

Dear Parents,

This Care Notebook has been developed just for you—parents with children with special health care needs. We offer this Notebook to you with deep appreciation for the central role you play in the life and care of your child. We hope it will serve as a guide in organizing and keeping track of your child's records, appointments, and other important information. The Care Notebook is produced by the Center for Children with Special Needs and the Washington State Department of Health, Children with Special Health Care Needs Program, with invaluable input from parents and community professionals.

Families tell us they value having a central place to keep information they can easily take to appointments.

"I used a paper bag for my file! It took forever to find what I needed! Now I can just turn to the right section."

"This way I don't have to keep it all in my head."

"I'd use the notebook to organize my thoughts and concerns before a doctor's appointment. It gave me confidence and credibility."

Families also use the Notebook to improve communication with doctors and other health care providers.

"Didn't have to repeat information...I've taken it to all the doctors and when they ask what happened, I just pull out the notebook and show them."

"I use the notes as a diary. I write down what the doctor has said, word for word. This really helps when I go to the next doctor and he wants to know what that doctor said."

We encourage you to make this Notebook work for you! Create your own sections; remove and rearrange pages to fit your needs; and personalize it with drawings, stickers, photographs, and special articles and resources you've found helpful. The Care Notebook pages may be downloaded and printed from <http://www.cshcn.org>. You can find other resources and information for you and your family at this website.

If you have suggestions or comments about the Care Notebook, please feel free to contact Megan Sety at (206) 987-5310 or megan.sety@seattlechildrens.org.

Most sincerely,

Kathy Fennell
Manager

Megan Sety
Program Assistant

Care Notebook: A Quick Guide

What is a Care Notebook?

A Care Notebook is an organizing tool for families who have children with special health care needs. Use a Care Notebook to keep track of important information about your child's health and care.

How can a Care Notebook help me?

In caring for your child with special health needs, 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 child's care team.

Use your Care Notebook to:

- 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, daycare 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 in your absence.
- Add new information to the Care Notebook whenever there is a change in your child's treatment.
- Consider taking the Care Notebook with you to appointments and hospital visits so that information you need will be close at hand.

How do I set up my child's Care Notebook?

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

Step 1: Gather information you already have.

- Gather up any health information you already have about your child. This may include reports from recent doctor's visits, immunization records, 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. The Care Notebook pages are available from the Internet at <http://www.cshcn.org>. Go to "Resources" and then choose "Care Organizing Tools."

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 is needed by others caring for your child?
- Consider storing other information in 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.

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Care Notebook

List of Pages

Pages to Keep Track of Appointments and Care

- Appointment Log
- Diet Tracking Form
- Emergency Information Form
- Equipment/Supplies
- Growth Tracking Form
- Hospital Stay Tracking Form
- Lab Work/Tests/Procedures
- Make-a-Calendar
- Medical Bill Tracking Form
- Medical/Surgical Highlights
- Medications
- Notes

Pages to Create a Care Summary: Abilities and Special Care Needs

- Activities of Daily Living
- Care Schedule
- Child's Page—Now and Later
- Communication
- Coping/Stress Tolerance
- Mobility
- Nutrition
- Respiratory
- Rest/Sleep
- Social/Play
- Transitions—Looking Ahead

Pages to Create a Care Team and Resources List

- Children's Hospital and Regional Medical Center

Community Health Care/Service Providers:

- Medical/Dental
 - Public Health
 - Home Care
 - Therapists
 - Early Intervention Services
 - School
 - Child Care
 - Respite Care
 - Pharmacy
 - Special Transportation
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- Family Information
 - Family Support Resources
 - Funding Sources
 - Alphabet Soup Acronym Index

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Family Information

- Child's Name: _____ Nickname: _____
Date of Birth: _____ Social Security Number: _____
Diagnosis: _____
Blood Type: _____

Legal Guardian: _____
Address: _____ Phone: _____

Family Members

- Mother's Name: _____
Social Security Number: _____
Address: _____
Daytime Phone: _____ Evening Phone: _____
- Father's Name: _____
Social Security Number: _____
Address: _____
Daytime Phone: _____ Evening Phone: _____
- 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: _____
Interpreter: _____ Phone: _____

Emergency Contact

- Name: _____
Address: _____
Daytime Phone: _____ Evening Phone: _____

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Family Support Resources

• Parent to Parent: _____
Contact Person: _____
Address: _____

Phone: _____ Fax: _____

• Parent Group: _____
Contact Person: _____
Address: _____

Phone: _____ Fax: _____

• Religious Organization: _____
Contact Person: _____
Address: _____

Phone: _____ Fax: _____

• Service Organization: _____
Contact Person: _____
Address: _____

Phone: _____ Fax: _____

• Counseling Services: _____
Contact Person: _____
Address: _____

Phone: _____ Fax: _____

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Family Support Resources

• Division of Developmental Disabilities: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

• Other: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

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Funding Sources

- Insurance Name: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____

Phone: _____ Fax: _____

- Insurance Name: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____

Phone: _____ Fax: _____

- Insurance Name: _____
Number: _____
Contact Person / Title: _____
Address: _____

Phone: _____ Fax: _____

- Supplemental Security Income (SSI): _____
Contact Person / Title: _____
Address: _____

Phone: _____ Fax: _____

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Funding Sources

• Other: _____

Contact Person / Title: _____

Address: _____

Phone: _____ Fax: _____

• Other: _____

Contact Person / Title: _____

Address: _____

Phone: _____ Fax: _____

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Children's Hospital and Regional Medical Center

4800 Sand Point Way NE
Seattle, WA 98105

Hospital Operator (206) 987-2000 or 1-866-987-2000
Resource Line (206) 987-2500 or 1-866-987-2500
Emergency Room (206) 987-2222

Medical Record Number: _____

• CHRMC Clinic: _____

Date of First Visit: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____

• CHRMC Clinic: _____

Date of First Visit: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____

• CHRMC Clinic: _____

Date of First Visit: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____

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Medical / Dental Community Health Care Providers

• Primary / Community Care Provider: _____
Date of First Visit: _____
Office Nurse: _____
Address: _____

Phone: _____ Fax: _____

• Community Hospital: _____
Medical Record Number: _____
Address: _____

Phone: _____ Fax: _____

• Community Specialty Care Provider: _____
Date of First Visit: _____
Address: _____

Phone: _____ Fax: _____

• Community Specialty Care Provider: _____
Date of First Visit: _____
Address: _____

Phone: _____ Fax: _____

• Dentist / Orthodontist: _____
Date of First Visit: _____
Address: _____

Phone: _____ Fax: _____

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Public Health

Community Health Care / Service Providers

• Public Health Department: _____

Address: _____

Phone: _____ Fax: _____

• Public Health Nurse: _____

Phone: _____ Date of First Visit: _____

• Nutritionist: _____

Phone: _____ Date of First Visit: _____

• Social Worker: _____

Phone: _____ Date of First Visit: _____

• Other: _____

Phone: _____ Date of First Visit: _____

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Home Care Community Health Care / Service Providers

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

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Therapists

Community Health Care / Service Providers

Therapists:

• Occupational Therapist (OT): _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

• Physical Therapist (PT): _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

• Speech-Language Pathologist: _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

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Early Intervention Services Community Health Care / Service Providers

• Developmental Center: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

• Family Resources Coordinator: _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

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School Community Health Care / Service Providers

• School / Preschool: _____

Start Date: _____

Address: _____

Phone: _____ Fax: _____

• School Nurse: _____

Phone: _____ Fax: _____

• Contact Person / Title: _____

Phone: _____ Fax: _____

• Contact Person / Title: _____

Phone: _____ Fax: _____

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Child Care Community Health Care / Service Providers

• Child Care Provider: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

• Child Care Provider: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

• Child Care Provider: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

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Respite Care Community Health Care / Service Providers

• Respite Care Provider: _____

Start Date: _____

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

• Respite Care Provider: _____

Start Date: _____

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

• Respite Care Provider: _____

Start Date: _____

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

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Pharmacy

Community Health Care / Service Providers

• Pharmacy: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

• Pharmacy: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

• Pharmacy: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____

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Special Transportation Community Health Care / Service Providers

- Transportation (to and from medical / therapy appointments)

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

- Transportation (to and from medical / therapy appointments)

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

Alphabet Soup

Acronym Index

The following index lists a wide variety of acronyms used by professionals who work with families.

ACCH	Association for the Care of Children's Health
ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AFDC	Aid to Families with Dependent Children
AIDS	Acquired Immune Deficiency Syndrome
ARC	The Arc: Advocates for the Rights of Citizens with Developmental Disabilities and their families
ARNP	Advanced Registered Nurse Practitioner
BIA	Bureau of Indian Affairs
BD	Behaviorally Disabled
CAP	Community Alternative Program (Medicaid), Community Action Program (Dept. of Community Development), Client Assistance Program (Division of Vocational Rehabilitation)
CD	Communication Disorders
CDS	Communication Disorders Specialist
CEC	Council for Exceptional Children
CFR	Code of Federal Regulations
CHAP	Children Have a Potential (Air Force assistance program)
CHDD	Center on Human Development and Disability at the University of Washington
CHRMC	Children's Hospital and Regional Medical Center
CP	Cerebral Palsy
CPS	Child Protective Services
CSHCN	Children with Special Health Care Needs
CSO	Community Service Office, DSHS
DCD	Department of Community Development
DCFS	Division of Children and Family Services
DD	Developmentally Disabled
DDD	Division of Developmental Disabilities, DSHS
DDPC	Developmental Disabilities Planning Council
DH	Developmentally Handicapped
DMH	Division of Mental Health
DOH	Department of Health
DSB	Department of Services for the Blind
DSHS	Department of Social and Health Services
DVR	Division of Vocational Rehabilitation
ECDAW	Early Childhood Development Association of Washington
ECEAP	Early Childhood Education and Assistance Program
ED	Emotionally Disturbed
EEG	Electroencephalogram
EEU	Experimental Education Unit, CHDD
EFMP	Exceptional Family Member Program (helps military families locate to areas with services)
EKG	Electrocardiogram
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
ESD	Educational Service District
FAPE	Free Appropriate Public Education
FRC	Family Resources Coordinator
HHS	Health and Human Services
HI	Health Impaired or Hearing Impaired
HMO	Health Maintenance Organization
HO	Healthy Options, DSHS, Medicaid Managed Care Program
HOH	Hard of Hearing
ICC	Interagency Coordinating Council; county ICC and state ICC.
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
IFSP	Individual Family Service Plan

(continued)

Alphabet Soup

Acronym Index

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
MAA	Medical Assistance Administration
MCH	Maternal and Child Health
MD	Medical Doctor
MDT	Multi-Disciplinary Team
MH	Multiply Handicapped
MR	Mentally Retarded
MS	Multiple Sclerosis
NICU	Neonatal Intensive Care Unit
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
PFTH	Program for the Handicapped (military program)
PHN	Public Health Nurse
PL	Public Law
PT	Physical Therapy/Therapist
PTA	Parent Teacher Association
RCW	Revised Code of Washington (state law)
RN	Registered Nurse
RPT	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
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
TTY	Telecommunication Device for Deaf, Hearing Impaired, and Speech Impaired Persons
VI	Visually Impaired
WAC	Washington Administrative Code
WACD	Washington Association for Citizens with Disabilities
WIC	Women, Infants and Children Supplemental Food Program
WSMC	Washington State Migrant Council
WSSB	Washington State School for the Blind

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

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Equipment / Supplies

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

Date obtained: _____ Supplier: _____
Contact Person: _____ Phone: _____

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

Date obtained: _____ Supplier: _____
Contact Person: _____ Phone: _____

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

Date obtained: _____ Supplier: _____
Contact Person: _____ Phone: _____

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

Date obtained: _____ Supplier: _____
Contact Person: _____ Phone: _____

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Care Schedule

TIME	CARE
Morning	
Afternoon	

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Care Schedule

TIME	CARE
Evening	
Night	

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Diet Tracking Form

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

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“MAKE-A-CALENDAR”

Month _____ **Year** _____

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY