



# **CdLS HEALTH CARE NOTEBOOK**

for families of individuals with CdLS



**CdLS Foundation**  
Cornelia de Lange Syndrome Foundation, Inc.

# TABLE OF CONTENTS

- 03  **ABOUT YOUR HEALTH CARE NOTEBOOK**
- 04  **PERSONAL INFORMATION**
- 06  **IMPORTANT/ EMERGENCY CONTACT INFORMATION**
- 08  **MY PHARMACY**
- 09  **PREPARING FOR A HOSPITAL STAY**
- 13  **DOCTOR INFORMATION**
- 16  **MEDICAL EQUIPMENT AND SUPPLIES**
- 17  **MY SCHOOL**
- 18  **MY RECREATION AND LEISURE ACTIVITIES**
- 19  **FAMILY SUPPORT RESOURCES**
- 20  **CHARTS AND LOGS**
- 22  **PLANNING FOR WHEN YOUR CHILD TURNS 18**
- 24  **ADDITIONAL RESOURCES**

# ABOUT YOUR HEALTH CARE NOTEBOOK

## What is a Health Care Notebook, and how can it help?

A Health Care Notebook is a tool to keep track of important information for individuals with CdLS. It helps organize important information in one place. Your Health Care Notebook can be kept in electronic or print format. You can fill this out online, print it out, and save it as a paper notebook. The KEY is choosing the form that works best for you. You can use all the pages or only those most important to you and your family.

## Once you set up your Health Care Notebook

- Store the Health Care Notebook where it is easy to find. It will help you and anyone who needs this information when you are not there. Share its location with those who may need to access it.
- You can share this information with anyone caring for your family member(s) or helping you coordinate their care.
- Take the Health Care Notebook with you to appointments and hospital visits so the information you need will be easy to find.
- When appropriate, include your child when working on the Health Care Notebook. Let them know that the Health Care Notebook contains information about them and their care.
- Keep your Health Care Notebook updated by adding new medicines and treatments and keep important contact information accurate.
- It may also be helpful to share certain important pages of this Health Care Notebook with your child's providers by uploading them to the secure app or online portal your providers use.

## How do I build my Health Care Notebook?

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://adobe.ly/> or look for Adobe Acrobat Reader on the App or Google Play Store. The PDF files allow you to complete the forms on your phone or computer or print the documents and complete them by hand.

## How to fill out your Health Care Notebook?

Be sure to **fill out your loved one with CdLS' information in the pages that follow**. This will be their health care notebook and it is the CdLS Foundation's hope that this publication will assist them throughout their life.



## INDIVIDUAL WITH CdLS:

### Who I am:

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

Nickname \_\_\_\_\_ Date of Birth \_\_\_\_\_

### I live with:

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

Relationship \_\_\_\_\_ Phone Number \_\_\_\_\_

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

Relationship \_\_\_\_\_ Phone Number \_\_\_\_\_

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

Relationship \_\_\_\_\_ Phone Number \_\_\_\_\_

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

Relationship \_\_\_\_\_ Phone Number \_\_\_\_\_

I have a pet at home:  Yes  No

Type of Pet \_\_\_\_\_ Pets Name \_\_\_\_\_

### How I react to things:

When I am sad I \_\_\_\_\_

When I am nervous or scared I \_\_\_\_\_

When I am angry/frustrated I \_\_\_\_\_

What helps calm me or improve my mood \_\_\_\_\_

### My Favorite Things

My favorite toys or games \_\_\_\_\_

My favorite thing to do when I am playing \_\_\_\_\_

My favorite TV shows \_\_\_\_\_

My favorite food \_\_\_\_\_

My favorite music to listen to \_\_\_\_\_

My favorite hobby \_\_\_\_\_

My favorite people are \_\_\_\_\_



### Independence Rating

Mark each row with an X to indicate how independent I am.

	By Myself	With Help	Not At All
Getting Dressed			
Bathing			
Eating (Oral/Tube Feeding)			
Toileting			
Walking			
Communication (Speak/ Sign)			
Take my Medicine *please state if medicine is crushed or taken with food or water			
Tell a doctor or nurse whats wrong			
Ask a question during a doctor's visit			
Answer a question during a doctor's visit			
Tell someone about CdLS			

### Medical Supports

Check ALL items needed.

- Tube feeding
- NG
- NJ
- G tube
- Mic-Key button
- Oxygen
- Apnea Monitor
- Suction Machine
- Tracheostomy
- Wheelchair
- Walker/ Cane or crutches that help me walk
- Glasses
- Hearing Aids

### Providers

Check ALL providers seen.

- Behavioral Health:
  - Psychiatry
  - Psychology
  - Social Worker
  - Counselor
- Cardiology
- Dietician/Nutritionist
- ENT
- Endocrine
- GI
- Genetics
- Infectious Disease
- Neurology/Neurosurgery
- Ob/Gyn
- Occupational Therapist
- Orthopedics
- Physical Therapist
- Primary Care Provider
- Pulmonary
- Respiratory Therapy
- Speech/Language Therapist
- Urology
- Other



## IMPORTANT/ EMERGENCY CONTACT INFORMATION

### Case of Emergency Call 911

Name of Person with CdLS:

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

DOB \_\_\_\_\_

Diagnoses Cornelia de Lange Syndrome (CdLS), \_\_\_\_\_

CdLS gene change, if identified \_\_\_\_\_ Blood Type \_\_\_\_\_

Language Spoken at Home (includes ASL) \_\_\_\_\_

Is an interpreter needed?  Yes  No

### Allergies

Have Epi-Pen  Have Medic Alert tag  Latex Precautions

Allergy to: \_\_\_\_\_ Reaction: \_\_\_\_\_

Allergy to: \_\_\_\_\_ Reaction: \_\_\_\_\_

Allergy to: \_\_\_\_\_ Reaction: \_\_\_\_\_

### Emergency Contacts

Emergency Contact Name \_\_\_\_\_

Phone \_\_\_\_\_ Can make health care decisions?  Yes  No

Relationship to Person with CdLS \_\_\_\_\_

Emergency Contact Name \_\_\_\_\_

Phone \_\_\_\_\_ Can make health care decisions?  Yes  No

Relationship to Person with CdLS \_\_\_\_\_

### Primary/Preferred Hospital

Primary Hospital Name \_\_\_\_\_

Phone \_\_\_\_\_ ER Phone Number \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

### Primary Care Provider

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Patient Portal / App \_\_\_\_\_

Care Coordinator \_\_\_\_\_



### Emergency Contact to Care for Other Children or Family Members

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

Relationship \_\_\_\_\_ Phone Number \_\_\_\_\_

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

Relationship \_\_\_\_\_ Phone Number \_\_\_\_\_

### Medical Insurance

Insurance \_\_\_\_\_

Member ID or Policy Number/Group Number \_\_\_\_\_

Subscriber Name \_\_\_\_\_

Subscriber DOB \_\_\_\_\_ Member Services Phone Number \_\_\_\_\_

Case Manager/ Care Coordinator Name \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

Secondary Insurance \_\_\_\_\_

Member ID or Policy Number/Group Number \_\_\_\_\_

Subscriber Name \_\_\_\_\_

Subscriber DOB \_\_\_\_\_ Member Services Phone Number \_\_\_\_\_

### Upload/attach a photo of the insurance card.



Front



Back





# ADVOCATING DURING A HOSPITAL STAY

Hospitals can be challenging to navigate. Having an advocate to clarify information, describe how your family member typically behaves and share information about what care provided at home is always helpful.

A strong advocate can make a difference in what care is received, when and how care is provided, how informed you feel, and how well care after the hospital is planned.

**Speak with your primary care nurse, hospital care manager, or patient advocate to identify key individuals on your care team and your primary contact for updated information.**

Whenever possible, have someone else with you. Another set of ears is often helpful.

## 1 If English is not your primary language, request an interpreter.

Hospitals are required to provide them at no cost to you.

## 2 Identify your primary contact for updated information.

There is usually one person on the medical team reviewing information and making treatment decisions. Learn who this is and how and when to contact them for updates.

## 3 Ask if the hospital has a Palliative Care or Complex Care team

These teams guide and coordinate care in the hospital and after discharge. If the hospital has a Palliative Care or Complex Care Team, ask how to get them involved.

## 4 Identify who helps coordinate discharge planning and how to contact them.

## 5 Request a Patient Care Conference.

Within 24 hours of admission, set up a Patient Care Conference. The primary hospital physician, specialist(s), case manager, or discharge planner should be involved. Use this meeting to discuss current issues and treatment, any concerns you have, and plans for a safe discharge from this unit or hospital

## 6 Access the online patient portal.

Many hospitals offer a patient portal you access from an app. You can view laboratory, pathology, and radiology reports in this portal. If you have not already downloaded this app on your smartphone, consider doing so now.

## 7 Ask Questions Until You Understand:

When asking questions, write down the answers and all the information you hear. When possible, have someone else with you for another set of ears.

## 8 Contact your health plan or program.

Confirm that any procedures or procedures that require prior authorization have been approved. Speak with a care coordinator or care manager to see how they can assist in discharge planning or in obtaining services after the hospital stay.

## 9 Ask how to obtain a second opinion during this hospital stay.



**If you are not sure what to ask or how to ask it, here are some suggestions that may be helpful.**

If this is a new issue/condition:	What caused this? What are our next steps? Will this new condition result in any long-term effects? What can we do to prevent this from happening again? Can this condition be spread to others? Is my family member's immune system compromised? Should we monitor who visits and what they bring into the hospital?
When tests or treatments are recommended:	What is the goal of this test/treatment? What are all of our treatment choices? What are the risks and benefits of each of these choices? What will happen if we don't have this test or treatment? Are there safer or simpler options we could take first? How can we prepare my loved one for this test/ treatment to help them comply with this care? How/when will we get results from this test or know if the treatment is working?
When new medications are recommended:	Why is this being prescribed? How long does it take to see if it is working? Are there reasons this medication would not be recommended? (Side effects or risks)? Will this medicine be needed at home? <ul style="list-style-type: none"><li>• If so, does my insurance cover this medicine, or is there an equally safe alternative you can prescribe?</li></ul>



## Planning for a Safe Hospital Discharge

<p>When planning for a safe discharge:</p>	<p>What services, equipment, training, and follow-up appointments need to be in place PRIOR TO a safe discharge?</p> <p>Is the plan for discharge to home or discharge to another facility?</p>
<p><b>Discharge to Home</b></p> <p>If you will not be transporting your family member home:</p> <p>Who will arrange transportation?</p> <ul style="list-style-type: none"> <li>• Is this transportation covered by my insurance?</li> </ul> <p>Is home health care needed?</p> <ul style="list-style-type: none"> <li>• If so, who orders these services and locates the home care agency?</li> </ul> <p>When will I be taught any new care needed at home?</p> <p>Will we need any new medical equipment or medical supplies?</p> <ul style="list-style-type: none"> <li>• If so, who orders these and selects the company that provides them?</li> <li>• When and where will these items be delivered?</li> <li>• How do I know if my insurance covers these items and the company selected</li> </ul> <p>Will follow-up tests or procedures be needed?</p> <ul style="list-style-type: none"> <li>• If so, who schedules them and when should they occur?</li> <li>• When is the follow-up appointment with the primary care provider and/or specialists?</li> </ul> <p>If we have questions/concerns at home or we don't notice improvement, who do we contact, and what is the best way to reach this person?</p> <p>Who do we contact if there is a problem in the middle of the night?</p>	<p><b>Discharge to another facility</b></p> <p>Is this facility covered by my insurance?</p> <p>How long do you feel my family member will stay at the new facility?</p> <p>Is the plan to return home after this inpatient stay?</p> <p>Who will arrange transportation to this new facility?</p> <ul style="list-style-type: none"> <li>• Is this transportation covered by my insurance?</li> </ul> <p>Will follow-up tests or procedures be needed?</p> <ul style="list-style-type: none"> <li>• If so, who schedules them and when should they occur?</li> </ul> <p>When is the follow-up appointment with the primary care provider and/or specialists?</p> <p>If we have questions/concerns or we don't notice improvement, who do we contact, and what is the best way to reach this person?</p>



## **If You Have a Complaint About the Medical Care Your Family Member is Receiving/Has Received in the Hospital**

1. Bring your complaint to the Patient Advocate, the hospital's Risk Management Department, or Rapid Response Team to investigate. Try to meet with someone in person to resolve the issue.
2. If you cannot meet with anyone, write a complaint letter addressed to the Risk Management or Quality Assurance Department of the hospital, the head of the Department, and/or the head of the hospital. The letter should include the following:
  - Your name and contact information
  - The date(s) of the occurrence
  - A brief and factual description of the occurrence
  - What you would like to see next such as a second opinion, a referral, or a different test or procedure.
3. Contact your insurance company and file a complaint/grievance. Be sure to let them know if your family member is still in the hospital. Ask if the Appeals and Grievances Department will review medical records from the hospital.
4. If your family member has Medicare, locate the Medicare Quality Improvement Organization in State [qioprogram.org/locate-your-bfcc-qio](http://qioprogram.org/locate-your-bfcc-qio). You will find directions on filing a quality-of-care complaint on each organization's website.



# CHECK LIST FOR HOSPITAL GO BAG

- Items or toys that calm or entertain your family member with CdLS**
- Pens and notebook for keeping track of information and appointments**
- Extra-long phone charging cord (the outlet is always far away!)**
- Paper copies of these pages from the Health Care Notebook:**
  - Who Am I?
  - Important Contact Information
  - My Providers
  - Medical Equipment and Supplies
  - Medications
  - Hospital Note Forms
- Copies of critical medical and legal forms such as:**
  - Power of Attorney
  - Guardianship
  - Advanced Directives
  - Attorney Contact Information
- A set of comfortable clothes – you may be staying**
- Personal hygiene items like hand sanitizer, lip balm, toothpaste/toothbrush, face wipes**
- Reusable water bottle and snacks**
- A copy of your health insurance card. Keep the original in your wallet**
- Cash or credit card for snacks and incidentals**
- Passwords for online patient portals to access prior discharge summaries and current orders for equipment or medication**

If your loved one with CdLS requires frequent hospitalization, consider keeping a Go Bag ready. Here are some things to keep handy.



## HOSPITAL VISIT NOTES

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Medical Staff: \_\_\_\_\_

What was Discussed: \_\_\_\_\_

\_\_\_\_\_

Next Steps: \_\_\_\_\_

\_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Medical Staff: \_\_\_\_\_

What was Discussed: \_\_\_\_\_

\_\_\_\_\_

Next Steps: \_\_\_\_\_

\_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Medical Staff: \_\_\_\_\_

What was Discussed: \_\_\_\_\_

\_\_\_\_\_

Next Steps: \_\_\_\_\_

\_\_\_\_\_



## PROVIDERS

### Primary Care Provider (PCP)

PCP Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Patient Portal / App \_\_\_\_\_

Care Coordinator \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

### Urgent Care/After Hours/Advice Line

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Advice Line \_\_\_\_\_

Email \_\_\_\_\_ Website / App \_\_\_\_\_

### Dentist

Dentist Name \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Patient Portal / App \_\_\_\_\_

Is sedation is required for ALL dental cleanings and treatments?  Yes  No

### Specialists

Provider's Name and Specialty (e.g., GI, Orthopedics) \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_

Why I see this specialist (what diagnosis) \_\_\_\_\_

Provider's Name and Specialty \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_

Why I see this specialist (what diagnosis) \_\_\_\_\_



Provider's Name and Specialty \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
Phone \_\_\_\_\_ Fax \_\_\_\_\_  
Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_  
Why I see this specialist (what diagnosis) \_\_\_\_\_

Provider's Name and Specialty \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
Phone \_\_\_\_\_ Fax \_\_\_\_\_  
Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_  
Why I see this specialist (what diagnosis) \_\_\_\_\_

### **Rehabilitation Medicine Physical, Occupational and Speech/Language Therapy**

Provider's Name and Specialty (e.g., PT, OT, ST) \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
Phone \_\_\_\_\_ Fax \_\_\_\_\_  
Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_  
Why I see this specialist (what diagnosis) \_\_\_\_\_

Provider's Name and Specialty \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
Phone \_\_\_\_\_ Fax \_\_\_\_\_  
Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_  
Why I see this specialist (what diagnosis) \_\_\_\_\_

Provider's Name and Specialty \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
Phone \_\_\_\_\_ Fax \_\_\_\_\_  
Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_  
Why I see this specialist (what diagnosis) \_\_\_\_\_



## Behavioral Health Providers (Psychiatry, Psychology, Social Worker, Therapist)

Provider's Name and Specialty \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_

Why I see this specialist (what diagnosis) \_\_\_\_\_

Provider's Name and Specialty \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_

Why I see this specialist (what diagnosis) \_\_\_\_\_

Provider's Name and Specialty \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Patient Portal/App \_\_\_\_\_

Why I see this specialist (what diagnosis) \_\_\_\_\_

### Home Health Agency

Name \_\_\_\_\_

Primary Contact \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Emergency Number \_\_\_\_\_

### Transportation Vendor

Name \_\_\_\_\_

Phone \_\_\_\_\_

Email or Portal \_\_\_\_\_

Transportation is used for  School  Medical appointments  After school program

Type of transportation needed  Taxi  Wheel chair van  Stretcher  School bus



## MEDICAL EQUIPMENT AND SUPPLIES

Item Description						
Brand of Item						
Model Number						
Serial Number						
Prescribing Doctor						
Supply Company.						
Supply Comp Contact Person						
Supply Comp Phone Number						
Supply Comp Email						
Is Item Owned/ Rented						
Supply Schedule						
Insurance Requires Prior Authorization?						
Next Delivery Date						



## MY SCHOOL

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

Principal Name \_\_\_\_\_

Principal Email \_\_\_\_\_

Website \_\_\_\_\_

School Nurse Name \_\_\_\_\_

Form on file:  Nurse to give medication/treatments  Child to self-administer meds/treatments

Teacher and Para/Assistant Name \_\_\_\_\_

Special Education Teacher Name \_\_\_\_\_

Contact Information \_\_\_\_\_

Resource Instructor Name \_\_\_\_\_

Contact Information \_\_\_\_\_

School Guidance Counselor Name \_\_\_\_\_

Contact Information \_\_\_\_\_

### **Additional School Resources:**

Special Education Coordinator for your School District Name \_\_\_\_\_

Contact Information \_\_\_\_\_

Local Advocacy, Parent Information Training, or Community Parent Resource Center.

Find yours: [bit.ly/findparentcenter](http://bit.ly/findparentcenter)

Transportation Vendor \_\_\_\_\_

Contact Information \_\_\_\_\_



## MY RECREATION AND LEISURE ACTIVITIES

Closest Accessible Playground. Find one here: <a href="http://bit.ly/playgroundfinder">bit.ly/playgroundfinder</a>	
Adaptive Sports Program in your area (eg. Town Park and Recreation, local Rehabilitation hospital, local YM/YWCA)	
Contact Information	
Coach/ leader: Contact information phone/email	
Summer Camp options: Find one here: <a href="http://bit.ly/veryspecialcamps">bit.ly/veryspecialcamps</a>	



## FAMILY SUPPORT RESOURCES

CdLS Foundation

Phone [1.800.753.2357](tel:18007532357) or [860.676.8166](tel:8606768166) Email: [familyserVICESTeam@CdLSUSA.org](mailto:familyserVICESTeam@CdLSUSA.org) Website [www.cdlsusa.org](http://www.cdlsusa.org)

Support Group Contact

Phone \_\_\_\_\_ Email \_\_\_\_\_ Website \_\_\_\_\_

Religious Organization

Phone \_\_\_\_\_ Email \_\_\_\_\_ Website \_\_\_\_\_

Your state agency for those with Disabilities. Find yours here: [www.nasddds.org/state-agencies](http://www.nasddds.org/state-agencies)

Phone \_\_\_\_\_ Email \_\_\_\_\_ Website \_\_\_\_\_

Behavioral Health/Counseling Services: (through your insurance or free/sliding scale)

Phone \_\_\_\_\_ Email \_\_\_\_\_ Website \_\_\_\_\_

Sibling Support: Sibshops, Sibling Leadership Network, Fathers Network

Phone: \_\_\_\_\_ Email: [siblingsupport.org/contact-us](http://siblingsupport.org/contact-us) Website: [siblingsupport.org](http://siblingsupport.org)

Other

Phone \_\_\_\_\_ Email \_\_\_\_\_ Website \_\_\_\_\_

Other

Phone \_\_\_\_\_ Email \_\_\_\_\_ Website \_\_\_\_\_

Other

Phone \_\_\_\_\_ Email \_\_\_\_\_ Website \_\_\_\_\_





## ER Visits, Procedures, Surgeries, and Inpatient Stays

Setting	Reason for Visit	What Hospital or Outpatient Setting	Date(s)	Provider Seen for Follow Up
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				

## PLANNING FOR WHEN YOUR CHILD TURNS 18

Even with a disability, in most states, your child is legally considered to be an adult at the age of 18. This means that when a child turns 18, they are considered capable of making decisions about their property, education and health care.

When your child turns 18, providers may expect your 18-year-old to ask and answer questions about their health care and make their own health care decisions. If your 18-year-old is insured under a parent's health insurance and you use your insurance company member portal to see medical information or claims, you may find you no longer have access to your child's information. Your child's provider may ask for proof of guardianship or power of attorney.

If at the age of 18 your child will need your continued support in making decisions and signing documents involving:

- Medical, behavioral health and dental care
- Residence
- Educational or vocational programs
- Release of clinical records and photographs

You may want to consider pursuing guardianship, so you retain the ability to make such decisions for him or her.

The procedure for obtaining guardianship varies from state-to-state, but generally the process is initiated by filing a petition with the court that states why guardianship is necessary. A hearing is held after the completion of an evaluation. The court will decide if guardianship is necessary.

If at age 18, your child will not be able to make responsible decisions regarding management of property and finances, you may want to explore Conservatorship. The process for obtaining a conservatorship is like the process of obtaining guardianship, and the two can be done in tandem.

Courts generally seek the least restrictive alternative to conservatorship. They will tailor the conservatorship so that the person in need of support and supervision is allowed to maintain rights to make decisions about things that they can manage in a responsible manner. Options that are less restrictive than guardianship or conservatorship include a Medical or Durable Power of Attorney or a Representative Payee for benefits such as Social Security Income.

The most important thing is to determine what is in the best interest of your child and your family. Take time to review your options and discuss them with competent professionals in your area to assist you.

We encourage you to:

- Start planning early! Work with your provider on a transition plan that also includes a discussion on the future need for guardianship or a conservator
- Review the *Navigating Health Transitions: Pediatric to Adult Medical Care* published by the CdLS Foundation. Request a copy by emailing [familyservicesteam@cdlsusa.org](mailto:familyservicesteam@cdlsusa.org).
- Learn about Guardianship and Supported Decision-Making Laws in your State: [bit.ly/supporteddecisions](http://bit.ly/supporteddecisions)
- Utilize national and local resources to learn specifics that apply in your state: [bit.ly/stateguardianship](http://bit.ly/stateguardianship)

- Special Needs Alliance. This is a National Alliance of Attorneys for Special Needs Planning. [www.specialneedsalliance.org](http://www.specialneedsalliance.org)
- The National Academy of Elder Law Attorneys: [www.naela.org](http://www.naela.org)
- You can find additional information on the Protected Tomorrows website: [www.protectedtomorrows.com](http://www.protectedtomorrows.com).

### **Planning for Other Changes as Your Child Becomes an Adult**

As your child becomes an adult you may also need to make decision about:

- Moving from a pediatric provider to an adult health care provider
- Learning if and when your child will no longer be able to be covered under a parent's health insurance plan.
- Applying for SSI and/or Medicaid health care coverage for your child

The Family Service Team at the CdLS Foundation can help you navigate these choices. In addition to providing information or helping you obtain answers to questions you may have about CdLS, we can help you obtain the care and services your family member with CdLS requires.

There are several ways to reach us. You can reach us by phone at 1.800.753.2357, (press 1 for Family Services) or by email at [familyserVICESTeam@cdlsusa.org](mailto:familyserVICESTeam@cdlsusa.org). You can also reach us through forms located on our website.

We are here to provide information and support to you and your family throughout your journey.

## ADDITIONAL RESOURCES

### CdLS Specific Growth Charts

- [bit.ly/growthchartgirls](https://bit.ly/growthchartgirls)
- [bit.ly/growthchartsboys](https://bit.ly/growthchartsboys)

### My Recreation and Leisure Activities

- Closest Accessible Playground: [bit.ly/playgroundfinder](https://bit.ly/playgroundfinder)
- Summer Camp options: [bit.ly/veryspecialcamps](https://bit.ly/veryspecialcamps)

### CdLS Foundation Medical alert card

- [bit.ly/CdLSalertcards](https://bit.ly/CdLSalertcards)

### Critical Care Information

- [www.cdlsusa.org/critical-care](https://www.cdlsusa.org/critical-care)

Thank you to Medical Home Portal for providing resources to the CdLS Health Care Notebook.



## MEDICAL EQUIPMENT AND SUPPLIES

Item Description						
Brand of Item						
Model Number						
Serial Number						
Prescribing Doctor						
Supply Company.						
Supply Comp Contact Person						
Supply Comp Phone Number						
Supply Comp Email						
Is Item Owned/ Rented						
Supply Schedule						
Insurance Requires Prior Authorization?						
Next Delivery Date						



## MEDICAL EQUIPMENT AND SUPPLIES

Item Description						
Brand of Item						
Model Number						
Serial Number						
Prescribing Doctor						
Supply Company.						
Supply Comp Contact Person						
Supply Comp Phone Number						
Supply Comp Email						
Is Item Owned/ Rented						
Supply Schedule						
Insurance Requires Prior Authorization?						
Next Delivery Date						



## ER Visits, Procedures, Surgeries, and Inpatient Stays

Setting	Reason for Visit	What Hospital or Outpatient Setting	Date(s)	Provider Seen for Follow Up
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				
<input type="checkbox"/> ER <input type="checkbox"/> Outpatient <input type="checkbox"/> Procedure/ Surgery <input type="checkbox"/> Inpatient Stay				