CdLS HEALTH CARE NOTEBOOK

for families of individuals with CdLS

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

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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

MY PHARMACY

Name ______________________________ Phone ______________________________

Address ____

This pharmacy ☐ Pre-pour/packets are available ☐ Pharmacy Delivers

Name of Mail Order Pharmacy ______________________________ Phone ____________________

My Specialty/Compound Pharmacy

Name ______________________________ Phone ______________________________

Address ____

My Medication List

List ALL prescription medicines, supplements, vitamins, and over-the-counter medication taken

Name of Medication	Prescribed by	When to take						How is it taken?
		A.M.	Noon	P.M.	Bed time	As needed	Dose (see label)	

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. Focusing on enhancing the quality of life for individuals facing serious illness. Palliative care helps patients navigate the complexities of their conditions with dignity and grace.

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 Request a Patient Advocate

Plays a crucial role in the hospital by ensuring that a patient's needs, preferences, and concerns are communicated effectively to the healthcare team. Their support helps to empower patients, navigate complex medical decisions, and ensure a compassionate and personalized approach to care.

7 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.

8 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.

9 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.

10 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? • If so, does my insurance cover this medicine, or is there an equally safe alternative you can prescribe?

PALLIATIVE CARE

What is palliative care? Palliative care is an invaluable approach provided by a specially trained team of doctors, nurses, and other specialists that focuses on enhancing the quality of life for individuals facing complex medical conditions. By prioritizing comfort, relief from symptoms, and emotional support, palliative care helps patients navigate the complexities of their conditions with dignity and grace. Ultimately, palliative care provides compassion, support, and a pathway to a fulfilling life, regardless of the diagnosis.

How do I know if Palliative care is right for my child?

1

Is your voice not being heard by your child's medical team?

Palliative care emphasizes communication. With palliative care support, healthcare providers take the time to listen to patients and families, understand their concerns and answer their questions. This open dialogue fosters a sense of trust and empowerment, allowing individuals to make informed decisions about their care while exploring their hopes, fears, and goals for the future.

2

Are you feeling lost and alone while navigating complex decisions?

Palliative care providers can help by clarifying choices and providing guidance when making difficult treatment decisions or navigating the healthcare system.

3

Do you feel like your child's care is disjointed?

Palliative care uses a multidisciplinary approach, focusing on working with your medical team to create a comprehensive care plan. The palliative care team coordinates care to ensure effective coordination between different providers and services, ensuring seamless care.

4

Are you struggling with managing your child's symptoms?

If your child experiences pain, discomfort, or other distressing symptoms that are not adequately managed, Palliative care focuses on providing relief from the symptoms and stress of a complex medical condition such as CdLS. The goal is to improve comfort and support both the patient and their loved ones.

5

Are you struggling to meet your child's complex needs?

The emotional and psychological impact of your child's illness can be significant; palliative care offers support not just to your child but to the family, providing resources, counseling, and respite care.

If your child/family is struggling with any of these, Palliative Care may benefit your loved one with CdLS and your family.

PALLIATIVE CARE

How to Access Palliative Care

Accessing palliative care for a child with a rare disease involves several steps to ensure they receive the appropriate support and resources. By following these steps, you can help ensure that your child with CdLS gains access to the compassionate and comprehensive support offered by palliative care, enhancing their overall quality of life.

1 Be Clear About Your Child's Needs:

Begin by assessing your child's specific symptoms and challenges associated with CdLS. Document your child's physical and emotional wellbeing and any relevant family dynamics.

2 Consult the Primary Care Provider:

Discuss with your primary care physician or specialist your desire to incorporate palliative care into your child's treatment plan, outlining the specific needs you have identified.

3 Request a Referral:

If the primary care provider or specialist agrees that palliative care is appropriate, request a formal referral to a palliative care specialist or team. This may involve contacting your area's hospitals, hospices, or palliative care clinics.

4 Finding a Palliative Care Team:

Many hospitals and healthcare systems have specialized palliative care teams. Inquire about these services through the primary care provider. Alternatively, you can search for local palliative care programs using resources such as the Palliative Care Provider Directory (GetPalliativeCare.org), Get Palliative Care, or the Center to Advance Palliative Care.

5 What to do if Your Referral is Denied:

Contact your doctor to discuss the reasons for denial, contact the CdLS Foundation to explore alternative options in your local area, and appeal the decision. Ask about other supportive care services available in your area and consider seeking a second opinion from another healthcare professional if needed.

Other Items for Your Consideration

Explore Telehealth Options:

If in-person services are limited, ask about telehealth options, especially useful for children with rare conditions who may need consultations with specialists in different locations.

Engage with the Palliative Care Team:

Once connected with a palliative care team, participate in an initial meeting to discuss your child's goals, preferences, and any necessary adjustments to the care plan. This team will work collaboratively with your child and other healthcare providers.

Communicate Openly:

Keep communication lines open with the palliative care team and other medical professionals. Regular updates about your child's condition and needs will ensure everyone is aligned to provide the best support.

Involve Family and Caregivers:

Encourage family members and caregivers to be part of the discussions regarding palliative care. Their involvement can provide additional insights into the child's wishes and enhance support.

Evaluate and Adjust:

Periodically review the effectiveness of the palliative care provided and adjust the plan as necessary. Continuous feedback can help tailor the care to fit your child's evolving needs better.

Planning for a Safe Hospital Discharge

When planning for a safe discharge:	What services, equipment, training, and follow-up appointments need to be in place PRIOR TO a safe discharge? Is the plan for discharge to home or discharge to another facility?
Discharge to Home If you will not be transporting your family member home: Who will arrange transportation? • Is this transportation covered by my insurance? Is home health care needed? • If so, who orders these services and locates the home care agency? When will I be taught any new care needed at home? Will we need any new medical equipment or medical supplies? • If so, who orders these and selects the company that provides them? • When and where will these items be delivered? • How do I know if my insurance covers these items and the company selected Will follow-up tests or procedures be needed? • If so, who schedules them and when should they occur? • When is the follow-up appointment with the primary care provider and/or specialists? 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? Who do we contact if there is a problem in the middle of the night?	**Discharge to another facility** Is this facility covered by my insurance? How long do you feel my family member will stay at the new facility? Is the plan to return home after this inpatient stay? Who will arrange transportation to this new facility? • Is this transportation covered by my insurance? Will follow-up tests or procedures be needed? • If so, who schedules them and when should they occur? When is the follow-up appointment with the primary care provider and/or specialists? 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?

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. You will find directions on filing a quality-of-care complaint on each organization's website.

CHECK LIST FOR HOSPITAL GO BAG

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

- ☐ **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**

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

Transportation Vendor ______________________________

Contact Information ______________________________

MY RECREATION AND LEISURE ACTIVITIES

Closest Accessible Playground. Find one here: bit.ly/playgroundfinder	
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: bit.ly/veryspecialcamps	

FAMILY SUPPORT RESOURCES

CdLS Foundation

Phone 1.800.753.2357 or 860.676.8166 Email: familyservicesteam@CdLSUSA.org Website 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

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 Website: siblingsupport.org

Other

Phone______________________________Email_________________________Website________________

Other

Phone______________________________Email_________________________Website________________

Other

Phone______________________________Email_________________________Website________________

MEDICAL APPOINTMENT REMINDERS

Provider Name	Appointment Date	Appointment Time	Questions to Ask at the Appointment

ER Visits, Procedures, Surgeries, and Inpatient Stays

Setting	Reason for Visit	What Hospital or Outpatient Setting	Date(s)	Provider Seen for Follow Up
☐ ER ☐ Outpatient ☐ Procedure/ Surgery ☐ Inpatient Stay				
☐ ER ☐ Outpatient ☐ Procedure/ Surgery ☐ Inpatient Stay				
☐ ER ☐ Outpatient ☐ Procedure/ Surgery ☐ Inpatient Stay				
☐ ER ☐ Outpatient ☐ Procedure/ Surgery ☐ Inpatient Stay				
☐ ER ☐ Outpatient ☐ Procedure/ Surgery ☐ Inpatient Stay				
☐ ER ☐ Outpatient ☐ Procedure/ Surgery ☐ 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.
- Learn about Guardianship and Supported Decision-Making Laws in your State: bit.ly/supporteddecisions
- Utilize national and local resources to learn specifics that apply in your state: bit.ly/stateguardianship

- Special Needs Alliance. This is a National Alliance of Attorneys for Special Needs Planning. www.specialneedsalliance.org
- The National Academy of Elder Law Attorneys: www.naela.org
- You can find additional information on the Protected Tomorrows website: 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. 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
- bit.ly/growthchartsboys

My Recreation and Leisure Activities

- Closest Accessible Playground: bit.ly/playgroundfinder
- Summer Camp options: bit.ly/veryspecialcamps

CdLS Foundation Medical alert card

- bit.ly/CdLSalertcards

Critical Care Information

- www.cdlsusa.org/critical-care

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