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:

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

you need will be close at hand.

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

+ 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.

□ Wha	at information	do vo	u look i	in most	often?
U VVIII	at imiomiation	uo yu	iu iook i	นม เมอรเ	OILEH!

- 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.

Ш	3-ring	note	book	or I	arge	accordion	enve	lope.
---	--------	------	------	------	------	-----------	------	-------

- ☐ Tabbed dividers. Create your own sections.
- □ Pocket dividers. Store reports.
- Plastic pages. Store business cards and photographs.



List of Pages

Pages to Create a Care Team and Resources List ☐ Hospital Information Form	Pages to Keep Track of Appointments and Care ☐ Appointment Log
□ Community Health Care/Service Providers: □ Medical/Dental	□ Medical/Surgical Highlights
☐ Public Health	□ Lab Work/Tests/Procedures
☐ Home Care	☐ Growth Tracking Form
	□ Equipment/Supplies
☐ Therapists	□ Notes
□ Early Intervention Services	☐ Medications
□ School	□ Diet Tracking Form
□ Child Care	☐ Hospital Stay Tracking Form
□ Respite Care	□ Medical Bill Tracking Form
□ Pharmacy	☐ Make-a-Calendar
☐ Special Transportation	O-m Diamaina D-ma
☐ Family Information	Care Planning Pages ☐ Emergency Preparedness for Families of
□ Family Support Resources	Children with Special Needs
☐ Help Finding Resources	☐ Getting to Know Me
☐ Insurance/Funding Sources	☐ In Case of Emergency
□ Alphabet Soup Acronym Index	□ What's the Plan
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	

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:	

Medical / Dental Community Health Care Providers

		Email:	
	_		
Community Hospital	l:		
		Email:	
Website:			
,	•		
		Email:	
Website:			
Community Specialt	y Care Provider:		
Address:			
Phone:	Fax:	Email:	
Website:			
Dentist / Orthodontis	st:		
		Email:	
Website:			

Public Health Community Health Care / Service Providers

 Public Health Depart 	ment:		
Address:			
Phone:	Fax:	Email:	
Website:			
Public Health Nurse:			
Address:			
Phone:	Fax:	Email:	
Nutritionist:			
Address:			
Phone:	Fax:	Email:	
Social Worker:			
Address:			
		Email:	
• Other:			
Address:			
	Fay:		

Home Care Community Health Care / Service Providers

Home Nursing Agency:		
	Email:	
Website:		
Home Nursing Agency:		
Start Date:		
Contact Person:		
Address:		
	Email:	
Home Nursing Agency:		
Start Date:		
Contact Person:		
Address:		
	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:				

Early Intervention Services
Community Health Care / Service Providers

 Developmental Center: 		
Start Date:		
Contact Person:		
Phone:	Fax:	Email:
Website:		
 Family Resources Coordina 	tor:	
Address:		
		Email:

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:			
		Email:	

Respite Care Community Health Care / Service Providers

Respite Care Provider:		
Start Date:		
Address:		
		_ 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:

Pharmacy

Community Health Care / Service Providers

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

Special Transportation Community Health Care / Service Providers

Transportation (to and from me	edical / therapy appointmer	nts)
Contact Person:		
Agency:		
Address:		
Phone:	Fax:	Email:
Website:		
Transportation (to and from m	edical / therapy appointmer	nts)
Contact Person:		
Agency:		
Address:		
Phone:	_ Fax:	Email:
Wehsite:		

Family Information

Child's Name:		_ Nickname	e:	
Date of Birth:				
Diagnosis:				
Blood Type:				
Legal Guardian:				
Address:				
Phone:				
Family Members				
Parent's Name:				
Address:				
Daytime Phone:	Evening Ph	none:	Cell: _	
Parent's Name:				
Address:		Email:		
Daytime Phone:	Evening Ph	none:	Cell: _	
Sibling's Name:	Age:	Name:		_ Age:
Name:	Age:	Name:		_ Age:
Other Household Membe	rs:			
 Important Family Information 	tion:			
•				_
 Language Spoken at Hon 	ne:			
Other Language(s):				
Interpreter Needed? Yes				
Interpreter:		_	Phone:	
Emergency Contact				
• Name:				
Address:				
Daytime Phone:				

Family Support Resources

Parent to Parent:			
Contact Person:			
Address:	Fax:	Email:	
Phone:			
Website:			
Parent Group: Conta	act		
Person: Address:			
Phone:	Fax:	Email:	
Website:			
Religious Organizati	on:		
Contact Person:			
Address:			
Dhana		Email:	
Website:			
Service Organization	ո:		
Contact Person:			
Address:			
Phone:	Fax:	Email:	
Website:			
Counseling Services): :		
Contact Person:			
Address:			
Phone:	Fax:	Email:	
Website:			

Family Support Resources

Division of Developmen	tal Disabilities:		
		Email:	
Website:			
Other:			
Phone:	Fax:	Email:	
Website:			
Other:			
		Email:	
Website:			

Insurance/Funding Sources

Insurance Company:			
Policy Number:			
Contact Person / Title	::		
Address:			
Phone:	Fax:	Email:	
Website:			
• Insurance Company:			
Contact Person / Title	i:		
Phone:	Fax:	Email:	
Website:			
 Insurance Company: 			
		Email:	
Website:			
 Supplemental Securit 	y Income (SSI):		
Contact Person / Title	i:		
Address:			
		Email:	
Wehsite:			

Insurance/Funding Sources

Other:			_
		Email:	
Website:	_		
Other:			
Phone:			
Wehsite:			

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.

Care Summary: Activities of Daily Living

Use this page to write about your child's abilities to feed themself, bathe, get dressed, use the bathroom, comb hair, brush teeth, etc. Describe what your child can do by themself 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

T:	Come
Time	Care
Morning	
Afternoon	

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.

Care	
Schedule	•

Time	Care
Evening	
Night	

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.

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:

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 situations, a hospital stay, or procedures such as having blood drawn. Describe what things upset y child and what your child does when upset or when they have "had enough". Describe your child's way 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 themself and any help or equipment they use to get around. Describe any activitimits 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 chineds and any special techniques or precautions you use when giving care. Include any special routine your child has for respiratory care.		
Date:		

Care Summary: Rest / Sleep

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

Care Summary: Social / Play

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

Medical / Surgical Procedures

Date	Procedure	Results	Comments	

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.

Lab Work / Tests / Procedures

Date	Test	Results	Comments

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.

Growth Tracking Form

Date	Height	Weight	Head Circumference	Checked By

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.

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:		
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:		



Notes

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							

......

Hospital Stay Tracking Form

Date	Hospital	Reason	Notes

.......

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