

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 hospital stays, 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.

+ 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.

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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
- 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

Care Planning Pages

- Emergency Preparedness for Families of Children with Special Needs
- Getting to Know Me
- In Case of Emergency
- What's the Plan

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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: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____ Email: _____

• Clinic: _____ Hours/Days of Operation: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____ Email: _____

• Clinic: _____ Hours/Days of Operation: _____

Physician: _____

Contact Person / Title: _____

Phone: _____ Fax: _____ Email: _____

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Medical / Dental Community Health Care Providers

• Primary / Community Care Provider: _____
Office Nurse: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

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

• Community Specialty Care Provider: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Community Specialty Care Provider: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Dentist / Orthodontist: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

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Public Health

Community Health Care / Service Providers

• Public Health Department: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Public Health Nurse: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Nutritionist: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Social Worker: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Other: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

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Home Care

Community Health Care / Service Providers

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

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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: _____

.....

Early Intervention Services Community Health Care / Service Providers

• Developmental Center: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Family Resources Coordinator: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

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School Community Health Care / Service Providers

• School / Preschool: _____

Start Date: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• School Nurse: _____

Phone: _____ Fax: _____ Email: _____

• Contact Person/Title: _____

Phone: _____ Fax: _____ Email: _____

• Contact Person/Title: _____

Phone: _____ Fax: _____ Email: _____

.....

Child Care Community Health Care / Service Providers

• Child Care Provider: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Child Care Provider: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Child Care Provider: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

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Respite Care Community Health Care / Service Providers

• Respite Care Provider: _____

Start Date: _____

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Respite Care Provider: _____

Start Date: _____

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Respite Care Provider: _____

Start Date: _____

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

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Pharmacy

Community Health Care / Service Providers

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

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

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

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Special Transportation Community Health Care / Service Providers

- Transportation (to and from medical / therapy appointments)

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

- Transportation (to and from medical / therapy appointments)

Contact Person: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

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Family Information

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

Legal Guardian: _____
Address: _____
Phone: _____

Family Members

- Parent's Name: _____
Address: _____ Email: _____
Daytime Phone: _____ Evening Phone: _____ Cell: _____

- Parent's Name: _____
Address: _____ Email: _____
Daytime Phone: _____ Evening Phone: _____ Cell: _____

- Sibling's Name: _____ Age: _____ Name: _____ Age: _____
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: _____ Email: _____
Daytime Phone: _____ Evening Phone: _____ Cell: _____

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Family Support Resources

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

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

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

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

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

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Family Support Resources

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

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

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

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Insurance/Funding Sources

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

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

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

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

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Insurance/Funding Sources

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

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

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
CD	Communication Disorders
CDS	Communication Disorders Specialist
CHDD	Center on Human Development and Disability at the University of Washington
CAN	Certified Nursing Assistant
CNS	Clinical Nurse Specialist
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
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
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
HIPAA	Health Insurance Portability and Accountability Act
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
IHP	Individual Health Plan
ISP	Individual Service Plan
IRB	Institutional Review Board
ITEIP	Infant Toddler Early Intervention Program
LD	Learning Disabled
LDA	Learning Disabilities Association
LRE	Least Restrictive Environment
MCH	Maternal and Child Health
MD	Medical Doctor

(continued)

Acronym Index

MDT	Multi-Disciplinary Team
MH	Multiply Handicapped
MR	Mentally Retarded
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)
RD	Registered Dietician
RN	Registered Nurse
RPT	Registered Physical Therapist
SBD	Seriously Behaviorally Disabled
SCHIP	Statewide Children's Health Insurance Program
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
WATA	Washington Assistive Technology Act Program
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 Summary: Activities of Daily Living

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

Date: _____

.....

Care Schedule

Time	Care
Morning	
Afternoon	

.....

Care Schedule

Time	Care
Evening	
Night	



**Care Summary:
Child’s Page—Now and Later**

Use this page for your child’s words and thoughts about their life now as well as in the future. What are your child’s dreams? What do they do well now that might give direction for life later? What does your child want to be when they grow up?

Date: _____

Lined writing area consisting of 20 horizontal lines.

Care Summary: Communication

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: _____

.....

Care Summary: Coping / Stress Tolerance

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 they have "had enough". Describe your child's way of asking for help and things to do or say to comfort your child.

Date: _____

.....

Care Summary:

Mobility

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 themselves and any help or equipment they use to get around. Describe any activity limits and any special routines your child has for transfers, pressure releases, positioning, etc.

Date: _____

.....

Care Summary:

Nutrition

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: _____

.....

Care Summary: Respiratory

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: _____

.....

Care Summary:

Transitions—Looking Ahead

Your child and family may go through or have many transitions, small and large, over the years. Three key transitions are: when your child reaches school age, when they nears adolescence, and when your child moves from adolescence into adulthood. 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 of others.

It's not always easy to think about the future. There may be many things, including what has to be done today, that keep you from looking ahead. It may be helpful to take some time 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: _____



Appointment Log

Date	Provider	Reason for appointment / Care Provided	Next Appointment



Originally produced by the Center for Children with Special Healthcare Needs at Seattle Children's Hospital and the Washington State Department of Health, Children with Special Healthcare Needs Program, with invaluable input from parents and community professionals.

Medical / Surgical Procedures

Date	Procedure	Results	Comments

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Lab Work / Tests / Procedures

Date	Test	Results	Comments



Growth Tracking Form

Date	Height	Weight	Head Circumference	Checked By

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: _____

.....

Medications

Allergies:

Pharmacy:

Phone:

Medication	Date Started	Date Stopped	Dose/route (with or without food?)	Time Given	Prescribed By

Diet Tracking Form

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

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Hospital Stay Tracking Form

Date	Hospital	Reason	Notes

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Medical Bill Tracking Form

Date	Provider	Cost	Insurance Paid	Date Paid	Family Owes	Date Paid

“MAKE-A-CALENDAR”

Month

Year

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

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