

# 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://cshcn.org/planning-record-keeping/care-notebook>.

### + 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: \_\_\_\_\_

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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

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• 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

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• 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

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• 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

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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

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• 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

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• 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: \_\_\_\_\_

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# Child Care Community Health Care / Service Providers

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• 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

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• 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

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• 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

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- 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

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- 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: \_\_\_\_\_ Cell: \_\_\_\_\_
  
- Father'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

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• Parent to Parent: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Email: \_\_\_\_\_  
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

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- 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: \_\_\_\_\_





# Finding Resources for Your Child with Special Needs

Having a child with special needs can be a challenge. You may feel confused and overwhelmed. Here you will find descriptions of some of the people that may be of help to you and your family.

## Public Health Nurses

Public health nurses work in local health departments. They can answer questions about your child's health, growth and development and help you find local resources.

## Children with Special Health Care Needs Coordinators (CSHCN)

CSHCN Coordinators are public health nurses who can provide screening and assessment of your child, refer you to services and resources, provide health information and help you coordinate services. There is a CSHCN Coordinator in every county.

## Family Resource Coordinator (FRC)

FRCs provide information about child growth and development, coordinate resources and services for your family, and find screening for your child if you have concerns about his or her development.

## Health Care Providers

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

## People at Your Child's School

Teachers, school nurses, counselors, or therapists can help your child 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

Other parents can tell you about their experiences, give you tips, tell you about helpful providers, and give you hope. Parent to Parent [www.arcwa.org/parent\\_to\\_parent.htm](http://www.arcwa.org/parent_to_parent.htm) and The Fathers Network [www.fathersnetwork.org](http://www.fathersnetwork.org) are two parent-run organizations that provide emotional and informational support to parents.

## To find these resources and others in your community:

1. Call the toll-free ASK Resource Line (Answers for Special Kids) at 1-800-322-2588, or visit [www.ParentHelp123.org](http://www.ParentHelp123.org). They can connect you to Family Resource Coordinators, Children with Special Health Care Needs Coordinators, health insurance coverage, parenting support, recreational opportunities, local and national disability-related organizations and adolescent transition care.
2. Call Seattle Children's Resource Line and ask for a copy of *Starting Point*, a free resource guide for Washington families who have a child with special needs: (206) 987-2500, option 3, or toll-free 1-866-987-2500. *Starting Point* is also online at [www.cshcn.org](http://www.cshcn.org).

## Create a Contact List for Your Child



### Health Care Providers

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

### School Contacts

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

### Parents

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

### Other Important Numbers

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

**Name:** \_\_\_\_\_

Phone/Email: \_\_\_\_\_

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# Insurance/Funding Sources

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• 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

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

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

# Alphabet Soup

## Acronym Index

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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)

# Alphabet Soup

## Acronym Index

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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

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

Date: \_\_\_\_\_



# Care Schedule

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TIME	CARE
Morning	
Afternoon	



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# Care Schedule

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TIME	CARE
Evening	
Night	

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# Care Summary: Child's Page—Now and Later

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Use this page for your child's words and thoughts about his or her life now as well as in the future. What are your child's dreams? What does he or she do well now that might give direction for life later? What does your child want to be when he or she grows up?

Date: \_\_\_\_\_

Developed in partnership with staff from the Adolescent Health and Transition Project, University of Washington

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# Care Summary: Communication

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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: \_\_\_\_\_

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## Care Summary: Coping / Stress Tolerance

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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 he or she has "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

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

Date: \_\_\_\_\_



# Care Summary:

## Nutrition

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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

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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:

## Rest / Sleep

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

Date: \_\_\_\_\_



.....

## Care Summary: Social / Play

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Use this page to write about your child's ability to get along with others. Describe how your child shows affection, shares feelings, or plays with other children. Describe what works best to help your child get 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

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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 he or she 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: \_\_\_\_\_









.....

# 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: \_\_\_\_\_

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# Notes







.....

# 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



# Emergency Preparedness for Children with Special Needs

*“I used to get overwhelmed about emergency preparedness, but once I broke it down into small steps it got easier. Each week I put a few items on my shopping list. Then I got other supplies at second hand stores and the Red Cross. I feel better knowing I’m ready instead of worrying about getting ready”. –Parent*

In an emergency, we all have to plan to be self sufficient and possibly spend several days without utilities, medical aid or communications.

## Three Ways to Get Ready

1. *Think* about your child’s special needs in an emergency.
2. *Plan* now for emergencies that can happen in your area.
3. *Pack* an emergency supplies kit.

### 1. Think about your child’s special needs in an emergency.

Consider your child’s needs if there was:

- No water
- No electricity, telephone, heat, air conditioning, computer
- No local access to prescription refills or health products
- No refrigeration
- Separation from your family
- Evacuation to a shelter or elsewhere
- Confinement to home
- Limited health care access
- Lack of transportation
- Limited emergency rescue services

### 2. Planning for Special Needs

- Talk with your family about different types of emergencies, how to prepare for them, and how to care for your child with special needs during an emergency.
- Talk with your child’s doctor or health care team about how to care for your child during different types of emergencies. Develop a plan for how you will communicate with your child’s care team during an emergency.

- Plan for back up sources of heat, refrigeration, and electricity. Your family can use an emergency shelter for storing medicine, charging equipment, help with medical needs, getting a meal and more. You do not have to be staying in a shelter to use its resources.
- If your child depends on dialysis or other life sustaining treatment, know the location of more than one facility and find out *their* plans for emergencies and how your child will get treatment, medications etc. Get their emergency contact numbers (these may be out of state).
- Store extra medicines and equipment at your child's school.
- Create and practice an escape plan for your home. Are there clear exit paths for a child who uses mobility devices or has vision loss?
- For each person in the home, keep a pair of shoes stored under their bed to use in an evacuation.
- Talk to your local police and fire departments to see if they have emergency services or plans for people with special needs.
- Plan for your child's service animal.
- Obtain a medical alert and/or identification bracelet for your child.
- In the event of a disaster, listen to your emergency radio station (710-AM KIRO for King, Kitsap, and North Mason Counties)

### Create a Support Network

A support network includes family, neighbors or friends that can help you and your child. They may be your first source of help in an emergency.

- Tell your support network about your child's special needs and where your emergency supplies are stored.
- Give a trusted member of your network a key to your house or apartment.
- Agree upon a system with your neighbors to signal for help if phones and electricity are not working.
- Show others how to handle your child's wheelchair or other equipment.
- Talk to other families who have a child with the same condition as your child about ideas and tips.

Continued

### 3. Pack Emergency Supplies Including:

- A copy of your child's up to date Emergency Information Form and care plan (sample forms at <http://www.cshcn.org/Docs/InCaseofEmergency.doc> and <http://www.aap.org/advocacy/eif.doc>).
- Current medical information and important records stored in an easy to carry format such as a CD or flash drive. Keep at least one paper copy in a waterproof bag.
- Two-weeks worth of medical supplies such as syringes, dressing materials, nasal cannulas, or suction catheters.
- At least a 3 day supply of medications-fourteen days is ideal. It may be a challenge to get extra medications for emergencies, so talk with your child's doctor about how to obtain an extra supply. Keep prescription information in your wallet, car, and survival kit, along with the name, location and phone number of an out of town pharmacy. Ask your doctor or pharmacist how to properly store medication for use in an emergency. In a disaster, if you can't contact your doctor or pharmacy, you can ask for help from emergency responders or staff at emergency shelters or service centers. You can also call your local Red Cross or the Washington State Information Network 211.
- Back up power support (generator or battery) for electrical medical equipment. Due to deadly fumes, use generators, camp stoves or grills outdoors.
- Have a way to charge your cell phone without electricity. You can use a car adaptor or crank radio/flashlight that includes a cell phone charger. These are available at home and hardware stores. Look for battery powered or travel versions of medical equipment your child uses.
- An AC adaptor for your car that can run small electrical equipment such as a nebulizer. Know how long your battery will last while using the adaptor.
- Manual wheelchair or other non-electric equipment.
- Extra contact lenses, glasses, and lens supplies.
- Batteries for hearing aids, communication devices
- Special dietary foods and supplies
- Cooler and chemical ice packs for storing medications that must be kept cold.
- Items that calm or entertain your child.
- Identification to be carried by each child in case your family gets separated.
- Proof of service animal status to insure it can go with you into a shelter.

Continued



- ❑ Pack a smaller “to go” version of items for use in an evacuation. See link below for more information.

Store your supplies in water and pest-proof containers that are easy to get to. Update supplies and emergency contact and medical forms each year and replace water every six months. Store batteries out of devices until ready to use.

### Links to Other Emergency Preparedness Resources for Special Needs

- **The American Red Cross:**  
[http://www.redcross.org/museum/prepare\\_org/disabilities/disabilitiesprep.htm](http://www.redcross.org/museum/prepare_org/disabilities/disabilitiesprep.htm)  
Includes tips for people with:
  - cognitive disabilities
  - communication disabilities
  - disabilities and medical concerns
  - environmental or chemical sensitivities
  - life support systems
  - mobility concerns
  - psychiatric disorders
  - visual disabilities / hearing loss
  - service animals
- **The Department of Homeland Security.** Instructional video on emergency preparedness for individuals with disabilities and or special needs.  
<http://www.ready.gov/america/about/flash/movie14.html>
- **Disability Resource Center.** Emergency preparedness for special needs including specific tips by disability.  
<http://www.disabilitypreparedness.gov/ppp/disabil.htm>
- **Family Voices.** “Emergencies and Disasters: Keeping Children and Youth with Special Health Care Needs Safe”.  
<http://www.familyvoices.org/work/caring?id=0004>
- **National Hemophilia Foundation.** Individual and family preparedness.  
<http://www.hemophilia.org/NHFWeb/Resource/StaticPages/menu0/menu8/menu125/AtAGlanceIndividual.pdf>
- **Washington State Department of Health.** Emergency Resource Guide. Includes disability specific planning.  
[http://www.doh.wa.gov/phepr/handbook/hbk\\_pdf/Emer\\_Res\\_Guide07.pdf](http://www.doh.wa.gov/phepr/handbook/hbk_pdf/Emer_Res_Guide07.pdf)
- **U. S. Department of Health and Human Services.** Helping children with cognitive disabilities cope with disaster.  
<http://www.acf.dhhs.gov/programs/add/Sept11/addcoping.html>

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# Getting to Know Me

<b>My Name:</b>	<b>Nickname:</b>
<b>Date of Birth:</b>	<b>Today's Date:</b>
<b>A Little About Me:</b>	
<b>My Strengths:</b> (things that are easy for me)	
<b>My Challenges:</b> (communication, feeding, learning, mobility, social, energy, behavior)	
<b>My Life in the Community:</b> (school, childcare, place of worship, my favorite places)	
<b>My Home and Family Information:</b>	
<b>My Diagnosis (Diagnoses):</b>	
<b>My Overall Health:</b>	
<b>My Prior Surgeries, Procedures, Lab/Diagnostic Studies:</b>	

# Getting to Know Me

<b>My Name:</b>	<b>Nickname:</b>
<b>Date of Birth:</b>	<b>Today's Date:</b>
<b>My Current Medicines/Doses:</b>	
<b>My Allergies:</b>	
<b>Things to Avoid:</b> (food, activities, and procedures)	
<b>My Equipment/Assistive Technology:</b> (braces/orthotics, walker, wheelchair, communication device, home O <sub>2</sub> , insulin pump, nebulizer, suction)	
<b>Other Things I'd Like You to Know About Me:</b>	
<b>Ways You Can be Helpful to Me:</b>	

Copies of this form are available at <http://www.cshcn.org>

# In Case of Emergency

Today's Date: \_\_\_\_\_

<i>CHILD'S INFORMATION</i>		
Name:		Nickname:
Birth Date:	Primary Language/Communication:	
Home Address:		
Parents/Guardians:	Relationship:	Home #: Other #'s:
Diagnosis:		
<b>Medications</b>	<b>Dose</b>	<b>Time</b>
Allergies:		
Emergency Contact:	Relationship:	Phone #'s:
<i>PHYSICIAN INFORMATION</i>		
Primary Doctor:	Phone:	Fax:
Specialist:	Phone:	Fax:
Specialist:	Phone:	Fax:
Insurance:		
<i>HOSPITAL INFORMATION</i>		
Name: Address:		Phone:  ER Phone:
<i>PHARMACY INFORMATION</i>		
Name: Address:		Phone:
<i>OTHER</i>		
Most Important Things to Know About My Child in an Emergency:		

Copies of this form are available at <http://www.cshcn.org>

# What's the Plan?

<b>Child's Name:</b>		<b>Date of Birth:</b>	<b>Provider:</b>
<b>Parent's Name:</b>		<b>Today's Date:</b>	
<b>Questions/Concerns: What do I want to talk about today?</b>			
<b>What do I hope to have happen?</b>			
<b>Next steps? What needs to be done?</b>			
<b>Who will do this?</b>			
<b>By when? (time frame)</b>			
<b>How will we follow-up?</b>			

Copies of this form are available at <http://www.cshcn.org>