CareNOTEBOOK

A Tool for Organizing a Child's Health Care Information

ecac
exceptional children's assistance center
Empowering Families★Improving Lives

www.ecac-parentcenter.org
800.962.6817

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What is a CareNOTEBOOK?

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

How can a CareNOTEBOOK help?

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

How is a CareNOTEBOOK used?

The CareNOTEBOOK may be used to:

- File information about the child's health history,
- List telephone numbers for health care providers and community organizations,
- Share new information with the child's primary doctor, public health clinic, 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 helpful hints for using a child's CareNOTEBOOK?

These suggestions may be helpful:

- Keep the CareNOTEBOOK 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 CareNOTEBOOK whenever the child's treatment changes.
- Consider taking the the CareNOTEBOOK to appointments and hospital visits to make
- sure the information is easy to find.

CareNOTEBOOK Tips:

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

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 CareNOTEBOOK pages.

Which of the CareNOTEBOOK 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 CareNOTEBOOK pages are available electronically on the ECAC website: www.ecac-parentcenter.org. Keep the electronic CareNOTEBOOK 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 CareNOTEBOOK and save 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.

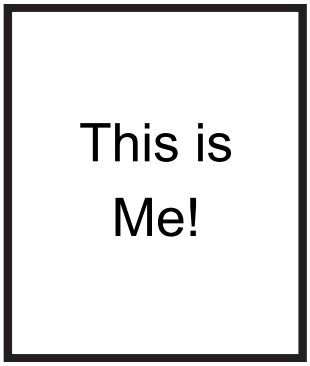
Step 4: Put the CareNOTEBOOK together.

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 CareNOTEBOOK that works well:

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


Family
Information



My name: _____

My nickname: _____ **My birthday:** _____

My pet's name: _____ **My pet:** _____

My favorites:

Friends: _____

Toys: _____

Games: _____

Foods: _____

Animals: _____

Things to do: _____

Places to go: _____

Music: _____

When I am happy, I act like: _____

When I am sad or when I 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: _____

Use this page for the child's words and ideas about his or her life. Date each entry.

Family Members

Parent: _____

Address: _____

Phone: _____

Email: _____

Parent: _____

Address: _____

Phone: _____

Email: _____

Legal Guardian: _____

Address: _____

Phone: _____

Email: _____

Siblings

Name: _____ Age: _____ Name: _____ Age: _____

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: _____

Evening phone: _____

Friends and Family

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: _____

Medical Emergency Instructions: **FOR A LIFE THREATENING EMERGENCY, DIAL 911**

_____

_____

First call to: _____

Hospital of choice: _____

Primary doctor: _____

Primary doctor phone: _____

Insurance provider: _____

Insurance number: _____

To whom it may concern: I/We: _____,

the parent/legal guardian of (full name): _____,

birth date: _____, give permission to qualified medical personnel to provide care recovery, as well as to protect life and limb. Known allergies to: _____

_____

Date: _____ Authorization expires: _____

Home address: _____

Phone number: _____ Parent/Guardian 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: _____

Medications located here: _____

Medications special instructions: _____

_____

Medical equipment and supplies are located here: _____

Fire extinguisher location: _____

Flashlight location: _____

First aid kit location: _____

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: _____

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: _____

_____

_____

Provider Information

Primary Insurance Company

Insurance company name: _____

Policy number: _____ Group number: _____

Contact person/title: _____

Address: _____

Phone: _____ Fax: _____

Secondary Insurance Company

Insurance company name: _____

Policy number: _____ Group number: _____

Contact person/title: _____

Address: _____

Phone: _____ Fax: _____

Medicaid

Number (last 6 digits only): _____

Contact person/title: _____

Address: _____

Phone: _____ Fax: _____

Other

Insurance company name: _____

Policy number: _____ Group #: _____

Contact person/title: _____

Address: _____

Phone: _____ Fax: _____

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: _____

Hospitals

Local Hospital

Hospital name: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Specialty Hospital

Hospital name: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Dental Providers

Dentist

Dentist name: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Orthodontist

Dentist name: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

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: _____

Web Address: _____ Open 24 hours? Y _____ N_____

Compounding Pharmacy

Name: _____ Contact person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Web Address: _____ Open 24 hours? Y _____ N_____

Online/Mail Pharmacy

Name: _____ Contact person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Web Address: _____

Important Information (allergies, etc.): _____

_____

_____

Medicines requiring compounding: _____

_____

Medicines requiring flavoring: _____

_____

Occupational Therapist (OT)

Start date: _____

Agency/hospital/clinic: _____

Address: _____

Location where therapy occurs: _____

Phone: _____ Email: _____ Fax: _____

Frequency: _____ Duration: _____

Physical Therapist (PT)

Start date: _____

Agency/hospital/clinic: _____

Address: _____

Location where therapy occurs: _____

Phone: _____ Email: _____ Fax: _____

Frequency: _____ Duration: _____

Speech/Language Pathologist (S/LP)

Start date: _____

Agency/hospital/clinic: _____

Address: _____

Location where therapy occurs: _____

Phone: _____ Email: _____ Fax: _____

Frequency: _____ Duration: _____

Other Therapy

Start date: _____

Agency/hospital/clinic: _____

Address: _____

Location where therapy occurs: _____

Phone: _____ Email: _____ Fax: _____

Frequency: _____ Duration: _____

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.

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 the child needs, and describe special techniques used and precautions necessary when giving care. Date the entries.

Managed Care Agency

Agency name: _____ Case manager: _____

Application date: _____ Recertification date: _____

Other contacts: _____

Phone: _____ Email: _____ Fax: _____

CAP Waiver Agency

Agency name: _____ Case manager: _____

Application date: _____ Recertification date: _____

Other contacts: _____

Phone: _____ Email: _____ Fax: _____

Home Care Agency

Agency name: _____ Case manager: _____

Application date: _____ Recertification date: _____

Other contacts: _____

Phone: _____ Email: _____ Fax: _____

Home Care Agency

Agency name: _____ Case manager: _____

Application date: _____ Recertification date: _____

Other contacts: _____

Phone: _____ Email: _____ Fax: _____

Company: _____ Contact person: _____

Phone: _____ Email: _____ Fax: _____

Address: _____

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

_____

_____

Name of Equipment: _____

Description (brand name, size, ect.): _____

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: _____

Transportation

Company: _____ Contact person: _____

Address: _____

Phone: _____ Email: _____ Fax:_____

Important information (such as bus route, rules regarding pick-up, etc.): _____

_____

Transportation

Company: _____ Contact person: _____

Address: _____

Phone: _____ Email: _____ Fax:_____

Important information (such as bus route, rules regarding pick-up, etc.): _____

_____

Transportation

Company: _____ Contact person: _____

Address: _____

Phone: _____ Email: _____ Fax:_____

Important information (such as bus route, rules regarding pick-up, etc.): _____

_____

_____


Medical
Care
Forms

PORTABLE MEDICAL SUMMARY

Name:
Address:
Home phone: Cell phone: Email:

DOB: Do Not Resuscitate Signed? ☐ Yes ☐ No

Learns best by:

Supports needed:

Legal decision makers ☐ Self ☐ HC/POA ☐ General POA Guardianship: ☐ Limited ☐ Full

Name:
Address: Phone:

Emergency Contact/HC POA:

Phone:

Primary Diagnosis	Age:	Height:	Weight:
1. 2. 3. 4. 5.			

MEDICAL

Doctors:	**Hospital:**
Medicines: Daily: Monthly: PRN / As needed:	**Immunizations:** **Allergies:**
Medicaid/Medicare #:	
Name of insurance company: **Primary Subscriber:**	**Name of insurance company:** **Subscriber:**

Health Care/Case Manager
Health Vendor
Health Nursing Agency
Pharmacy
Dentist

Time	Care Provided/Needed
Morning	
Afternoon	
Evening	

Allergies: _____

_____

_____

Date Started	Date Stopped	Medication	Treats	Dose	Time Given	Prescribed By	Reason for Stopping

*Note: Make additional copies as needed

Child's Allergy	Description	Treatment	Date

Steps to a satisfactory medical appointment:

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

Date	Provider	Questions to be Discussed	Reason Seen/Care Provided	Next Appointment

Date	Test	Result	Comments

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

Item	Description	Quantity	Notes

Date	Height	Weight	Head/Waist Circumference	Blood Pressure	Heart Rate	BMI	Notes

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

Date	Hospital	Reason	Notes

Date	Procedure	Result	Comments

Bill Information				Contact Information			Notes
Account #	Provider	Service Date	Service Provided	Contact Date	Name	Title	

Transitions involve changes. The child and family will experience many transitions over time. New expectations, responsibilities and moving forward in life are part of every person's experiences.

Not all transitions are major transitions. Three predictable transitions occur for most children; reaching school age, approaching the teen years, and moving from teen to adulthood. For children and youth with special health care needs or disabilities, additional changes may be more frequent. Staff rotation, insurance changes, and medical treatments are considered more routine transitions.

Managing transitions may be hard. There may be limited time to do what needs to be done. There may be questions about future planning that seem too complex. Because children, youth, and families experience transitions differently, it may be helpful to jot down ideas about the child's and family's future.

A good place to start is by thinking about child and family strengths. How can these strengths help plan for "what's next" and for reaching long-term goals? What are the dreams for the child's, youth's, and the family's future?

ECAC, **The Exceptional Children's Assistance Center**, is NC's non-profit parent organization that is committed to improving the lives and education of ALL children, with a special emphasis on children and youth with special health care needs or disabilites. **ECAC** believes that what's best for kids are families empowered to be their child's best advocate.

ECAC's services are provided at no cost to families and include individual assistance, web-based learning, print and electronic materials, a lending library, and parent workshops.

ECAC
907 Barra Row, Suites 102-103
Davidson, NC, 28036
1-800-962-6817
www.ecac-parentcenter.org

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