐
- Manage bacterial burden ☐
- Rehydrate wound bed ☐
- Protect granulation/epithelial tissue ☐

Periwound skin Assessment

Management goals

- Manage exudate ☐
- Protect skin ☐
- Rehydrate skin ☐
- Remove non-viable tissue ☐



Wound Management Goals

Write all management goals



Wound edge Assessment



Management goals

- Manage exudate ☐
- Rehydrate wound edge ☐
- Remove non-viable tissue ☐
- Protect granulation/epithelial tissue ☐



Treatment choice

Treatment: _____ Dressing type/name: _____

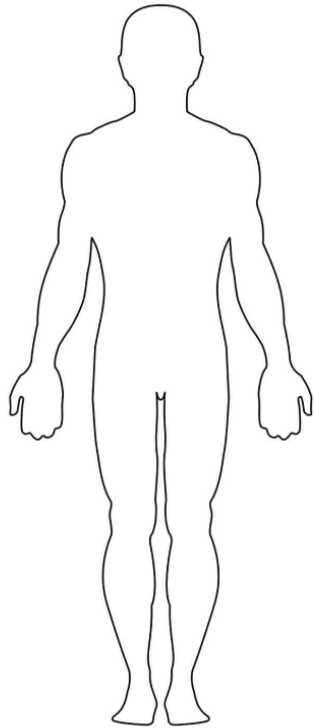
Reason for choosing dressing: _____

Follow up plan

Date of next visit: _____ Main objective at next visit: _____

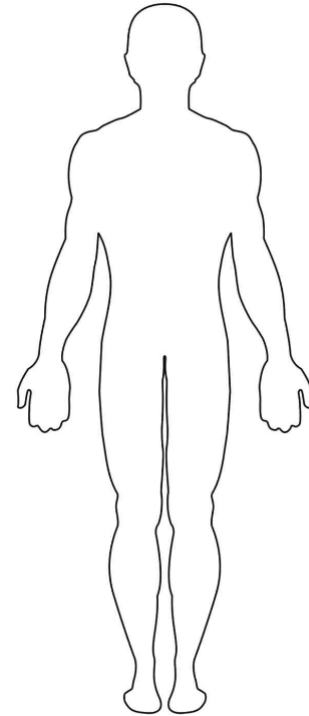
Where Does It Hurt?

Front



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

Back



Wong-Baker Pain Rating Scale



0

2

4

6

8

10



No
Hurt

Hurts
Little Bit

Hurts
Little More

Hurts
Even More

Hurts
Whole Lot

Hurts
Worst

Insurance and expenses

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: _____



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

Insurance Information Continued

Dental Insurance: _____

Member ID: _____ **Group Number:** _____

Group Name/Employer: _____

Subscriber's Name: _____ **Date of Birth:** _____

Subscriber's Phone: _____

Mailing Address: _____

Vision Insurance: _____

Member ID: _____ **Group Number:** _____

Group Name/Employer: _____

Subscriber's Name: _____ **Date of Birth:** _____

Subscriber's Phone: _____

Mailing Address: _____

Prescription Insurance: _____

Member ID: _____ **Group Number:** _____

Group 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.

Medical Bill Communication Log

[illegible]

Out-of-pocket Expenses

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

[illegible]

School Information

SCHOOL INFORMATION

(KINDERGARTEN THROUGH TRANSITION YEARS)

Preschool

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

Preschool

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

Kindergarten

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

1st Grade

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

2nd Grade

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

3rd Grade

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

4th Grade

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

5th Grade

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

6th Grade

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

7th Grade

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

8th Grade

School: _____ Address: _____

Principal: _____ Principal Phone: _____

Teacher/Aide/
Inclusion Specialist: _____ Teacher/Aide/Inclusion
Specialist Phone: _____

ST/PT/OT
Name: _____ ST/PT/OT
Phone: _____

9th Grade

School: _____ Address: _____

Principal: _____ Principal Phone: _____

Teacher/Aide/
Inclusion Specialist: _____ Teacher/Aide/Inclusion
Phone: _____

ST/PT/OT
Name: _____ ST/PT/OT
Phone: _____

10th Grade

School: _____ Address: _____

Principal: _____ Principal Phone: _____

Teacher/Aide/
Inclusion Specialist: _____ Teacher/Aide/Inclusion
Phone: _____

ST/PT/OT
Name: _____ ST/PT/OT
Phone: _____

11th Grade

School: _____ Address: _____

Principal: _____ Principal Phone: _____

Teacher/Aide/
Inclusion Specialist: _____ Teacher/Aide/Inclusion
Phone: _____

ST/PT/OT
Name: _____ ST/PT/OT
Phone: _____

12th Grade

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

Transition Year

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

Transition Year

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

Transition Year

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



My Child's Individualized Education Plan (IEP)

(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)

Legal Paperwork

Medical Power of Attorney

Effective Upon Execution

I, NAME , a resident of ADDRESS. COUNTY.STATE Social Security Number NUMBER designate NAME , presently residing at ADDRESS , telephone number PHONE NUMBER as my agent to make any and all health care decisions for me, except to the extent I state otherwise in this document. For the purposes of this document, "health care decision" means consent, refusal of consent, or withdrawal of consent to any care, treatment, service, or procedure to maintain, diagnose, or treat an individual's physical or mental condition. This medical power of attorney takes effect if I become unable to make my own health care decisions and this fact is certified in writing by my physician.

Limitations: Describe any desired limitations, for example, concerning life support, life-prolonging care, treatment, services, and procedures.

Inspection and Disclosure of Information Relating to My Physical or Mental Health: Subject to any limitations in this document, my agent has the power and authority to do all of the following:

1. Request, review, and receive any information, verbal or written, regarding my physical or mental health, including, but not limited to, medical and hospital records
2. Execute on my behalf any releases or other documents that may be required in order to obtain this information
3. Consent to the disclosure of this information.

Additional Powers: Where necessary to implement the health care decisions that my agent is authorized by this document to make, my agent has the power and authority to execute on my behalf all of the following:

1. Documents titled or purporting to be a "Refusal to Permit Treatment" and "Leaving Hospital Against Medical Advice"
2. Any necessary waiver or release from liability required by a hospital or physician.

Duration: This power of attorney exists indefinitely from its date of execution, unless I establish herein a shorter time or revoke the power of attorney. ***If applicable:*** This power of attorney expires on DATE . If I am unable to make health care decisions for myself when this power of attorney expires, the authority I

have granted my agent shall continue to exist until such time as I become able to make health care decisions for myself.

Alternative Agent: In the event that my designated agent becomes unable, unwilling, or ineligible to serve, I hereby designate NAME , presently residing at ADDRESS , telephone number PHONE NUMBER as my as my first alternate agent, and NAME , presently residing at ADDRESS , telephone number PHONE NUMBER as my as my second alternate agent.

Prior Designations Revoked: I revoke any prior Medical Power of Attorney.

Location of Documents: The original copy of this Medical Power of Attorney is located at Location .

Signed copies of this Medical Power of Attorney have been filed with the following individuals and institutions: Names and Addresses .

I sign my name to this Medical Power of attorney on the date of DATE , at ADDRESS, COUNTY, STATE .

NAME

Statement of Witnesses

I hereby declare under penalty of perjury that the person who signed or acknowledged this document is personally known to me (or proved to me on the basis of convincing evidence) to be the principal, that the principal signed or acknowledged this durable medical power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud, or undue influence. I am not the person appointed an agent by this document. I am not related to the principal by blood, marriage, or adoption. I would not be entitled to any portion of the principal's estate on the principal's death. I am not the attending physician of the principal or an employee of the attending physician. I have no claim against any portion of the principal's estate on the principal's death. Furthermore, if I am an employee of a health care facility in which the principal is a patient, I am not involved in providing direct patient care to the principal and am not an officer, director, partner, or business office employee of the health care facility or of any parent organization of the health care facility.

WITNESS

WITNESS

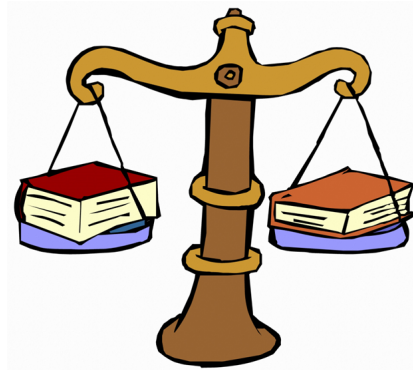
Subscribed and sworn to before me on DATE .

Notary Public, COUNTY, STATE

My commission expires_____ .

LEGAL PAPERS

(Insert copies of important legal papers, such as:
Custody, guardianship, or advanced directives forms.)



Resource/ School Information

Letter Log

Always keep a copy of every letter you write for your own records.

[illegible]

Telephone Log

Always keep a log of telephone calls made for your own records.

[illegible]

"What's the Plan? Prepare for a Meeting

Use this form to gather your thoughts and questions before appointments, i.e. create an Agenda. Write notes during the appointment and track follow-up tasks.

Person:	Staff/Provider:
Bring:	Event Date & Time:
<p>Questions or concerns:</p> <ol style="list-style-type: none">1.2.	
<p>Requests or desired outcomes:</p> <ol style="list-style-type: none">1.2.	
<p>Notes & Next Steps: (follow up, email, call, research, timeline, calendar, communicate with, data tracking, monitor: Who - What - When - Where - How)</p> <ol style="list-style-type: none">1.2.	



4 1 Questions

Person's Name:

Date:

Instructions: Collect group input - what do we know, what should we do next? This is a quick way to understand how to improve the support and intervention plan.

What we have tried	What we have learned
What we are pleased about	What are we concerned about?

NOTES TO TAKE TO THE INDIVIDUAL FAMILY SERVICES PLAN (IFSP)

This is a form to help you prepare for the Individualized Family Service Plan (IFSP) meeting. The IFSP is the plan for your child and family's support plan and services to be provided.

What are your main concerns about your child?

What are your child's strengths?

In order to put together a plan that is tailored to your child, rather than your child's diagnosis, please describe your child.

What is your child's diagnosis or qualifying condition?

Who diagnosed your child?

Who would you like to be at your IFSP?

What support does your family need? What services does your child need?

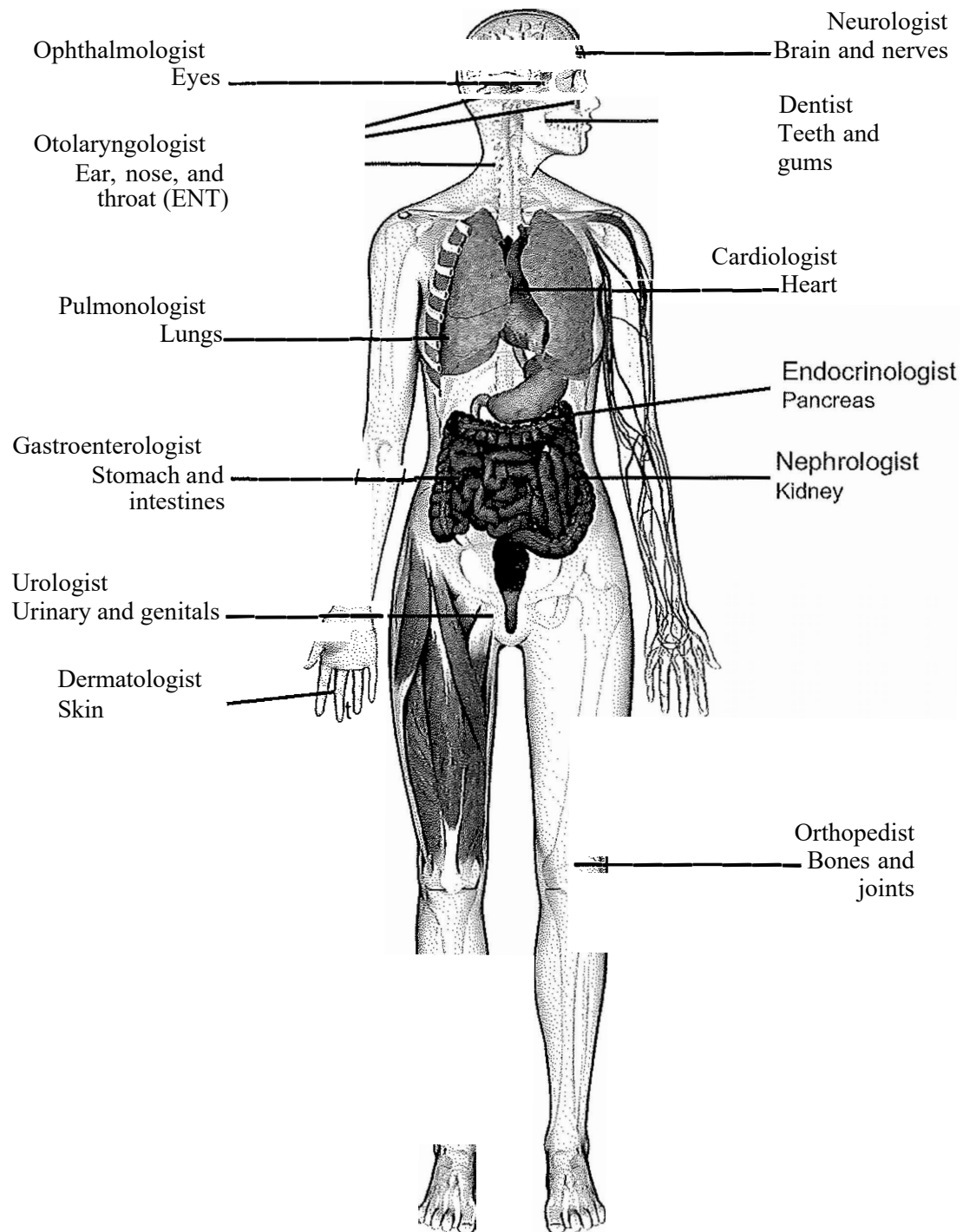
Miscellaneous

Month:

Year:

Body
map and
words to
know

Body Map



Important words to know

Allergist -A doctor who diagnoses and treats allergies.

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

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

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

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

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

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

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

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

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

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 at certain ages. These are also called vaccinations.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Surgeon - A doctor who performs operations.

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

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

Vaccinations - See Immunizations.

Other important words:

CNRJ CDGV'UQWR'CETQP[O 'KPF GZ

Vj g'hqmy lpi 'kpf gz 'hmu'et q{ o u'wugf 'd{ 'rtqhgukpcn'y j q'y qtniy kj 'hco krgu

ADA	Co gtlecpu'y kj 'F kucdkrkgu'Cev'
ADD	Cwgpvkp'F ghlek'F kuqtf gt"
ADHD	Cwgpvkp'F ghlek'J {r gtcevkv'F kuqtf gt"
AIDS	Cesvktgf 'K o wpg'F ghlekpe{ 'U{pf tqo g"
ARC	Vj g'CTE<' Cf xqecvgu'hqt'y g'Tki j u'qhEkkl gpu'y kj 'F gxgnr o gpvcn'F kucdkrkgu'cpf 'y gk'Hco krgu"
ARNP	Cf xcpegf 'Tgi kngtgf 'P wtug'''
BIA	Dwtgcw'qh'kpf kcp'Chckt u"
BD	Dgj cxkqtcn'F kucdrf "
CAP-C	Eqo o wpk{ 'Cngtpcvxgu'Rtqi tco 'hqt'Ej kftgp"
CAP-MR/DD	Eqo o wpk{ 'Cngtpcvxgu'Rtqi tco 'hqt'O gpvcn' 'Tgctf gf /Developmentally Disabled Individuals
CD	Eqo o wplecvkp'F kuqtf gtu"
CDS	Eqo o wplecvkp'F kuqtf gtu'Ur gekcnv"
CFR	Eqf g'qhHgf gtcn'Tgi wrcvku'''
CHRM	Ej kftgp'u'J qur kcn'cpf 'Tgi kpcn'O gf kcn'Egpgt "
CP	Egtgdcn'Rcn{ "
CPS	Ej kft 'Rtqvexg'Ugrxlegu"
CSHCN	Ej kftgp'y kj 'Ur gekcn'J gcnj 'Ectg'P gfg u"
CSO	Eqo o wpk{ 'Ugrxleg'Qhleg.'F UJ U"
DCFS	F kxkukp'qh'Ej kftgp'cpf 'Hco kl 'Ugtxlegu"
DD	F gxgnr o gpvcn'F kucdrf "
DDD	F kxkukp'qh'F gxgnr o gpvcn'F kucdkrkgu.'F UJ U"
DDPC	F gxgnr o gpvcn'F kucdkrkgu'Rncppkpi 'Eqwpekl'
DH	F gxgnr o gpvcn'J cpf kcr r gf "
DMH	F kxkukp'qh'O gpvcn'J gcnj "
DH	F gr ctvo gpv'qh'J gcnj "
DSB	F gr ctvo gpv'qh'Ugtxlegu'hqt'y g'Drkpf "
DSHS	F gr ctvo gpv'qh'Ugekn'cpf 'J gcnj 'Ugtxlegu"
DVR	F kxkukp'qh'Xqecvqpcn'Tgj cdkkcvkp'''
ECDAW	Gctn' 'Ej kft j qgf 'Gf wecvkp'cpf 'Cuukncpeg'Rtqi tco "
ED	Go qvqpcn'F kwwdgtf "
EEG	Grgextqgpegr j cnj tco "
EFMP	Gzr gtko gpvcn'Gf wecvkp'Wpks.'EJ F F 'Gzegr vqpcn'Hco kl 'O go dgt'Rtqi tco 'y gr u'o kksct{ 'hco krgu locate to areas with services)
EKG	Grgextqectf kqi tco "
EPSDT	Gctn' 'Rgtkqf le'Uetggplpi .'F kci pquku'cpf 'Vtgcvo gpv'
ESD	Gf wecvqpcn'Ugtxleg'F kntlev'
FAPE	Htgg'Cr r tqr tlcvg'Rwdrle'Gf wecvkp"
FRC	Hco kl 'Tguqwtugu'Eqqtf kpcvt "
HHS	J gcnj 'cpf 'J wo cp'Ugrxlegu"
HI	J gcnj 'K r cktgf 'qt'J gctkpi 'K r cktgf "
HMO	J gcnj 'O clpvpcpeg'Qti cpl'cvkp"
HO	J gcnj { 'Qr vqpu.'F UJ U.'O gf leckf 'O cpci gf 'Ectg'Rtqi tco "
HOH	J ctf 'qh'J gctkpi "
ICC	Kpvtci gpe{ 'Eqqtf kpcvpi 'Eqwpekn=eqwpv' 'KEE'cpf 'wcvg'KEE0'
IDD	Kpvgngewcn'F gxgnr o gpvcn'F kucdkrk' "
IDEA	Kpf kklf wcn'y kj 'F kucdkrkgu'Gf wecvkp'Cev'
IEP	Kpf kklf wcn'Gf wecvkp'Rncp"
IFSP	Kpf kklf wcn'Hco kl 'Ugtxleg'Rncp"

I & 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 Individuals
MS	Multiple Sclerosis
NICU	Neonatal Intensive Care Unit
NORD	National Association of Rare Disorders
OCR	Office of Civil Rights
OFM	Office of Financial Management
OI	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.

HELPFUL WEBSITES

National Resources

<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

Citation Page

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

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

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

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

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

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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:

1307 Main 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



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