photograph of child

Care Notebook

This care notebook belongs to:

CHILD'S NAME

DATE OF BIRTH TIME OF BIRTH

HOSPITAL WHERE CHILD WAS BORN

ADDRESS

CITY STATE PHONE

FamilyConnection South Carolina

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 care.

How can a Care Notebook help me?
In caring for your child with special health care needs, you will get information and paperwork from many sources. A Care Notebook helps you organize the most important information in a central place. A Care Notebook makes it easier for you to find and share key information with others who are a part of your child's care team.

Use your Care Notebook to:
- Track changes in your child's medicines or treatments
- List telephone numbers for health care providers and community organizations
- Prepare for appointments
- File information about your child's health history
- Share new information with your child's primary doctor, public health or school nurse, daycare staff and others caring for your child

Find a place to keep your care notebook so you can always find it.
What are some helpful hints for using my child's Care Notebook?
- Store the Care Notebook where it is easy to find. Know where you keep it in case they nee information when you are not there.
- Add new information to the Care Notebook whenever your child's treatment changes
- Consider taking the Care Notebook with you to appointments and hospital visits so that information you need will be easy to find

Setting up your Care Notebook

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

Step 1: Gather information you already have.

- Gather up any health information about your child you already have. This may include reports from recent doctor's visits, recent summary of a hospital stay, this year's school plan, test results or informational pamphlets.

Step 2: Look through the pages of the Care Notebook.

- Which of these pages could help you keep track of information about your child's health or care?
- Use the entire notebook or choose the pages you like. The Care Notebook pages are available at www.familyconnectionSC.org.

Step 3: Decide which information about your child is most important to keep in the Care Notebook.

- What information do you look up most often?
- What information do people caring for your child need?

Consider storing other information in a file drawer or box where you can find it if needed.

Step 4: Put the Care Notebook together.

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

Yearly Calendar and Questions/Concerns for Doctors

Appointment Reminder List

2010

January

S	M	T	W	T	F	S
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

February

S	M	T	W	T	F	S
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28						

March

S	M	T	W	T	F	S
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

April

S	M	T	W	T	F	S
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

May

S	M	T	W	T	F	S
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

June

S	M	T	W	T	F	S
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

July

S	M	T	W	T	F	S
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

August

S	M	T	W	T	F	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

September

S	M	T	W	T	F	S
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

October

S	M	T	W	T	F	S
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

November

S	M	T	W	T	F	S
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

December

S	M	T	W	T	F	S
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

Questions/Concerns for the Doctor

Doctor: _____

Question: _____

_____

_____

_____

Date: _____ Answer: _____

_____

_____

Doctor: _____

Question: _____

_____

_____

_____

Date: _____ Answer: _____

_____

_____

Doctor: _____

Question: _____

_____

_____

_____

Date: _____ Answer: _____

_____

_____

Questions/Concerns for the Doctor

Doctor: _____

Question: _____

_____

_____

_____

Date: _____ Answer: _____

_____

_____

Doctor: _____

Question: _____

_____

_____

_____

Date: _____ Answer: _____

_____

_____

Doctor: _____

Question: _____

_____

_____

_____

Date: _____ Answer: _____

_____

_____

Important Information About My Child

This section contains:

1. general information about my child
2. phone numbers
3. emergency contact information
4. health care providers

About my child

Child's Name _____

Date of Birth _____ Social Security Number _____

Insurance Information _____

Parent/Guardian

Name/Address	Phone _____ Office _____ Hrs _____ Fax _____ Cell _____ Email _____

Parent/Guardian

Name/Address	Phone _____ Office _____ Hrs _____ Fax _____ Cell _____ Email _____

Emergency Contact

Name/Address	Phone _____ Office _____ Hrs _____ Fax _____ Cell _____ Email _____

Diagnosis _____

_____

Blood Type _____

Known allergies _____

Sibling's Name_____ Age _____

Sibling's Name_____ Age _____

Sibling's Name_____ Age _____

Sibling's Name_____ Age _____

Sibling's Name_____ Age _____

About my child

Insurance Information

Medicaid Number _____

Insurance Information

Special child's name _____ Insurance Company _____

Policyholder _____ Policy Number _____ Group # _____

Other child's name _____ Insurance Company _____

Policyholder _____ Policy Number _____

School Information

Name of school _____ Phone _____

Contact name _____ Teacher _____

Daycare Information

Where? _____ Head Teacher _____

Times/Days _____ Phone _____

Physicians

Primary physician's name _____ Office _____

Office Phone _____ Address _____

About my child

Specialty Care Physicians

Name _____ Address _____

Office Phone _____ Office Fax _____

Name _____ Address _____

Office Phone _____ Office Fax _____

Name _____ Address _____

Office Phone _____ Office Fax _____

Name _____ Address _____

Office Phone _____ Office Fax _____

Name _____ Address _____

Office Phone _____ Office Fax _____

Name _____ Address _____

Office Phone _____ Office Fax _____

Name _____ Address _____

Office Phone _____ Office Fax _____

Dentist:

Dentist's Name _____ Practice _____

Office Phone _____ Office Address _____

Hospital:

Preferred Hospital _____ Emergency Room Phone _____

Preferred Ambulance _____ Ambulance Phone _____

Pharmacy used for prescriptions _____

Phone Number _____

Medical Information

This section contains my child's:

1. medical history
2. medication list
3. immunization record
4. hospitalizations/ER visits

*Make sure your care providers update this information at each visit. This information will be a continuous record of your child's medical care.

My child's health

My medical diagnosis(es) _____

_____

_____

Baseline physical findings _____

_____

Baseline vital signs _____

_____

Baseline neurological status _____

_____

Procedures to be avoided and why:

Do I have any allergies? If yes, here's the list:

Latex _____ Type of reaction _____

Medications _____ Type of reaction _____

Food _____ Type of reaction _____

Other _____ Type of reaction _____

My height _____ My weight _____ Date last measured _____

Birth Weight _____ Full term____ Premature ____ Weeks gestation _____

Nursery Course _____

_____

My child's health

Seizure Information

Do I have seizures? ____ yes ____ no (If yes, describe in detail. If recorded on video, please show)

How long do my seizures last?

What happens before these seizures?

What should you do during the seizure?

How you need to record it after the seizure.

My shots, allergy information, asthma, etc.

Date of my last tetanus shot _____

Are all my shots updated? _____ Last date on which they occured _____

Asthma or respiratory distress or diabetic intervention? ____ yes ____ no (explain)

Special Equipment

Type	Supplier	Phone

Supply Needs (tube extensions, catheters, etc.)

Type	Supplier	Phone

My child's medical history

Illnesses

Date of Event	Description of Illness	Doctor	Outpatient or inpatient	Facility

My child's medical history

Surgeries

Date of Event	Description of surgery	Doctor	Outpatient or inpatient	Facility

My child's medical history

Test/radiology record

Date of Event	Where was the test done?	Type of test	Ordering physician's name	Result

My child's medications

Preferred pharmacist(y) _____ Phone _____

Medication	Rx #	Dosage	Time given	How to give	Purpose	Side effects	Prescribing physician	Phone

My child's medications

Medication					
Rx #					
Dosage					
Time given					
How to give					
Purpose					
Side effects					
Prescribing physician					
Phone					

Insert your child's immunization (shots) record here

My child's developmental history

Examples include: rolling over, sitting, walking, talking, etc.

Date of Event	Milestones/Achievements

Nutrition

Special nutritional needs _____

_____

Feeding schedule _____

_____

Allergies to food _____

_____

Abnormal reactions to diet or supplements _____

_____

Registered dietician _____ Phone _____

Weight Chart

Date	Weight	Height

Date	Weight	Height

Family Health History

Name:

Last Modified:

Is there anyone in the family (parent, brother, sister, grandparents, uncle, aunt, cousin, etc.) with a similar disability or chronic illness? ☐ No ☐ Yes

If yes, who?_____

_____

Does anyone in the family have:

Genetic conditions	☐ yes	☐ no	_____
Heart problems	☐ yes	☐ no	_____
Developmental disability	☐ yes	☐ no	_____
Seizure disorder	☐ yes	☐ no	_____
Diabetes	☐ yes	☐ no	_____
Blood disorder	☐ yes	☐ no	_____
Cancer	☐ yes	☐ no	_____
Vision and/or hearing impairment	☐ yes	☐ no	_____
Metabolic or nutritional disorder	☐ yes	☐ no	_____
Other _____	☐ yes	☐ no	_____

Has anyone in the family had genetic testing or counseling?

☐ yes ☐ no ☐ don't know

If yes, please describe _____

_____

Is there any other family health information that might be related to your child's special health needs?

Therapists and other important people in my child's life and my life

1. Therapists
2. Professional Support Resources
3. Family Support Resources
4. Personal Support Resources

My Therapists/Physical Therapist

Physicial Therapist
Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Occupational Therapist
Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Speech-Language Therapist
Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Early Interventionists
Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Vision Therapists
Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Other
Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Other
Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Professional Support Resources

(social worker, PCA companies, disability boards, counseling, transportation, DDSN, CRS, etc.)

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Professional Support Resources

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Family Support Resources

Family Connection of South Carolina
Family Connection provides emotional support, information and education to families that have a child with special needs.
2712 Middleburg Drive
Suite 103
Columbia, South Carolina 29204
803-252-0914
800-578-8750/toll-free
www.FamilyConnectionSC.org

Care Line
A statewide toll-free hotline that provides assistance with accessing services, information for children with special health care needs.
800-868-0404

Examples (Autism Society, ProParents, Epilepsy Foundation, etc.)

Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Name _____
Organization _____
Address _____
Phone _____ E-mail _____

Personal Support Contact Info

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

Name _____

Address _____

Phone _____

E-mail _____

School Information

School Contacts

School/Preschool _____

Address _____

Phone _____ Fax _____

School District _____ Name _____ Phone _____

Principal _____

Teacher _____

Special Educator _____

Other IEP/504 Team Members (PT, OT, Speech, SpEd)

_____

_____

_____

_____

_____

Guidance Counselor _____

Nurse _____

School Transportation _____

_____

District Spec. Ed Coordinator _____

Other _____

_____

_____

Insert copy of 504/IEP and Individualized Health Plan here

More About Me

Information for caregivers, PCA's, babysitters
1. In case of emergency
2. About me
3. My behavior
4. Emergency preparedness

In case of emergency in our house

Home liability/insurance information

Homeowner/renter insurance co: _____ Phone _____

Name of insured _____ Policy Number _____

In case of emergency, where do you find:

Smoke and carbon monoxide detector(s) (change batteries when time changes _____

_____

Fire extinguisher _____

Neighbor's house in case of fire _____

Water shut off _____

Gas shut off _____

Thermostat _____

Circuit breaker/fuse box _____

Extra fuses _____

Non-portable phone (to use during power outages) _____

Power company outage emergency number _____

Candles/matches _____

Flashlight _____

Extra batteries _____

Vacuum cleaner _____

Mop/broom _____

Other cleaning supplies _____

Does our house have…?

Firearms _____

Ammunition _____

Other hazardous material _____

Security measures _____

_____

About Me

I can communicate

Is my speech understood by those outside of my family? _____ If not, what other methods of communication do I use? _____

_____

Does my family know sign language? _____

Do I have any hearing problems? _____

Do I have any vision problems? _____

My bath

I prefer the _____ tub

_____ shower

_____ other

How it happens:

Do we bathe together? _____ Explanation _____

_____

My potty and me

Am I potty trained? _____

I need: _____ limited assistance _____ no assistance _____ supervision

How often between my visits to the toilet? _____

Do I need to be reminded? _____ How? _____

How do I tell you I've got to go potty? _____

Menstrual supplies needed? _____ Location _____

Any more you need to know _____

_____

If I am not trained, how often between my diaper changes? _____

Where are supplies kept? _____

My teeth

Do I need assistance brushing my teeth? _____ Here's the facts:

Dentist _____ Phone _____

About Me

My bedtime

Do I have a special position for sleeping? _____ Here's how:

My special props for bedtime _____ Where are they located? _____

_____

Here's how I act during sleep time? (Wakes during night? Interventions used)

Time to get dressed

Can I dress myself? _____ If no, what help do I need?

Time to eat

Do I know the difference between foods and things that cannot be eaten? _____ If no, explain:

What are my food preferences/etc.?

My likes _____

My dislikes _____

I can't eat _____

I shouldn't eat _____

I must eat _____

Am I able to feed myself? _____

Does my food need to be _____ cut up in pieces? _____ lightly blended? _____ pureed?

Do I prefer my right or left hand? _____

Do I drink from a bottle, sippy cup, or regular cup or glass? _____

I use a _____ knife _____ fork _____ spoon

I have a special position used for eating _____ If yes, explain:

Am I allowed to have snacks? _____ When? _____

What types? _____

How do I let you know I want food? _____

Drink? _____

Any specific diet or vitamin supplement(s)? _____

_____

About Me

Name _____

Nickname _____

Birthday/Age _____

Sibling's Names and dates of birth _____

_____

_____

Pet _____

Home _____

_____

Favorite Things _____

_____

Favorite Places _____

_____

Favorite Animals _____

_____

Favorite Foods _____

_____

Favorite Colors _____

Favorite Activities _____

_____

Favorite TV Shows _____

Favorite Books _____

Church _____

About Me

Favorite Songs _____

_____

Favorite Friends _____

_____

Favorite Games/Sports _____

_____

Things that usually upset me _____

_____

_____

_____

Things that help calm me when I'm upset _____

_____

_____

_____

Other important things about me (likes and dislikes) _____

_____

_____

_____

_____

_____

_____

_____

_____

About Me

How I behave

Here are some things you need to know which may cause you concern or which you may observe. My family has checked those that apply. Then, to the right, they've listed any interventions used at school or in the home.

Behavior Intervention

_____ very shy
_____ clingy
_____ does not like to be hugged
_____ does not like to be touched
_____ aggressive toward objects
_____ aggressive toward persons
_____ aggressive toward animals
_____ easily frustrated
_____ self-hating
_____ self-abusive
____ head banging
____ hand biting
____ gagging
____ other
_____ acts defiant
_____ ADHD (unable to sit still for more than a few minutes)
____ criticizes, belittles, swears or calls names
____ appears to be in her/her own private world
____ argues and must have last word in verbal exchanges
_____ has nervous ticks
____ muscle-twitching
____ eye-blinking
____ nail biting
____ hand wringing
_____ bed wetting
_____ temper tantrums (describe)
_____ has rapid mood changes
_____ weeps or cries without provocation
_____ possessive

About Me

Behavior Continued

Intervention

_____ feels inferior
_____ gets depressed, is depressed a lot
_____ uses inappropriate sexually-related language
_____ engages in inappropriate sexually-related behaviors
_____ physically runs away from people
_____ deliberately makes false statements
_____ must have immediate reward or gratification
_____ makes inappropriate noises
_____ fakes not hearing
_____ talks or has talked about suicide
_____ has abnormal sleep patterns
_____ will take property of others
_____ bites others
_____ very talkative
_____ questions everything
_____ whines
_____ accident-prone
_____ tears magazines or books

Other:

What rewards do I get for good behavior:

What methods of discipline should be used for misbehavior?

I show affection by:

Behavior Change Log

Date	Behavior	Notes

Emergency Preparedness

The time to prepare for a disaster is BEFORE it happens. Use this checklist to assist you in making sure that you have done everything possible to prepare for a disaster and prevent serious outcomes, should one hit your community.

Your Child with Special Needs

- ❑ Do you have a current care plan and list of medications from your child's physician?
- ❑ Do you have an emergency information form filled out on your child?
- ❑ Do you have a two week supply of medications and supplies for your child?
- ❑ Do you have back up systems or plans for medical equipment that require electricity?
- ❑ Have you discussed with your child's doctor the best place for him/her in the event there is a disaster?
- ❑ Are your local emergency management team and neighbors aware that you have a child with special needs and familiar with those needs?
- ❑ Do you have a disaster plan for your child while he/she is at school, day care or church?

Your Family

- ❑ Does your family have a disaster plan? Have you practiced your plan?
- ❑ Do you have a disaster supply kit for your family?
- ❑ Have you designated and shared with friends and family a "meeting" place and central point of contact should your family be separated during a disaster?
- ❑ Have you discussed disasters and preparation with your children and shared information on common disasters?
- ❑ Have you shown your small children pictures of emergency workers common to disaster scenes (such as workers in uniform, in fire suits, and workers wearing protective face gear)?
- ❑ Have you made plans for your pets?

Your Home

- ❑ Have you checked your home for materials and items that might pose a hazard during a disaster? (Don't forget the outside!)
- ❑ Have you located and learned how to turn on and off utilities such as gas and electricity?
- ❑ Do you have a working smoke and carbon monoxide detectors in your home?
- ❑ Does your home have necessary resources such as a water hose, fire extinguishers, generators, etc?
- ❑ Have you developed a plan with your neighbors on how you will assist one another in case of a disaster?

For additional information on emergency preparedness, please go to aap.org/advocacy/emergprep.htm