Care Notebook

For Children & Youth with Special Health Care Needs

Medical Home Portal

Utah Parent Center
Bringing Hope, Opening Doors, Elevating Inclusion

utah family voices

About Your Care Notebook

What is a Care Notebook and how can it help me?
A Care Notebook is a tool for families who have children with special health care needs to keep track of important information about their child's health care. It was designed for families, by families of Children and Youth with Special Health Care Needs.

Over time, you will get information and paperwork from many sources and providers involved in your child's care. A Care Notebook helps you organize the most important information in one place, and makes it easier for you to find and share this information with others who are part of your child's care team. This book can be used "as is" or you can remove or add pages according to your child's needs. You can store it online or print a copy.

Why build my own care notebook?
Care Notebooks are very personal to your child and ideally should be customized to reflect your child's medical history and current information. Utah Family Voices recommends use of the Medical Home Portal to create your individualized Care Notebook.

How do I build my own Care Notebook?
Go to the Medical Home Portal for tips on setting up your notebook, as well as to add extra pages or access additional information.

You will need the free Adobe Reader on your computer to open and view the PDF documents. This format allows you to save files that cannot be modified, but can be easily shared and printed. You can download a desktop version of Adobe Acrobat Reader at https://acrobat.adobe.com/us/en/acrobat/pdf-reader.html#tt or look for Adobe Acrobat Reader on the App Store or Google Play Store. The PDF files are set up to allow you to complete the forms on your phone or computer, or you may print the forms and complete them by hand. It is helpful to view the online examples before building your own care notebook. Here are some examples of information to include:

- https://cshcn.org/pdf/getting-to-know-me-teens-sample.pdf
- https://cshcn.org/pdf/whats-the-plan-teens-sample.pdf
- https://cshcn.org/pdf/in-case-of-emergency-form-teens-sample.pdf

Setting Up Your Care Notebook

Use your Care Notebook:

- Store the Care Notebook where it is easy to find. This helps you and anyone who needs information when you are not there.
- Share new information with your child's primary care physician, school nurse, daycare staff, and others caring for your child.
- Take the Care Notebook with you to appointments and hospital visits so that information you need will be easy to find.
- Include your child when working on the Care Notebook. Let them know that the Care Notebook contains information about them and their care.

Follow these steps to set up your Care Notebook:

Step 1: Gather information you already have to fill and update your Care Notebook.

- Track changes in your child's medicines or treatments.
- Add new information to the Care Notebook whenever your child's treatment changes.
- List telephone numbers for providers and contacts.
- Prepare for appointments.
- File information about your child's health history.

Step 2: Check out 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 Care Notebook as it is, or remove or add pages that will help you personalize your book to your child's needs. These are available at the Medical Home Portal.
- Use the PDF form fields to enter and store your information electronically, or you can print a copy to share with others caring for your child.
- For a printed copy, call Utah Family Voices at 801-272-1068.

Step 3: Decide which information is most important to keep in your child's Care Notebook

- What information do you look up often?
- What information do caregivers for your child need most?
- Consider storing other information in a file drawer or box where you can find it, if needed.

Step 4: Assemble your Care Notebook

Everyone has a different way of organizing information. The KEY is to make it easy for you to find again. Here are some suggestions for supplies used to create a Care Notebook:

- Three-ring notebook to hold papers securely.
- Tabbed dividers to create your own information sections.
- Pocket dividers to store reports.
- Plastic pages to store business cards and photographs.

Care Notebook Contents

My Child and Family

- Child Information Page
- Family Information Page
- Scheduling Calendar
- Notes

Health Care

- CSHCN Emergency Health Information Sheet
- Doctor's Appointments
- Diagnoses and Conditions
- Nutrition
- Diet and Tube Feed Tracking
- Growth Tracking
- Immunization and Allergies
- Medications
- Nebulizer Treatments and Vest Treatments
- Catheterization Schedule
- Respiratory/Breathing Notes
- Dental
- Surgeries or Procedures
- Lab Work/Tests/Procedures
- Event Tracker
- Seizure/Behavior Log
- Medical Supplies
- Notes

Contacts

- Health Care Providers
- Family Support Resources
- School Contacts
- Emergency Contacts
- Personal Contacts
- Contact Log
- Notes

Care Plan

- Care Schedule
- Mealtime Routine
- Therapy
- Activities of Daily Living
- Social Experiences
- Recreation
- Communication
- Communication Milestones
- Coping/Stress Tolerance
- Mobility
- Social/Play
- Rest/Sleep
- Transitions/Looking Ahead
- Notes

Health Coverage

- Insurance/Coverage
- Medical Bill Communication Log
- Medical Bills
- Medical Travel Expense Log
- Out-of-Pocket Expense Log
- Notes

Note: You may use all or just some of these pages. Not all of the pages may apply to your family situation. Look on the website to add different pages. Organize your pages any way that works for you. (See *Setting up Your Care Notebook*.) Use dividers or tabs to help you organize your notebook. Sheet protectors, plastic sleeves, and folders will also be helpful.

Use the "My Child and Family" section of your Care Notebook to create an identity profile for your child.

This section includes a personal profile, family, friends, and a calendar to schedule your child's appointments and activities.

Child's Information Page

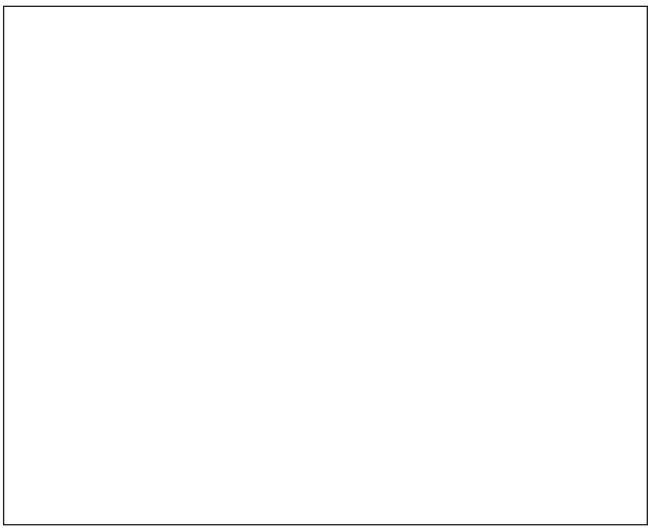

Photo of Me!

Name: _____

Nickname: _____

Birthday: _____

I like to: _____

_____

I don't like to: _____

_____

I have a pet yes ❒ no ❒ My pet is a _____Named _____

Friends: _____

Caregivers: _____

When I am happy I _____

When I am sad I _____

When I feel pain I _____

I need help with _____

I can do these things for myself _____

If you need to know something else, call _____

Favorite Things

Toys _____

TV shows _____

Games _____

Hobbies _____

Songs _____

Animals _____

Favorite foods _____

Least Favorite foods _____

Child's Information Page

Use this page for your child's words and thoughts about his or her life now as well as later.

Date: _____

Family Information

Child's Name: _____

Nickname: _____

Date of Birth: _____

Diagnosis: _____ Blood Type: _____

Legal Guardian: _____

Address: _____ Daytime Phone: _____

_____ Evening Phone: _____

Mother's Name: _____

Address: _____ Daytime Phone: _____

_____ Evening Phone: _____

Father's Name: _____

Address: _____ Daytime Phone: _____

_____ Evening Phone: _____

Other household members:

Name: _____ Age: _____

Name: _____ Age: _____

Name: _____ Age: _____

Name: _____ Age: _____

Name: _____ Age: _____

Name: _____ Age: _____

Important Family Information: _____

_____

_____

_____

_____

_____

Language(s) spoken at home: _____

_____

Interpreter Needed? Yes: ❒ No ❒

Preferred interpreter? Name: _____

Daytime Phone: _____ Evening Phone: _____

Emergency Contact

Name: _____

Address: _____ Daytime Phone: _____

_____ Evening Phone: _____

Scheduling Calendar

Month _____ **Year** _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Name: _____ **DOB:** _____

Notes

Notes

The "Health Care" section of your Care Notebook contains all information about your child's health care and health care needs. This section will be very helpful at appointments with doctors and specialists.

CSHCN Emergency Health Information Sheet (Información De Emergencia)

Demographics (Demografia)

Name: (nombre) _____
Birthdate: (fecha de nacimiento) _____ M ❒ F ❒ Age: (edad) _____
Primary Language: (idioma preferido) _____

Parent/Guardian: (nombre de Padre/Tutor) _____ Phone: _____
Emergency Contact: (contacto de emergencia) _____ Phone: _____
Preferred Hospital for Transport: (hospital perferido) _____

Baseline Status (Condicion normal)

Vital Signs: (los signos vitales) HR: _____ RR: _____ BP: _____ O2 Sat: _____%
Weight: (peso) _____lbs Height: (altura)ft/in _____ Best IV site: (major IV sitio) _____

Neuro Status/Your child's developmental level: (condicion neurologica del paciente)

_____
_____

❒ Nonverbal (no puede hablar) ❒ Hearing Impaired (No puede oir) ❒ Visually Impaired (No puede ver)

Medical History (Historial medico)

Allergies/Reaction: (alergias/reaccion)

1. _____ 4. _____
2. _____ 5. _____
3. _____ 6. _____

Medical Conditions: (condiciones medicas)

_____
_____
_____
_____
_____

Hospitalizations/Surgeries: (hospitalizaciones/cirugias)

_____
_____
_____
_____
_____

Medications: (medicinas)

1. _____ 6. _____
2. _____ 7. _____
3. _____ 8. _____
4. _____ 9. _____
5. _____ 10. _____

Special Needs/Equipment (Necesidades especiales/equipo)

❒ Feeding pump (bomba de aleimentacion)
❒ Wheelchair (silla de ruedas)
❒ Pulse Oximeter (oximetro)
❒ Apnea Monitor (monitor de apnea)
❒ Suction Machine (maquina de succion)
❒ Gastrostomy Tube (tubo gastronomico)
❒ Oxygen (oxigeno)
❒ NG/NJ Tube (tubo nasogastrico)
❒ Tracheostomy (traqueotomia) Size/type: (medida/marca) _____
❒ Ventililator (ventilador) Type/mode (marca/moda) _____

Any Other Information for Emergency Responders (Otra informacion de emergencia)

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Primary Care Physician: (medico de atencion primaria): _____

Phone: _____
Specialists or other services involved in your child's care (especialistas): _____

_____
_____
_____
_____

Instructions for utilizing the CSHCN Emergency Information Sheet

- Register – go to https://health.utah.gov/chirp/?user_type=parent_guardian
  Fill out the form, and your child will be registered. You will receive the storage tube in the mail.
- Update when there are changes in your child's health, medications, contacts, etc.
- Complete this form and keep one copy in the following places. This will give your child the best possible outcome in an emergency situation.
  - Doctor's office
  - Home: inside the refrigerator in a tube provided once you register at the website
  - At each parent's workplace
  - On file at School
  - Emergency contact: at the house of that person
  - Local ER
  - In each parent's vehicle
  - Purse/wallet of each parent
  - Child's backpack/travel bags

This form was provided by the Utah Department of Health Children's Health Information Red Pack (CHIRP) program.

Last Updated: _____
Name: _____

Doctor's Appointments

Doctor's Name	Appointment Date	Appointment Time	Questions to Ask at Appointment

Diagnoses and Conditions

This page helps you document your child's official and suspected diagnoses, along with the dates and other notes you may take about them.

Child's Name _____ Date of Birth _____

Diagnosis or Suspected Diagnosis	Provider Who Gave Diagnosis or Working on It	Date	Notes

Nutrition

Use this page to talk 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 for your child and family.

Date: _____

Foods/Nutritional Formulas
Allergies or Restrictions
Special Feeding Techniques, Precautions, or Equipment
Mealtime Routines

Diet and Tube Feed Tracking

Use this page to talk about your child's daily eating schedule. Whether they eat by mouth or use a tube, weekly schedule, and additional details to know about your child and family's mealtime routines.

	Sunday	Monday	Tuesday	Wednes-day	Thursday	Friday	Saturday
Night Tube Feed							
Breakfast/ Morning Tube Feed							
Lunch/ Noon Tube Feed							
Dinner/ Evening Tube Feed							
Snacks/ Extra Fluids							
Notes							

Growth Tracking

This page will help you keep track of your child's growth. This is especially helpful for parents of premature babies and children with hydrocephalus.

Date	Height	Weight	Head Circumference	Checked By

Immunizations and Allergies

Child's Name: _____

	Date	Physician	Reaction	Date	Physician	Reaction	Date	Physician	Reaction	Date	Physician	Reaction	Date	Physician	Reaction
Hepatitis B															
Diptheria-Tetanus (Combined: DT)															
Tetanus															
Polio															
Influenza Type B															
MMR (Measles, Mumps and Rubella)															
Measles (Rubeola)															
Mumps															
Rubella (3-day Measles)															
Varicella Zoster															
COVID-19															
Flu															

	Date	Result	Date	Result	Date	Result
Tuberculin Test						
Lead Screening						
Other						

Immunizations and Allergies

Communicable Diseases	Date	Duration	Drugs Taken

Allergy Record

Allergy	Type of Reaction	Date

Medications

Name of Medication	Prescription Number	Pharmacy	Strength (see label)	Reason for Medication	Dosage/ Frequence (amount)	Route (how taken)	Start Date	End Date	Reason for Ending Medication

Pharmacy	Pharmacist	Address	Phone Number

Nebulizer Treatments and Vest Treatments

Keeping track of how many breathing treatments you do can seem impossible. This page was created to help families keep track of what treatments are being given, who gave them, what time, and oxygen usage.

Only use this log if it applies to your child.

Name: _____

Date	Time	Neb given	O2 sat pre	O2 sat post	Vest given	O2 sat pre	O2 sat post	Comments	Initials

Catheterization Schedule

A catheterization schedule can help anytime, but especially if the doctor needs information about it. This page will help you keep track of cath times and urine output.

Only use this log if it applies to your child.

Catheterization Information for: _____ Month: _____

Date	Time	Amount of urine obtained	Additional comments (see chart)	Date	Time	Amount of urine obtained	Additional Comments (see chart)

Respiratory/Breathing Notes

Use this page to talk about your child's breathing/airway/asthma 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 during care.

Only use this log if it applies to your child.

Date: _____

Dental

Child's Name: _____
Dentist's Name: _____
Address: _____

_____
Telephone: _____

❒ Dentist has been informed of child's medical condition and medical specialists' recommendations.

All children should have routine dental care. Such care may be even more important when your child has a special health care need. He or she may need to be followed by a dentist with special skills. Consult with your family dentist or your child's medical specialist to determine if he or she requires specialized dental services.

Before your child is examined, the dentist should have information regarding your child's medical condition and current care. Any precautions recommended by your child's medical specialist should be discussed with the dentist. It is also essential that you provide the dentist with a list of current medications received by your child.

You can use the space below to keep track of your child's dental appointments.

Date	Time	Appointment Information

Surgeries or Procedures

Child's Name: _____

Type of Surgery/Procedure	Surgeon/Physician/Hospital	Date(s)

Hospital Admissions (For Reasons Other Than Surgery)

Reason for Admission	Hospital	Date(s)

Lab Work/Tests/Procedures

Date	Test	Result	Comments

Event Tracker

Use this sheet to keep track of important events related to your child's health that may happen from time to time. Some examples include behaviors, seizures, oxygen requirements, history of injuries, frequency of suctioning, and vomiting.

Child's Name: _____ Date of Birth: _____

Date	Activity/Information

Seizure/Behavior Log

Use this page to track seizures, possible seizures, or concerning behaviors. It is important to know the time between seizures and what they looked like when talking to the neurologist.

Only use this log if it applies to your child.

Child's Name: _____ Date of Birth: _____

Date	Duration of Seizure/ Behavior	Description of Seizure (extremities involved, intensity, etc.) or Behavior you are concerned about

Medical Supplies

Medical Supplies For: _____

Supply Company Name:_____Fax:_____
Email:_____Phone:_____

Product Description	Product Code	Quantity	Received	Back Order	Comments

Notes

Notes

Use the "Contacts" section of your Care Notebook for the people who provide services, give care to your child, and are a part of their life.

Include school, emergency, and personal contacts.

Health Care Providers

Name: _____ Date of Birth: _____

Primary Medical Provider _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Primary Medical Provider _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Specialty Hospital _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Specialist Name_____
Clinic/Hospital _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Specialist Name _____
Clinic/Hospital _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Specialist Name _____
Clinic/Hospital _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Health Care Providers

Specialist Name _____
Clinic/Hospital _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Specialist Name _____
Clinic/Hospital _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Dentist Name _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Orthodontist Name _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Public Health Nurse _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Nutritionist _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Health Care Providers

Social Worker _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Healthy Families Contact _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Home Health Agency _____
Start Date _____ End Date _____
Contact Person _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Home Health Agency _____
Start Date _____ End Date _____
Contact Person _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Home Health Agency _____
Start Date _____ End Date _____
Contact Person _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Pharmacy _____
Contact Person _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Health Care Providers

Pharmacy _____
Contact Person _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Occupational Therapist (OT) _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Physical Therapist (PT) _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Speech-Language Pathologist _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Other Therapist _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Health Care Providers

Other Therapist _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Respite Care Provider _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Contact _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Contact _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Contact _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Family Support Resources

Name:_____Date of Birth:_____

Parent-to-Parent _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Parent Group _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Religious Organization _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Service Organization _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Counseling Services _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Other _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Family Support Resources

School/Preschool _____
Principal _____
School Contact _____
Start Date _____ End Date _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

School Nurse _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Teacher _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Special Education Teacher _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Other _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Other _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Family Support Resources

Transportation Agency _____
Contact Person _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Transportation Agency _____
Contact Person _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Care Provider _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Care Provider _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

Care Provider _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

School Contacts

(Some parents store IEP and 504 plan information in sheet protectors following this section.)

School District _____
Address _____
City _____ State _____ Zip _____
Phone _____ Fax _____
Website _____

Special Education Coordinator _____
Address _____
City _____ State _____ Zip _____
Phone _____ Fax _____
Website/Email _____

504 Accommodation Plan Coordinator _____
Address _____
City _____ State _____ Zip _____
Phone _____ Fax _____
Website/Email _____

District Nurse assigned to your child's school _____
Address _____
City _____ State _____ Zip _____
Phone _____ Fax _____
Website/Email _____

Care Provider _____
Start Date _____ End Date _____
Agency _____
Address _____
City _____ State _____ Zip _____
Phone _____
Email _____

School/Preschool _____
Address _____
City _____ State _____ Zip _____
Phone _____ Fax _____
Website _____

School Contacts

Principal/Administrator _____
Address _____
City _____ State _____ Zip _____
Phone _____ Fax _____
Website/Email _____

Classroom Teacher _____
Phone _____ Fax _____
Website/Email _____

Resource Instructor _____
Phone _____ Fax _____
Website/Email _____

Aide/Assistant/Intervener _____
Phone _____ Fax _____
Website/Email _____

Special Education Director _____
Phone _____ Fax _____
Website/Email _____

Special Education Teacher _____
Phone _____ Fax _____
Website/Email _____

Therapist(s) _____
Phone _____ Fax _____
Website/Email _____

Other Contacts _____
Phone _____ Fax _____
Website/Email _____

Other Contacts _____
Phone _____ Fax _____
Website/Email _____

Emergency Contacts

Name: _____ Date of Birth: _____

Name _____
Address _____
City _____ State _____ Zip _____
Phone _____ Relationship _____
Email _____

Name _____
Address _____
City _____ State _____ Zip _____
Phone _____ Relationship _____
Email _____

Name _____
Address _____
City _____ State _____ Zip _____
Phone _____ Relationship _____
Email _____

Name _____
Address _____
City _____ State _____ Zip _____
Phone _____ Relationship _____
Email _____

Name _____
Address _____
City _____ State _____ Zip _____
Phone _____ Relationship _____
Email _____

Name _____
Address _____
City _____ State _____ Zip _____
Phone _____ Relationship _____
Email _____

Personal Contacts

Name:____Date of Birth:____________________

Name__________ Address__________ __________ City, State ZIP__________	Phone__________ Office__________ Fax__________ Cell__________ Email__________
Name__________ Address__________ __________ City, State ZIP__________	Phone__________ Office__________ Fax__________ Cell__________ Email__________
Name__________ Address__________ __________ City, State ZIP__________	Phone__________ Office__________ Fax__________ Cell__________ Email__________
Name__________ Address__________ __________ City, State ZIP__________	Phone__________ Office__________ Fax__________ Cell__________ Email__________
Name__________ Address__________ __________ City, State ZIP__________	Phone__________ Office__________ Fax__________ Cell__________ Email__________
Name__________ Address__________ __________ City, State ZIP__________	Phone__________ Office__________ Fax__________ Cell__________ Email__________

Contact Log

Date	Contact Person	What Was Discussed

Notes

Notes

The "Care Plan" section of your Care Notebook is where you can list what is happening in your child's life and what you would like to see happen in the future. This includes daily care, mealtime routines, therapies, recreation, communication, play, and more.

Care Schedule

Time	Care
Morning	

Afternoon	

Care Schedule

Time	Care
Evening	

Night	

Mealtime Routine

Usual eating times:_____

Usual length of time to eat:_____

Food Allergies	Foods to Avoid

Favorite Foods	Food Dislikes

Feeding Equipment	Utensils Used	Positioning

Feeding Tips: _____

Therapy

Use this page to track your child's therapy goals. This will allow you to measure improvement or know when to change the goals.

Only use this log if it applies to your child.

Physical ❒ Occupational ❒ Speech ❒ Behavioral ❒

Child's Name:_____

Month/Year: _____

			Weekly: Achieved(A)/ Continue (C)				
#	Goals	Comments	1	2	3	4	5

Activities of Daily Living

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

Date: _____

Social Experiences

What activities make life meaningful for your son or daughter? What leisure activities does he/she enjoy? List all hobbies, interests, recreational and social activities, and vacation preferences. Make a list of places and situations that your child is uncomfortable with or dislikes.

Favorite TV Shows/Movies

Hobbies/Activities In the Home

Leisure Activities/Clubs Outside the Home

Name of Club
Contact Person
Phone Number
How Often

Name of Club
Contact Person
Phone Number
How Often

Special Interests
(Example: loves baseball games in person, but not on TV)

Favorite Vacations/Travels

Recreation

A number of organizations have programs designed to give children and adults with special needs opportunities to get out and enjoy themselves. These include local park and recreation programs. Check with your local parent training and information center to find out more about recreation opportunities close to your home.

Some parents include brochures and activity calendars in this section of their Care Notebook.

Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____Fax: _____Email: _____
Schedule: _____

Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____Fax: _____Email: _____
Schedule: _____

Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____Fax: _____Email: _____
Schedule: _____

Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____Fax: _____Email: _____
Schedule: _____

Recreation Opportunity: _____
Contact Person: _____
Address: _____
Phone: _____Fax: _____Email: _____
Schedule: _____

Notes:

Communication

Use this page to talk about your child's ability to communicate and understand others. Describe how your child communicates. Include sign language, words, gestures, or any assistive technology your child uses to communicate or understand others. Include any special words your family and child use to describe things.

Date: _____

Communication Milestones

Use this page to keep track of your child's attempts and successes with communication. This will help you and the Speech Therapist see progress and measure goals.

Date	Place of Interaction	Child's Means of Communication	Type of Assistive Technology	Special Words, Signs, or Cues

Coping/Stress Tolerance

Use this page to talk 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: _____

Mobility

Use this page to talk about your child's physical ability to get around. Include what your child can do by himself/herself and any help or mobility equipment your child uses. Describe any activity limits and any special routines your child has for transfers, pressure releases, positioning, etc.

Date: _____

Social/Play

Use this page to talk about your child's social skills. Describe how they show affection, share feelings, or play with other children. Note what works best to help your child get along or cooperate with others, and their favorite things to do. Include any special family activities or traditions that are important.

Date: _____

Rest/Sleep

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

Date: _____

Transitions/Looking Ahead

Your child and family will experience many transitions, small and large, over time. Three predictable transitions occur for most children: reaching school age, approaching adolescence, and moving from adolescence into adulthood. Children with special health care needs do not experience these transitions in the way most children experience them. Their transitions may include moving into new programs, working with new agencies and care providers, or making new friends. Transitions involve changes: adding new expectations, responsibilities, resources, and letting go.

Looking at transitions may be hard, depending on your circumstances. You may have limited time just to do what needs to get done each day. You may find it helpful to jot down a few ideas about your child's and family's future. You might start by thinking about your strengths. How can these strengths help you plan for what's next and identify long-term goals? What are your dreams and your fears about your child's and family's future?

Date: _____

Notes

The "Health Coverage" section is where you can record all information on Health Care Coverage, Medical Bills, Correspondence, and Out-of-Pocket Expenses.

Insurance/Coverage

Insurance Name: _____
Policy Number: _____
Contact Person/Title: _____
Address: _____

_____
Phone: _____Fax: _____
Website/Email: _____

Medicaid (ACO Name, if applicable. This is the company name above your child's name and ID number on the Medicaid Card): _____
Policy Number: _____
Contact Person/Title: _____
Address: _____

_____
Phone: _____Fax: _____

Insurance Name: _____
Policy Number: _____
Contact Person/Title: _____
Address: _____

_____
Phone: _____Fax: _____
Website/Email: _____

Supplemental Security Income (SSI): _____
Contact Person/Title: _____
Address: _____

_____
Phone: _____Fax: _____
Website/Email: _____

Other: _____
Contact Person/Title: _____
Address: _____
Phone: _____Fax: _____
Website/Email: _____

Other: _____
Contact Person/Title: _____
Address: _____
Phone: _____Fax: _____
Website/Email: _____

Medical Bill Communication Log

Information About the Bill				Information About Who You Talk To			Notes
Account #	Provider	Date of Service	What bill is for	Date of Contact	Time	Name and Title/Credentials (Dr., RN, Account Representative, etc.)	

Medical Bills

Date of Service	Provider (hospital, doctor's office, etc.)	Service (tests, surgery, etc.)	Cost	Insurance Company	Insurance Paid	Date Paid	Family Owes	Date Paid
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	
			$		$		$	

Note: This sheet may be used for income tax filing purposes.

Medical Travel Expense Log

Child's Name _____

Date	Travel From	Travel To	Miles	Additional Expenses (Meals, Lodging, etc.)	Reason for Travel

Note: This sheet may be used for income tax filing purposes.

Out-of-Pocket Expense Log

Use this log to track expenses incurred that are not covered by insurance.
Make sure to save all receipts for tax purposes.

Date	Item Description/#	Cost

Date	Item Description/#	Cost

Note: This sheet may be used for income tax filing purposes.

Notes

Notes

Medical Home Portal

Utah Parent Center
Bringing Hope, Opening Doors, Elevating Inclusion

utah family voices

Distributed by the Medical Home Portal, Utah Family Voices, and Utah Parent Center.

For more information call 801-272-1068,
visit utahparentcenter.org,
or email tinap@utahparentcenter.org