

Care NOTEBOOK

A Tool for Organizing a Child's Health Care Information



FAMILY SUPPORT
NETWORK HOPE

EDUCATION * ADVOCACY
CARING CONNECTIONS



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Family Support Network Program

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Dear Parent,

We hope you find this Care Notebook helpful with organizing your child's records.

FSN/HOPE provides other useful tools like this to help families meet the needs of their child with special needs. Our staff also works directly with families by providing information, training and support for families who have children of all ages and with all types of special health care needs and disabilities.

Some specific ways we can help are:

- Help find and access resources
- Provide information about disabilities and ways families can help their child learn and grow
- Help parents understand their rights
- Help parents become their child's best advocate

Please visit our website (www.fsnhope.org) or our Family Support Network/HOPE Group on Facebook to find information and support or learn more about what we do.

Sincerely,

Vickie Dieter

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CARE Notebook: A Quick Guide

What is a CARE Notebook?

A CARE Notebook is an organizing tool for parents/guardians who have children or youth with special health care needs or disabilities. A CARE Notebook is used to keep track of important information about the child's health care.

How can a CARE Notebook help?

In caring for a child or youth with special health needs or disabilities, one will have information and paperwork from many sources. A CARE Notebook organizes important information in a central place. And a CARE Notebook makes it easier to find and share key information with others who are part of the child's care team.

How is a CARE Notebook used?

The CARE Notebook may be used to:

- File information about the child's health history
- List telephone numbers for health care providers & community organizations
- Share new information with the child's primary doctor, public health clinics, school nurse, day care staff, and others caring for the child
- Prepare for appointments; and
- Track changes in the child's medicines, equipment, or treatments.

What are some other helpful hints for using a child's CARE Notebook?

These suggestions may be helpful:

- Keep the CARE Notebook where it is easy to find. This helps anyone who is helping the child to quickly get information when the parent or guardian is not there to give it.
- Add new information to the CARE Notebook whenever the child's treatment changes.
- Consider taking the CARE Notebook to appointments and hospital visits to make sure the information is easy to find.

CARE Notebook Tips:

- The pages are designed to be used as needed. Not all pages may apply to a child's situation
- Organize the pages in a way that works. See setting up the CARE Notebook in the next section.
- Use dividers or tabs to help organize the CARE Notebook. Sheet protectors, plastic pages, and folders are helpful in organizing materials.

CARE Notebook: A Quick Guide

Step 1: Gather available information.

Collect health information about the child that is already available. This may include reports from recent doctor visits, recent summaries of a hospital stay, this year's school plan, test results, and important pamphlets about services and programs

Step 2: Review the CARE Notebook pages.

Which of the CARE Notebook pages could help organize information about the child's health? Choose the pages that are helpful.

Step 3: Decide which information is most important to keep.

Print copies of the pages that are helpful. Save them in a notebook or electronically. The CARE Notebook pages are available electronically on the FSN/HOPE (www.fsnhope.org). Keep the electronic CARE Notebook in a file or on the hard drive. Print out only the pages needed.

- Print useful pages for a personal notebook or create an electronic file for the CARE Notebook and save the pages to the file.
- Fill in relevant information.
- Organize the order of pages in a way that is useful.
- Print pages for appointments, if helpful.

Step 4: Put the CARE Notebook together.

Everyone has different ways of organizing the information. The important thing in putting together the notebook is to make it easy to find important information again.

Here are some suggestions for supplies that may be useful to create a CARE Notebook that works well:

- **3-Ring notebook** or large accordion envelopes hold paper securely
- **Tabbed dividers** create individual information sections
- **Pocket dividers** store reports
- **Plastic pages** store business cards and photographs.

CARE Notebook: Child's Page

My Name: _____

My Nickname: _____

My Birthday: _____

My Favorite:

Friends: _____

Toys: _____

Games: _____

Foods: _____

Animals: _____

Things To Do: _____

Places To Go: _____

Music: _____

This is Me!

My Pet:

My Pet's Name: _____

My Pet: _____

When I am happy, I act like: _____

When I am sad or when I am feel pain, I act like: _____

Things I can do for myself: _____

Things I need help with: _____

I communicate this way: _____

Others who help me speak are: _____

-

CARE Notebook: Family Information

FAMILY MEMBERS

Parent #1: _____

Address: _____

Phone: _____ Email: _____

Parent #2: _____

Address: _____

Phone: _____ Email: _____

Legal Guardian: _____

Address: _____

Phone: _____ Email: _____

SIBLINGS

Name: _____ Age: _____

Name: _____ Age: _____

Name: _____ Age: _____

Name: _____ Age: _____

Name: _____ Age: _____

Name: _____ Age: _____

Language Spoken at home:

Interpreter needed for professionals? Yes No

EMERGENCY CONTACT

Name: _____ Relationship: _____

Address: _____

Daytime Phone: _____

Cell Phone: _____

CARE Notebook: Family Support Resources

FAMILY & FRIENDS

Name: _____ Phone: _____ Email: _____
Name: _____ Phone: _____ Email: _____
Name: _____ Phone: _____ Email: _____
Name: _____ Phone: _____ Email: _____
Name: _____ Phone: _____ Email: _____
Name: _____ Phone: _____ Email: _____
Name: _____ Phone: _____ Email: _____

FAITH COMMUNITY

Contact Person: _____
Address: _____
Phone: _____ Fax: _____
Email: _____

ADVOCACY ORGANIZATION

Contact Person: _____
Address: _____
Phone: _____ Fax: _____
Email: _____

OTHER ORGANIZATION

Contact Person: _____
Address: _____
Phone: _____ Fax: _____
Email: _____

CARE Notebook: Babysitter Instructions

MEDICAL EMERGENCY INSTRUCTIONS:

*****FOR A LIFE-THREATENING EMERGENCY, DIAL 911*****

First call to: -----

Hospital of Choice: -----

Primary Doctor: -----

Primary Doctor Phone Number: -----

Insurance Provider: -----

Insurance Number: -----

To Whom It May Concern: I/We: -----

the parent/legal guardian of (full name) -----

birth date: -----, give permission to qualified personnel to provide care recovery, as well as to protect life and limb.

Known allergies to: -----

Date: ----- Authorization Expires: -----

Home address: -----

Phone: ----- Cell Phone: -----

Other contact person and phone: -----

Significant events during the last 48 hours, or symptoms to watch and report: -----

Medication needed: ----- Dosage: ----- Time: -----

Medication needed: ----- Dosage: ----- Time: -----

Medication needed: ----- Dosage: ----- Time: -----

Medications are located: -----

Medications special instructions: -----

Medical equipment and supplies are located: -----

Fire extinguisher location: -----

Flashlight location: -----

First Aid Kit location: -----

CARE Notebook: Child Care/ Respite Providers

Child Care Provider

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

Email: _____

Important Information: _____

Hours Available: _____

Respite Care Provider

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

Email: _____

Important Information: _____

Hours Available: _____

Additional Care Provider

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

Email: _____

Important Information: _____

Hours Available: _____

CARE Notebook: Recreational Resources

Recreation programs, including parks and rec programs in the community, have opportunities for children and youth with special health care needs or disabilities to participate. Check with community providers to discover more fun recreational activities.

Activity

Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Schedule: _____

Activity

Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Schedule: _____

Activity

Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Schedule: _____

Activity

Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Schedule: _____

Additional Activities:

CARE Notebook: Insurance Information

Primary Insurance Company

Insurance Company Name: _____
Policy Number: _____ Group Number: _____
Contact person/title: _____
Address: _____
Phone: _____ Fax: _____ Website: _____

Secondary Insurance Company

Insurance Company Name: _____
Policy Number: _____ Group Number: _____
Contact person/title: _____
Address: _____
Phone: _____ Fax: _____ Website: _____

Medicaid

Number (last 6 digits only): _____
Contact person/title: _____
Address: _____
Phone: _____ Fax: _____ Website: _____

Other

Insurance Company Name: _____
Policy Number: _____ Group Number: _____
Contact person/title: _____
Address: _____
Phone: _____ Fax: _____ Website: _____

CARE Notebook: Medical Providers

Primary Care Provider

Doctor Name: _____

Clinic Address: _____

Phone: _____ Fax: _____ Email: _____

Specialty Care Provider

Doctor Name: _____

Clinic Address: _____

Phone: _____ Fax: _____ Email: _____

Specialty Care Provider

Doctor Name: _____

Clinic Address: _____

Phone: _____ Fax: _____ Email: _____

Specialty Care Provider

Doctor Name: _____

Clinic Address: _____

Phone: _____ Fax: _____ Email: _____

Specialty Care Provider

Doctor Name: _____

Clinic Address: _____

Phone: _____ Fax: _____ Email: _____

CARE Notebook: Medical Providers, Cont.

Hospitals

Local Hospital

Hospital Name: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Specialty Hospital

Hospital Name: _____

Clinic Address: _____

Phone: _____ Fax: _____ Website: _____

Dental Providers

Dentist

Dentist Name: _____

Address: _____

Phone: _____ Fax: _____ Website: _____

Orthodontist

Dentist Name: _____

Address: _____

Phone: _____ Fax: _____ Website: _____

CARE Notebook: Pharmacy Information

Use this space to keep track of pharmacy providers. Doctors suggest that one pharmacy is used for all prescription medication needs. The pharmacist will keep track of all medications being used and share when interactions between meds may create problems. However, additional pharmacies may sometimes be necessary. Often, insurance requires the use of a specific online pharmacy. Other pharmacy possibilities include the hospital pharmacy and a compounding pharmacy.

Local Pharmacy

Name: _____ Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____ Open 24 hours? Yes No

Compounding Pharmacy

Name: _____ Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____ Open 24 hours? Yes No

Online/Mail Pharmacy

Name: _____ Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____ Open 24 hours? Yes No

Important Information

Allergies, etc.: _____

Medicines requiring compounding: _____
Medicines requiring flavoring: _____

CARE Notebook: Therapists

Occupational Therapist (OT)

Start Date: _____
Agency/hospital/clinic: _____
Address: _____
Location where therapy occurs: _____
Phone: _____ Fax: _____ Email: _____
Frequency: _____ Duration: _____

Physical Therapist (PT)

Start Date: _____
Agency/hospital/clinic: _____
Address: _____
Location where therapy occurs: _____
Phone: _____ Fax: _____ Email: _____
Frequency: _____ Duration: _____

Speech/Language Pathologist (S/LP)

Start Date: _____
Agency/hospital/clinic: _____
Address: _____
Location where therapy occurs: _____
Phone: _____ Fax: _____ Email: _____
Frequency: _____ Duration: _____

Other Therapy

Start Date: _____
Agency/hospital/clinic: _____
Address: _____
Location where therapy occurs: _____
Phone: _____ Fax: _____ Email: _____
Frequency: _____ Duration: _____

CARE Notebook: Therapy Notes

Communication

Use this section to write about the child's ability to communicate and to understand others. Describe how the child communicates. Include information about gestures, sign language, or any equipment used to help the child communicate. Also include any special words the family and child use to describe things. Date the entries.

Mobility

Use this section to write about the child's ability to move. Include what the child can do independently, with help, and list equipment the child uses to get around. Describe any activity limits, including any special routines the child has for transfers, pressure releases, positioning, etc. Date the entries.

CARE Notebook: Nutrition/Respiratory

Nutrition

Use this section to write about the child's nutritional needs. Describe foods, special mealtime routines, nutritional formulas, food allergies, and restrictions. Describe special feeding techniques, precautions, or equipment used for feedings. Date the entries.

Respiratory

Use this section to write about the child's respiratory care. List respiratory treatments and describe special techniques used and precautions necessary when giving care. Date the entries

CARE Notebook: Home/Community Providers

Managed Care Agency

Agency Name: _____ Case Manager: _____
Application Date: _____ Recertification Date: _____
Other Contacts: _____
Phone: _____ Fax: _____ Email: _____

CAP Waiver Agency

Agency Name: _____ Case Manager: _____
Application Date: _____ Recertification Date: _____
Other Contacts: _____
Phone: _____ Fax: _____ Email: _____

Home Care Agency

Agency Name: _____ Case Manager: _____
Application Date: _____ Recertification Date: _____
Other Contacts: _____
Phone: _____ Fax: _____ Email: _____

Home Care Agency

Agency Name: _____ Case Manager: _____
Application Date: _____ Recertification Date: _____
Other Contacts: _____
Phone: _____ Fax: _____ Email: _____

CARE Notebook: Durable Medical Equipment

Equipment Provider

Company Name: _____ Contact Person: _____
Phone: _____ Fax: _____ Email: _____
Address: _____
Notes (delivery schedule, order schedule, etc.): _____

Equipment

Name of Equipment: _____
Description (brand name, size, etc.): _____

Date Obtained: _____ Service Schedule: _____
Contact Person: _____
Phone: _____ Warranty Terms: _____

Name of Equipment: _____
Description (brand name, size, etc.): _____

Date Obtained: _____ Service Schedule: _____
Contact Person: _____
Phone: _____ Warranty Terms: _____

Name of Equipment: _____
Description (brand name, size, etc.): _____

Date Obtained: _____ Service Schedule: _____
Contact Person: _____
Phone: _____ Warranty Terms: _____

CARE Notebook: Portable Medical Summary

Name: _____ Email: _____			
Address: _____			
Home Phone: _____	Cell Phone: _____		
Date of Birth: _____	Do Not Resuscitate Signed? ___ Yes ___ No		
Learns Best by: _____			
Supports Needed: _____			
Legal Decision Makers: ___ Self ___ HC/POA ___ General POA			
Guardianship: ___ Limited ___ Full			
Name: _____ Phone: _____			
Address: _____			
Emergency Contact/HC POA:			
Name: _____ Phone: _____			
Primary Diagnosis	Age	Height	Weight
1 _____	_____	_____	_____
2 _____	_____	_____	_____
3 _____	_____	_____	_____
4 _____	_____	_____	_____
5 _____	_____	_____	_____
Doctors:		Hospital:	
Medicines: Daily:		Immunizations:	
Monthly:		Allergies:	
PRN/As Needed:			
Medicaid/Medicare #:			
Name of Insurance company:		Name of Insurance company:	
Primary Subscriber:		Subscriber:	
Healthcare/Case Manager: _____		Health Vendor: _____	
Health Nursing Agency: _____		Pharmacy: _____	
Dentist: _____			

CARE Notebook: Daily Care Schedule

Time	Care Provided/Needed
Morning	
Afternoon	
Evening	

CARE Notebook: Allergy Tracker

Allergies: _____

Child's Allergy	Description	Treatment	Date

CARE Notebook: Medical Visit Notes

CARE Notebook: Supplies

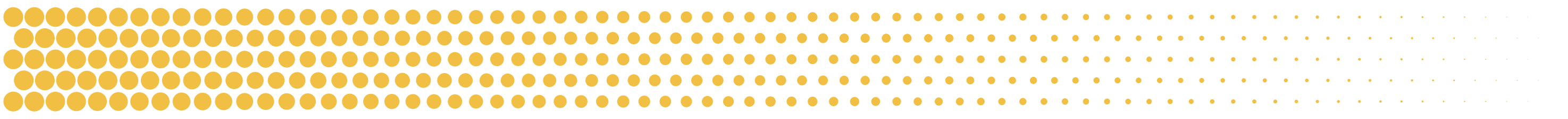
Contact Person: _____ Email: _____
Phone: _____ Fax: _____
Address: _____
Notes (delivery schedule, order schedule, etc.): _____ _____ _____

Item	Description	Quantity	Notes

CARE Notebook: Diet Log

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

Notes	
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A series of horizontal dashed lines for writing notes.