



Loma Linda University Children’s Hospital Patient Resource List for Caregivers and Families of Children with Ongoing Medical Conditions

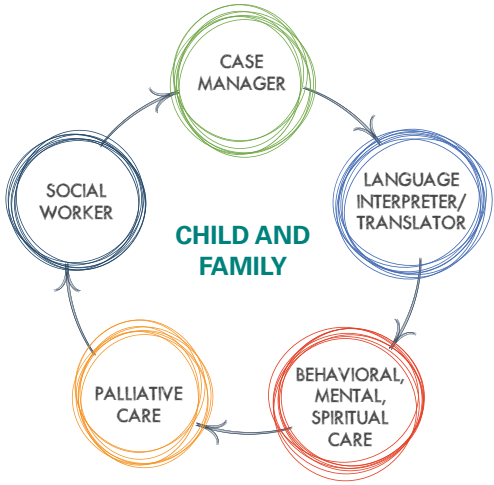
Caring for a child with a long-term medical condition(s) can be both rewarding and challenging, as medical needs touch all of life – including daily activities, relationships and management of family resources. It is very normal to feel burdened or overwhelmed at times with the steep learning curve about your child’s condition, in addition to the complexities of navigating the healthcare system and balancing everyday life. This resource list was generated through a collaboration between parents on the LLU Children’s Hospital Patient Family Advisory Council and LLU

Children’s Hospital social workers. While the road you travel is not easy, we want you to know you are not alone, and that there are people and resources available to encourage and equip you on your way. You are joining a village of families and communities who journey with medical complexity and find ways to encourage one another, share burdens and celebrate milestones along the way.

Who Can Help Me Coordinate My Child’s Care?

In addition to your child’s primary medical team, there are professionals trained to help you and your family navigate the healthcare system and balance everyday life. Many hospitals provide these professionals during inpatient care; check with outpatient clinics and your insurance providers for outpatient care coordination.

PROFESSIONAL	ROLE AND RESPONSIBILITIES
Social Worker	Identifies critical needs, offers referrals and resources, provides family support through stress and crisis.
Case Manager	Coordinates and manages all patient care service details; works with social worker to identify patient/family needs and resources.
Language Interpreter/Translator	Provides language interpretation (spoken) and translation (written) for patients with limited English proficiency or sensory impairments.
Behavioral, Mental, Spiritual Care	Professionals who support whole-person care to help you and your family manage stress and find encouragement and empowerment in your journey.
Palliative Care (not same as hospice)	Team of doctors and support staff who offer extra support for patients with potentially life-threatening conditions (e.g. manage pain/symptoms, coordinate care toward patient quality of life and family goals). Available at diagnosis.



Child Health Specialty Services



Children with long-term medical needs often qualify for special services (e.g. occupational, physical, speech therapy) funded by county centers. Insurances may cover home health services (e.g. medical supplies, equipment, home care) and palliative care services.

Regional Center – San Bernardino County

Coordination of specialty services (e.g. occupational, physical, speech therapy).
Note: Other counties also manage regional centers. Ask your child's pediatrician for an assessment referral.

Home Health Services

Ask your child's physician for recommendations; learn your insurance's preferred vendors for medical equipment, supplies, home care nursing.

Palliative Care (not same as hospice)

getpalliativecare.org/whatis/pediatric/

lluh.org/services/palliative-care

Palliative care teams are available from time of diagnosis to advocate for patient quality of life and family goals (e.g. pain/symptom management, coordinated care).

Financial and Resource Assistance



Children with long-term medical conditions and healthcare needs may be eligible for supplemental or primary financial assistance with healthcare bills and coordination of services. Families may also be eligible for government assistance with daily needs (e.g. nutrition, transportation).

California Children's Services (CCS)

dhcs.ca.gov/services/ccs

State program (children up to 21) to provide eligible families with medical bill assistance, medical case management, medical therapies.

Supplemental Security Income (SSI)

ssa.gov/benefits/disability/apply-child.html

Federal government program that pays benefits to disabled adults and children who have limited income and resources.

Medi-Cal (California's Medicaid)

dhcs.ca.gov/services/medi-cal/Pages/default.aspx

Public health insurance providing free or low-cost medical services for children and adults with limited income and resources.

CalFresh (California's Food Stamps SNAP)

getcalfresh.org/

Nutrition assistance. Service can be coordinated for SSI recipients.

Community Resource Center - SAC Health System

sachealth.org/community-resource-center/

Family Services Association (FSA) of Redlands

redlandsfamilyservice.org/

Services for families (e.g. food, clothing, utilities, rent, housing, healthcare access, case management). FSA offers parenting, pre-employment, basic skills classes (with childcare). Also in Yucaipa.

Transportation Assistance

dhcs.ca.gov/services/medi-cal/Pages/transportation.aspx

iehp.org

angelflightwest.org

Medi-Cal and IEHP recipients can request non-emergency medical transportation. Angel Flight offers non-emergency air transport for long-distance patients with serious health conditions.

SoCal Edison Medical Baseline Allowance

sce.com/residential/assistance/medical-baseline

Financial and resource assistance for eligible families requiring powered medical equivalent. May also apply to other needs.

Understanding Health Information



Finding and understanding information about your child's condition and/or diagnosis can be intimidating, especially with so many professional and public sources of health information. Here are a few helpful websites and tips to help you access trusted medical information.

MedLine Plus (English and Spanish)

medlineplus.gov/

Up-to-date, easy to read, trusted information on health conditions and wellness issues, by the U.S. National Library of Medicine.

KidsHealth

kidshealth.org/

Physician-reviewed information and advice on children's health and parenting issues.

Other tips: Ask medical providers for trusted websites about your child's specific condition(s).

Getting Organized with Ongoing Care



Here are some resources and tips to help you organize the volumes of information and notes pertaining to your child's health and ongoing care.

Care Notebook

medicalhomeinfo.aap.org/tools-resources/Pages/For%20Families.aspx

Downloadable worksheets to record and organize health and medical information in a care notebook.

Carezone Mobile Apps

carezone.com/

App to organize health information and access health services, including medication management and reminders.

MyChart (Loma Linda University Health)

lluh.org/mychart

Web and mobile app to track electronic medical records, appointments, messaging physicians and medications.

Pediatric-to-Adult Transition of Care

gottransition.org/

Websites with checklists and tips to equip your child to transition from pediatric to adult care.

Other tips: Check if insurance provides case management. Check if providers are willing to schedule multiple appointments or have telehealth services for remote patients.

Child Educational Support



Children with long-term medical needs often qualify for accommodations with school and for coordinated educational services to ensure that education is tailored to their individual health and developmental needs. These services often involve multidisciplinary teams.

Individualized Family Service Plan (IFSP) for children 0-3 years

kidshealth.org/NortonChildrens/en/parents/special-ed-support.html?ref=search

Coordinated plan of services and goals for children 0-3 years with developmental or medical needs that can lead to delays.

Individualized Education Program (IEP) for children 3-21 years

kidshealth.org/NortonChildrens/en/parents/iep.html

Coordinated plan of services and goals for children ages 3-21 with diagnosed physical or mental disabilities.

504 Education Plan

kidshealth.org/NortonChildrens/en/parents/504-plans.html

Educational accommodations and customized educational plans for children with physical or mental impairments to ensure students can access quality education.

NOTE: Follow child's school district's specific steps.

Other tips: Ask your child's physicians for forms needed for school accommodations and excused medical absences. Check your child's school and instructors' policies concerning disability and health accommodations (e.g. extra time to get to classes or for tests, help with missed work, note taking).

Caregiver and Family Support and Advocacy



Caregiving can be rewarding and joyful, but facing burnout, discouragement and financial strain can be real challenges. These resources are aimed at facilitating caregivers to tap into support resources for their own well-being and care, and to learn how to equip their child for self-advocacy over time.

Paid Family Leave and Family Medical Leave Act

edd.ca.gov/en/disability/paid-family-leave/
dol.gov/agencies/whd/fmla/

Eligible employees may take paid or unpaid leave for specific family medical reasons. Talk to your HR department about specific guidelines.

Rehabilitation Services

totallykids.com/

Acute, subacute, intermediate care for infants-21 years with medical needs.

Caregiver Respite

inlandrc.org/
(Coordinated through Inland Regional Center)

In-home, out-of-home respite care to reduce stress and increase self-care of caregivers of children with developmental disabilities.

In-Home Supportive Services

ihsscalifornia.com/
(Must be eligible for SSI/SSP or Medi-Cal)

CA government program providing financial stipends to parents serving as primary caregivers of children requiring constant care at home.

Sharing Health Updates and Needs Requests

caringbridge.org/
mealtrain.com/

Websites to coordinate one place to send health updates and organize practical help for others to support you through intense periods.

Help Me Grow Inland Empire (HMGIE)

helpmegrowie.org/
888-464-4316

A community resource for families with young children ages 0-8. HMGIE helps ensure children's growth stays on track by answering parent's everyday questions.

Building A Generation

buildingageneration.org
909-793-8822

Promotes a nurturing environment to end child abuse and foster positive relationships for children and their families.

Behavioral, Mental Health and Spiritual Care Services



The high stress of ongoing medical needs for one member affects the whole person, and the relationships in a whole family system. It is very common for patients and their caregivers and families to have ups and downs in the struggle to find a new normal, and to experience seasons of discouragement, anxiety, relational strain and traumatic stress. Here are resources that offer compassionate care to strengthen your child and whole family's mental and relational wellness.

LLU Children's Hospital Support Groups and Services

luch.org/patients-families/patients/support-services

An array of support groups and services, (e.g. grief recovery, illness-specific groups, health education programs, pet therapy, classes and workshops).

LLU Children's Hospital Child Life Specialists

luch.org/patients-families/child-life-services

Hospital staff to help children and families reduce fears and stress in the hospital. Offer hospital activity playroom, support groups, bedside, emotional support, sibling visits and school reintegration.

LLU SACHS Behavioral Health

sachealth.org/

Integrated healthcare with medical treatment, with services including individual, couple and family therapy, psychological and psychiatric assessment, medication management and treatment for specific needs.

LLU Behavioral Health

luch.org/behavioral-health

Specific recovery programs for substance use and eating disorders, treating chronic pain. Also offer outpatient individual, youth, couple and family therapy and support groups with therapists, psychologists and psychiatrists.

LLU Behavioral Medicine Center

luch.org/bmc

Full range of psychiatric and psychological services for youth and adults, including crisis care, inpatient and outpatient treatment.

Loma Linda University Health MEND Outpatient Program

luch.org/mend

Intensive outpatient program for children, adolescents, families promoting healthy coping and adjustment to life with acute or chronic health conditions.

LLU Children's Hospital Spiritual Care and Chaplaincy

luch.org/patients-families/visitors/chapel

Inpatient LLU Children's Hospital chapel and pastoral visitation available from chaplain services. Referrals available for various faith traditions.

National Parent Helpline

nationalparenthelpline.org

855-4A-PARENT or 855-427-2736

Parents can call for emotional support from a trained advocate. Hours of operation: Mon.-Fri., 10 a.m. PST to 7 p.m. PST.

Department of Behavioral Health

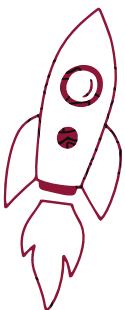
Resource is available by county.

wp.sbcounty.gov/dbh

Learn more about crisis services, mental health services, prevention and early intervention. Dial 2-1-1 (or 888-435-7565) to be connected to thousands of San Bernardino County community resources.

Other tips: Many additional services exist in the community outside of Loma Linda University Health. Ask your primary care provider or health insurance for referrals for your child, you and a partner, or your family. Many insurances offer mental health coverage, and many agencies offer sliding scale fees. Your child's school may also offer school-based counseling services.

Special Events, Camps and Treats



The lives and perseverance of children and families with ongoing medical needs ought to be recognized, empowered and celebrated in our community. Here are a few organizations that facilitate special experiences and events.

Tiny Super Heroes

tinysuperheroes.com/

Special child capes and community website for children to share their stories.

Make-a-Wish Foundation

wish.org/

Special experiences to strengthen and encourage children with critical illnesses.

Camp del Corazon

campdelcorazon.org/

Year-round programs and summer camps for children growing up with heart disease.

Painted Turtle Camps

thepaintedturtle.org/

Camps for children with a variety of serious medical conditions. Siblings/families too.

Diabetes Camp

diabetes.org/community/camp

Summer camps to build confidence in kids with diabetes, in a safe, supportive setting.

Other tips: Look into accommodations at public facilities and amusement parks. Tips on how to locate other special camps: kidshealth.org/en/parents/finding-camp-special-needs.html.