CareNOTEBOOK

A Tool for Organizing Your Child's Health Care Information

Presented By:

Exceptional Children's Assistance Center (ECAC)

The NC Family to Family Health Information Center

This document was Adapted with permission from Family Voices of North Dakota and Family Voices of Utah, Center for Children with Special Needs, Seattle Children's Washington State Department of Health, Children with Special Health Care Needs Program.

ECAC, the exceptional children's assistance center, is a private, non-profit parent organization committed to improving the lives and education of ALL children through a special emphasis on children with disabilities.

ECAC provides a variety of programs and services designed to empower parents to become their children's best advocates. Our services which are provided at no cost to families to include: parent information, individual assistance, Information and referral, lending library, newsletters, e-bulletins, parent education opportunities, information packets, and CDs.

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Funding provided by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs. The NC Family to Family Health Information Center operates under the auspices of grant # H84MC08000.

What is a Care Notebook?

A Care Notebook is an organizing tool for parents who have children with special health care needs or disabilities. Use a Care Notebook to keep track of important information about your childs' health care. This Care Notebook has been designed for parents living in North Carolina.

How Can a Care Notebook Help Me?

In caring for your child with special health needs and/or disabilities, you may get information and paperwork from many sources. A Care Notebook helps you organize the most important information in a central place. A Care Notebook makes it easier for you to find and share key information with others who are part of your childs' care team.

How Do I Use a Care Notebook?

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

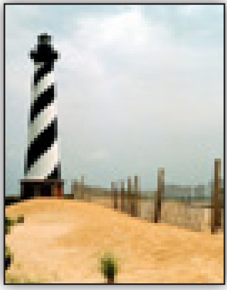
What are some helpful hints for using my child's Care Notebook?

- Store the Care Notebook where it is easy to find. This helps you and anyone who needs information when you are not there.
- Add new information to the Care Notebook whenever your child's treatment changes.
- Consider taking the Care Notebook with you to appointments and hospital visits so that the information you need will be easy to find.

Note: You may use all or just a part of these pages. Not all of the pages may apply to your family situation.

Organize your pages any way that works for you.
(See "**Setting up Your Care Notebook**" In the next section)

Use dividers or tabs to help you organize your notebook. Sheet protectors, plastic pages and folders will also be helpful in organizing material.



Follow these steps to set up your child's notebook:

Step 1: Gather information you already have.

- Gather up any health information about your child you already have. This may include reports from recent doctor's visits, recent summary of a hospital stay, this year's school plan, test results, or informational pamphlets.

Step 2: Look through the pages of the Care Notebook.

- Which of these pages could help you keep track of information about your child's health or care?
- Choose the pages you like. Print copies of any that you think you will use and keep them in a notebook or filing system.
- For the information on pages 6-22, we recommend you print and take to your child's medical appointments.
- The Care Notebook pages are available electronically. You can keep the electronic care notebook in a file on your hard drive and type in the online Notebook any relevant information, and print out only the pages you want or need for your appointments. Additional pages of interest are available at http://www.medicalhomeinfo.org/CareNoteBook/

Step 3: Decide which information about your child is most important to keep in the Care Notebook.

- What information do you look up often?
- What information do people caring for your child need?
- Consider storing other information in computer file, a file drawer or box where you can find it if needed.

Step 4: Put the Care Notebook together.

- Everyone has a different way of organizing information. The only important thing is to make it easy for **you** to find again. Here are some suggestions for supplies used to create a Care Notebook:
- **3-ring notebook** or large accordion envelope. Hold papers securely.
- **Tabbed dividers**. Create your own information sections.
- **Pocket dividers.** Store reports.
- **Plastic pages.** Store business cards and photographs.

CareNOTEBOOK | Table of Contents

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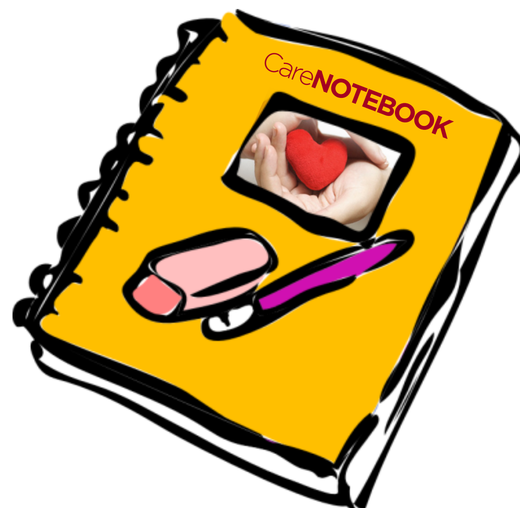

Date: ______________________

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:

★ Child's Name: Nickname:

Date of Birth: Social Security Number:

Diagnosis:

Blood Type:

Legal Guardian:

Address :

Phone:

Family Members

★ Father's Name:

Social Security Number:

Address :

Phone:

Email:

★ Mother's Name:

Social Security Number:

Address :

Phone:

Email:

★ Sibling's Name: Age ★ Name: Age:

★ Sibling's Name: Age ★ Name: Age:

★ Sibling's Name: Age ★ Name: Age:

★ Other household members:

★ Important Family Information:

★ Language spoken at home:

Other language(s):

Interpreter Needed? Yes: No:

Preferred interpreter? Name: Phone:

Emergency Contact

★ Name:

Address:

Daytime Phone: Evening Phone:

Cell Phone:

SAMPLE – ONE PAGE PORTABLE MEDICAL SUMMARY – ADAPTED **HRTW National Center** **www.hrtw.org**

NAME

Address, Home Phone, Cell Phone, Email

DOB	SS#	Allergy	**DNR Signed: N/Y – ADD DATE**

Learns best by:

Supports Needed:

Legal Decision Makers ❒ Self **Guardianship: ❒ Limited ❒ Full**

NAME: **PHONE:**
ADDRESS:

Legal Health Surrogate:

NAME: **PHONE:**

PRIMARY DIAGNOSIS/ICD-9 CODES	AGE: XX HEIGHTX'X" (XX Inches) WEIGHT XX lbs
1. 2. 3. 4. 5.	

MEDICAL

DOCTORS	HOSPITAL

MEDICINES	IMMUNIZATIONS
Rx DAILY Rx MONTHLY Rx PRN	

ADD NAME OF INSURANCE COMPANY	ADD NAME OF INSURANCE COMPANY
Primary Subscriber: ADD NAME ADD Plan Code # ADD Subscriber # Customer service: ADD PHONE #	***Subscriber:*** ADD NAME ADD Plan Code # ADD Subscriber # Customer service: ADD PHONE #

Health Care/Case Manager	ADD NAME	ADD PHONE #	ext. xx
Health Vendor	ADD COMPANY NAME/CONTACT	ADD PHONE #	ADD acc't #
Health Nursing Agency	ADD COMPANY NAME/CONTACT	ADD PHONE #	ADD acc't #
Pharmacy	ADD COMPANY NAME	ADD PHONE #	ADD Rx #s
Dentist	ADD NAME	ADD PHONE #	

Primary Insurance Company

Policy Number:

Contact Person / Title

Address:

Phone: Fax:

Secondary Insurance Company

Policy Number:

Contact Person / Title

Address:

Phone: Fax:

Medicaid / HMO ID Number

Policy Number:

Contact Person / Title

Address:

Phone: Fax:

Supplemental Security Income (SSI/SSDI) ID:

Contact Person / Title

Address:

Phone: Fax:

Other:

Policy Number:

Contact Person / Title

Address:

Phone: Fax:

CareNOTEBOOK | *Appointment Log*

Steps to a satisfactory medical appointment:

1. Write down your problems/questions before you go.
2. Number the problems in questions. Make the number one the most important.
3. Show the provider your list. Write down any
4. Talk to the provider about options for handling your problems/questions.

DATE	PROVIDER	QUESTIONS / PROBLEMS TO BE DISCUSSED	REASON SEEN / CARE PROVIDED	NEXT APPOINTMENT

Growth Tracking Form

DATE	HEIGHT	WEIGHT	HEAD CIRCUMFERENCE	BLOOD PRESSURE	HEART RATE	NOTES

Primary Care Provider

Date of First Visit:

Office Nurse/ Medical Assistant:

Address:

Phone: Fax: Email:

Other Primary Care Provider

Date of First Visit:

Office Nurse/ Medical Assistant:

Address:

Phone: Fax: Email:

Primary Children's Medical Center / Hospital:

Medical Records Number:

Address:

Phone: Fax: Email:

Specialty Hospital/ Clinic:

Physician:

Medical Records Number:

Address:

Phone: Fax: Email:

Dental Providers

Dental Provider Name:

Date of First Visit:

Address:

Phone: Fax: Email:

Orthodontist:

Date of First Visit:

Address:

Phone: Fax: Email:

Many specialty physicians may treat your child. You may keep track of some them here:

Speciality Care Providers

Specialty Care Provider
Specialty: Date of First Visit:
Office Nurse/ Medical Assistant:
Address:
Phone: Fax: Email:

Specialty Care Provider
Specialty: Date of First Visit:
Office Nurse/ Medical Assistant:
Address:
Phone: Fax: Email:

Specialty Care Provider
Specialty: Date of First Visit:
Office Nurse/ Medical Assistant:
Address:
Phone: Fax: Email:

Specialty Care Provider
Specialty: Date of First Visit:
Office Nurse/ Medical Assistant:
Address:
Phone: Fax: Email:

Specialty Care Provider
Specialty: Date of First Visit:
Office Nurse/ Medical Assistant:
Address:
Phone: Fax: Email:

Specialty Care Provider
Specialty: Date of First Visit:
Office Nurse/ Medical Assistant:
Address:
Phone: Fax: Email:

Specialty Care Provider
Specialty: Date of First Visit:
Office Nurse/ Medical Assistant:
Address:
Phone: Fax: Email:

Pharmacy Information

Use this space to keep track of all your pharmacy providers.

Medical professionals suggest that, if possible, you use one pharmacy for all your prescription medicine needs. In this way, your pharmacist may keep track of all medications being used and any possible problems with interactions between medications. Sometimes, however, you may need to have prescriptions filled at your neighborhood pharmacy and other times your may need to have them filled at the hospital pharmacy.

Pharmacy:

Contact Person:

Address :

Phone: Fax: Email:

Web Address:

Pharmacy:

Contact Person:

Address :

Phone: Fax: Email:

Web Address:

Pharmacy:

Contact Person:

Address :

Phone: Fax: Email:

Web Address:

Important information for the pharmacist (Such as allergies to medication):

Medicines requiring liquid form:

Medicines requiring flavoring:

CareNOTEBOOK | *Medications Log*

Allergies:

Pharmacy:

Address: Phone:

Fax: Email:

DATE STARTED	DATE STOPPED	MEDICATION	TO TREAT	DOSE / ROUTE	TIME GIVEN	PRESCRIBED BY	SIDE EFFECTS

TRACKING FORM

DATE	TEST	RESULT	COMMENTS

TRACKING FORM

DATE	ALLERGEN	REACTION	ANECDOTE (w/Dosage)

TRACKING FORM

DATE	HOSPITAL	REASON	NOTES

DATE	PROCEDURE	RESULT	COMMENTS

Care**NOTEBOOK** | *Diet Log*

	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

Date:

TRACKING FORM

Information About the Bill				Information About Who You Talk To					NOTES
Account #	Provider	Date of Service	What bill is for:	Date of Contact	Time	Name	Title (like Account Representative)	Credentials (RN, DR., none)	

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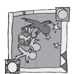


Durable Medical Equipment Supplier (DME):

Contact Person :

Phone: Fax : E-Mail:

Address:

Notes (delivery schedule, order schedule, etc.):

Name of Equipment:

Description (brand name, size, etc.):

Date Obtained: Service Schedule:

Contact Person :

Phone :

Name of Equipment:

Description (brand name, size, etc.):

Date Obtained: Service Schedule:

Contact Person :

Phone :

Name of Equipment:

Description (brand name, size, etc.):

Date Obtained: Service Schedule:

Contact Person :

Phone :

Name of Equipment:

Description (brand name, size, etc.):

Date Obtained: Service Schedule:

Contact Person :

Phone :

★ **Durable Medical Equipment Supplier (DME)**:		
Contact Person :		
Phone:	Fax :	E-Mail:
Address:		
Notes (delivery schedule, order schedule, etc.):		

ITEM	DESCRIPTION	QUANTITY	NOTES

Support Group / Organization:

Contact Person:

Address/Directions:

Phone: Fax: E-Mail:

Group Focus :

Religious Organization:

Contact Person:

Address/Directions:

Phone: Fax: E-Mail:

Notes :

Counseling Service:

Contact Person:

Address/Directions:

Phone: Fax: E-Mail:

Group Focus :

Dept. of Human Services:

Contact Person:

Address/Directions:

Phone: Fax: E-Mail:

Notes :

Other:

Contact Person:

Address/Directions:

Phone: Fax: E-Mail:

Notes :

Home Care Agency:

Start Date:

Case Manager:

Other Contacts (scheduler, billing, etc.):

Primary Care Nurse:

Phone: Fax: E-Mail:

Home Care Agency:

Start Date:

Case Manager:

Other Contacts (scheduler, billing, etc.):

Primary Care Nurse:

Phone: Fax: E-Mail:

Home Care Agency:

Start Date:

Case Manager:

Other Contacts (scheduler, billing, etc.):

Primary Care Nurse:

Phone: Fax: E-Mail:

Home Care Agency:

Start Date:

Case Manager:

Other Contacts (scheduler, billing, etc.):

Primary Care Nurse:

Phone: Fax: E-Mail:

Home Care Agency:

Start Date:

Case Manager:

Other Contacts (scheduler, billing, etc.):

Primary Care Nurse:

Phone: Fax: E-Mail:

Respite/Child Care Provider:

Start Date:

Contact Person:

Address:

Phone: Fax: E-Mail:

Important Information :

Respite/Child Care Provider:

Start Date:

Contact Person:

Address:

Phone: Fax: E-Mail:

Important Information :

Respite/Child Care Provider:

Start Date:

Contact Person:

Address:

Phone: Fax: E-Mail:

Important Information :

Fiscal Agent if applicable:

Fiscal Agent:

Contact:

Phone: Fax: E-Mail:

Medical Emergency Instructions:

First Call:

Hospital of Choice:

Primary Medical Doctor:

Primary Medical Doctor Phone:

Insurance Provider:

Insurance No.

To whom it may concern: I/we ______________________, the parent/legal guardian(s) of (full name) ______________________, whose birth date is ______________, give permission to qualified medical personnel to provide care and treatment to minimize unnecessary pain, complications, scarring, or delays in recovery, as well as to protect life and limb. Known allergies to: ______________________

______________________.

Date ____________ This authorizations is good until: ______________.

Your are at (address):

Phone Number (at address):

Parent or Guardian's Phone:

Other Contact Person and Phone:

SIGNIFICANT EVENTS DURING THE LAST 48 HRS. OR SYMPTOMS TO WATCH AND REPORT:

Medical Currently Taking - Dosage –– Time To Be Administered:

Special Instructions:

Important Items to Locate:

Medications are kept:

Medical equipment and supplies are located:

Fire extinguisher is located:

Flashlight is located:

First Aid Kit is located:

★ Occupational Therapist (OT)

Start Date:

Agency/Hospital/ Clinic:

Address:

Phone: Fax: E-Mail:

★ Physical Therapist (PT)

Start Date:

Agency/Hospital/ Clinic:

Address:

Phone: Fax: E-Mail:

★ Speech – Language Pathologist (SP)

Start Date:

Agency/Hospital/ Clinic:

Address:

Phone: Fax: E-Mail:

★

Start Date:

Agency/Hospital/ Clinic:

Address:

Phone: Fax: E-Mail:

★

Start Date:

Agency/Hospital/ Clinic:

Address:

Phone: Fax: E-Mail:

A number of organizations have programs designed to give children and adults with special needs recreation opportunities. These include local park and recreation programs. Check with your providers to find out more about recreation opportunities close to your home.

Recreation Opportunity:

Recreation Opportunity:

Contact Person:

Address:

Phone: Fax: E-Mail:

Schedule :

Recreation Opportunity:

Contact Person:

Address:

Phone: Fax: E-Mail:

Schedule :

Fun Activities:

Transportation (to and from medical / therapy appointments)

Contact Person:

Agency :

Address:

Phone: Fax: E-Mail:

Important Information (such as bus route, rules regarding pick-up, etc.)

Transportation (to and from medical / therapy appointments)

Contact Person:

Agency :

Address:

Phone: Fax: E-Mail:

Important Information (such as bus route, rules regarding pick-up, etc.)

Transportation (to and from medical / therapy appointments)

Contact Person:

Agency :

Address:

Phone: Fax: E-Mail:

Important Information (such as bus route, rules regarding pick-up, etc.)

Transportation (to and from medical / therapy appointments)

Contact Person:

Address:

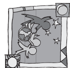
Phone: Fax: E-Mail:

Schedule :

Use this page to write about your child's development to feed him or herself, bathe, get dressed, use the bathroom, comb hair, brush teeth, etc. Describe what your child can do by him or herself and any help or equipment your child uses for these activities. Describe any special routines your child has for bath time, getting dressed, etc.

Date:

TIME	CARE
Morning	
Afternoon	



TIME	CARE
Evening	
Night	

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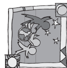

Use this page for your child's words and thoughts about his or her life now as well as later.

Date:

Use this page to write about your child's ability to communicate and to understand others. Describe how your child communicates. Include sign language words, gestures, or any equipment or help your child uses to communicate or understand others. Include any special words your family and child use to describe things.

Date:

Use this page to write about how your child copes with stress. Stressful events might include new people or situations, a hospital stay, or procedures such as having blood drawn. Describe what things upset your child and what your child does when upset or when he or she has "had enough." Describe your child's way of asking for help and things to do or say to comfort your child.

Date:

Use this page to write about your child's ability to get around. Describe how your child gets around. Include what your child can do by him or herself and any help or equipment your child uses to get around. Describe any activity limits and any special routines your child has for transfers, pressure releases, positioning, etc.

Date:

Use this page to write about your child's nutritional needs. Describe foods and any nutritional formulas your child takes, any food allergies or restrictions, and any special feeding techniques, precautions, or equipment used for feedings. Describe any special mealtime routines your family and child have.

Date:

Use this page to write about your child's respiratory care needs. Describe the care or treatments your child needs and any special techniques or precautions you use when giving care. Include any special routines your child has for respiratory care.

Date:

Use this page to write about your child's ability to get to sleep and to sleep through the night. Describe your child's bedtime routine and any security or comfort objects your child uses.

Date:

Use this page to write about your child's ability to get along with others. Describe how your child shows affection, shares feelings, or plays with other children. Describe what works best to help your child get along or cooperate with others. Describe your child's favorite things to do. Include any special family activities or customs that are important.

Date:

Your child and family will experience many transitions, small and large, over time. Three predictable transitions occur for most children: reaching school age, approaching adolescence, and moving from adolescence into adulthood. Many children do not experience these transitions in the way most children experience them. Other transitions may involve moving into new programs, working with new agencies and care providers, or making new friends. Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go.

Looking at transitions may be hard, depending on your circumstances. You may have limited time just to do what needs to get done today. You may find it helpful, though, to jot down a few ideas about your child's and family's future. You might start by thinking about your child's and family's strengths. How can these strengths help you plan for "what's next" and for reaching long-term goals? What are your dreams and your fears about your child's and family's future?

Date:

Date: