

Center for Children with Special Needs

A Program of

Children's

Hospital & Regional Medical Center
Seattle, Washington

Dear Parents and Caregivers,

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."

"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 Andrea McCullough at (206) 987-5325 or andrea.mccullough@seattlechildrens.org.

Most sincerely,

Kathy Fennell
Manager

Andrea McCullough
Project 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 papers 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 phone 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?

- Keep 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 when there is a change in your child's treatment.
- Take 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:

+ Step 1: Gather information

- 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: Review 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. You can get additional Care Notebook pages at <http://www.cshcn.org>.

+ Step 3: Choose what to keep in the Care Notebook.

- What information do you look up most often?
- What information is needed by others caring for your child?
- Store other information in a file drawer or box where you can find it if needed.

+ Step 4: Put the Care Notebook together.

- Each of us has our own way of organizing information. The only key is to make it easy for you to find again. Here are some ideas for supplies used to create a Care Notebook:
 - 3-ring notebook or large accordion envelope.
 - Tabbed dividers. Create your own sections.
 - Pocket dividers. Store reports.
 - Plastic pages. Store business cards and photographs.

Care Notebook

List of Pages

Pages to Create a Care Team and Resources List

- Hospital Information Form
- Community Health Care/Service Providers:
 - Medical/Dental
 - Public Health
 - Home Care
 - Therapists
 - Early Intervention Services
 - School
 - Child Care
 - Respite Care
 - Pharmacy
 - Special Transportation
- Family Information
- Emergency Information Form
- Family Support Resources
- Help Finding Resources
- Insurance/Funding Sources
- Alphabet Soup Acronym Index

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 Keep Track of Appointments and Care

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

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Hospital Name

Address: _____

City, State, Zip Code: _____ Website: _____

Phone Numbers:

Main Number: _____ Emergency Room: _____

Medical Record Number: _____

• Clinic: _____ Hours/Days of Operation: _____

Date of First Visit: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____ Email: _____

• Clinic: _____ Hours/Days of Operation: _____

Date of First Visit: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____ Email: _____

• Clinic: _____ Hours/Days of Operation: _____

Date of First Visit: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____ Email: _____

.....

Medical / Dental Community Health Care Providers

- Primary / Community Care Provider: _____
Date of First Visit: _____
Office Nurse: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

- Community Hospital: _____
Medical Record Number: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

- Community Specialty Care Provider: _____
Date of First Visit: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

- Community Specialty Care Provider: _____
Date of First Visit: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

- Dentist / Orthodontist: _____
Date of First Visit: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

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Public Health

Community Health Care / Service Providers

• Public Health Department: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Public Health Nurse: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Nutritionist: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Social Worker: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Other: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

.....

Home Care

Community Health Care / Service Providers

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

.....

Therapists

Community Health Care / Service Providers

Therapists:

- Occupational Therapist (OT) _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

- Physical Therapist (PT): _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

- Speech-Language Pathologist: _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

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Early Intervention Services

Community Health Care / Service Providers

• Developmental Center: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Family Resources Coordinator: _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

.....

School Community Health Care / Service Providers

• School / Preschool: _____

Start Date: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• School Nurse: _____

Phone: _____ Fax: _____ Website/Email: _____

• Contact Person/Title: _____

Phone: _____ Fax: _____ Website/Email: _____

• Contact Person/Title: _____

Phone: _____ Fax: _____ Website/Email: _____

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Child Care Community Health Care / Service Providers

• Child Care Provider: _____
Start Date: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Child Care Provider: _____
Start Date: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Child Care Provider: _____
Start Date: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

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Respite Care Community Health Care / Service Providers

• Respite Care Provider: _____
Start Date: _____
Contact Person: _____
Agency: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Respite Care Provider: _____
Start Date: _____
Contact Person: _____
Agency: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Respite Care Provider: _____
Start Date: _____
Contact Person: _____
Agency: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

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Pharmacy

Community Health Care / Service Providers

• Pharmacy: _____ Hours/Days of Operation: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Pharmacy: _____ Hours/Days of Operation: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Pharmacy: _____ Hours/Days of Operation: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

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Special Transportation Community Health Care / Service Providers

- Transportation (to and from medical / therapy appointments)

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

- Transportation (to and from medical / therapy appointments)

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

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Family Information

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

Legal Guardian: _____
Address: _____
Phone: _____

Family Members

- Mother's Name: _____
Address: _____ Email: _____
Daytime Phone: _____ Evening Phone: _____

- Father's Name: _____
Address: _____ Email: _____
Daytime Phone: _____ Evening Phone: _____

- Sibling's Name: _____ Age: _____ Name: _____ Age: _____
- Sibling's Name: _____ Age: _____ Name: _____ Age: _____

- Other household members: _____

- Important Family Information: _____

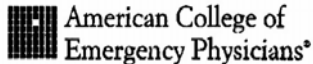
- Language spoken at home: _____
Other language(s): _____
Interpreter Needed? Yes: _____ No: _____
Interpreter: _____ Phone: _____

Emergency Contact

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

Emergency Information Form for Children With Special Needs

Last name:



American Academy of Pediatrics



Date form completed
By Whom

Revised
Revised

Initials
Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:		Emergency Contact Names & Relationship:	
Signature/Consent*:			
Primary Language:		Phone Number(s):	
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician:		Emergency Phone:	
Specialty:		Fax:	
Current Specialty physician:		Emergency Phone:	
Specialty:		Fax:	
Anticipated Primary ED:		Pharmacy:	
Anticipated Tertiary Care Center:			
Diagnoses/Past Procedures/Physical Exam:			
1. _____		Baseline physical findings: _____	
_____		_____	
2. _____		_____	
_____		_____	
3. _____		Baseline vital signs: _____	
_____		_____	
4. _____		_____	
_____		_____	
Synopsis: _____		Baseline neurological status: _____	
_____		_____	
_____		_____	

*Consent for release of this form to health care providers

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Diagnoses/Past Procedures/Physical Exam continued:	
Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	Prostheses/Appliances/Advanced Technology Devices:
5. _____	_____
6. _____	_____

Management Data:	
Allergies: Medications/Foods to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____
Procedures to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____

Immunizations (mm/yy)											
Dates						Dates					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

Antibiotic prophylaxis: _____ Indication: _____ Medication and dose: _____

Common Presenting Problems/Findings With Specific Suggested Managements		
Problem	Suggested Diagnostic Studies	Treatment Considerations
Comments on child, family, or other specific medical issues:		
Physician/Provider Signature:		Print Name:

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Family Support Resources

• Parent to Parent: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Parent Group: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Religious Organization: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Service Organization: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Counseling Services: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

(continued)

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Family Support Resources

- Division of Developmental Disabilities: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

- Other: _____
Contact Person: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

Help Finding Resources for Children with Special Needs

Having a child with special needs can be a challenge. You may feel confused and overwhelmed. Parents have said,
“There is so much to learn and know! Where do I begin?”

“There must be an easier way. Our family can’t be the first to go through this.”

Below are some people that can help you. Their help may be free. Just ask.

Public Health Nurses (PHN)

are registered nurses at your local health department who can help you with general health questions and services like immunizations.

Children with Special Health Care Needs (CSHCN) Coordinators

are public health nurses who help families of children with ongoing health problems. They can help you find resources and health information.

Family Resource Coordinators (FRC)

are case managers who can help you find services if you are worried about how your child under age 3 is growing or developing.



People at your child's school

Teachers, school nurses, counselors, principals, or therapists can help your child at school with medications, equipment, therapies and homework. If your child goes to a private school, you can still get help from the public school system.

Other Parents

can tell you about their experiences. They can give you tips, tell you about helpful providers and give you hope. You can meet other parents at support groups or the doctor's office. Parent to Parent, Fathers Network and the Children's Resource Line can help you find a support group.

Health Care Providers

Your child's doctors, nurses, or social workers can also tell you about services and resources.

Where do I start?

1. Call the toll free Healthy Mothers Healthy Babies **ASK (Answers for Special Kids) Line** to find these people in your home town: 1-800-322-2588
2. Call the **Children's Resource Line** and ask for a copy of **Starting Point**, a free resource guide for Washington families who have children with special needs: (206) 987-2500, option 4, or toll free 1-866-987-2500, option 4. Starting Point and other resources are available online at www.cshcn.org.

Create your child's contact list:

Public Health Nurse (PHN)

Name:

Phone/Email:

Children with Special Health Care Needs (CSHCN) Coordinator

Name:

Phone/Email:

Family Resource Coordinator

Name:

Phone/Email:

People at school

Name:

Phone/Email:

Name:

Phone/Email:

Name:

Phone/Email:

Other Parents

Name:

Phone/Email:

Name:

Phone/Email:

Name:

Phone/Email:

Health Care Providers

Name:

Phone/Email:

Name:

Phone/Email:

Center for Children with Special Needs
A Program of

Children's
Hospital & Regional Medical Center
Seattle, Washington

Washington State Department of
Health
Children with Special Health Care Needs Program

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Insurance/Funding Sources

• Insurance Name: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Insurance Name: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Insurance Name: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Supplemental Security Income (SSI): _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

(continued)



Insurance/Funding Sources

• Other: _____
Contact Person/Title: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

• Other: _____
Contact Person/Title: _____
Address: _____
Phone: _____ Fax: _____ Website/Email: _____

Alphabet Soup

Acronym Index

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

ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
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
CD	Communication Disorders
CDS	Communication Disorders Specialist
CFR	Code of Federal Regulations
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
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
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
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
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
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
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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Care Schedule

TIME	CARE
Morning	
Afternoon	

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Care Schedule

TIME	CARE
Evening	
Night	

.....

Equipment / Supplies

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____ Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____ Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____ Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____ Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

.....

Diet Tracking Form

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



‘MAKE-A-CALENDAR’

Month

Year

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY