

Resources For Families of Children with Serious Illness

Compiled by the members of the Maine Collaborative for Care of Children with Serious Illness-this information is up to date as of 6/1/2025

This guide is not intended to be inclusive of all services available but was compiled with the cooperative efforts of the members of the Collaborative. There are many other well qualified resources available for these families that are not listed in this guide.

Resource Categories

Cancer care

Complementary/Integrative medicine

Education

Emergency Services

Equipment supplies and services

Financial Support

Medical care/home health care/hospice

Recreation

Spiritual support

State Resources

Support for families and children

Transportation

Cancer care

Lucy's Love Bus

Lucy's Love Bus delivers comfort and quality of life by providing free integrative therapies such as massage, yoga, acupuncture and therapeutic horseback riding to children with cancer (birth to 21) throughout New England. They also offer integrative therapy grants to siblings of pediatric cancer patients.

Contact info

Www.LucysLoveBus.org; contact person Jackie Walker, Jackie@LucysLoveBus.org;

Cell: (978) 764-4300

MCCP (Maine Children's Cancer Program)

Provides emotional support/counseling to patients and families from diagnosis and treatment of oncology or hematology diagnosis, as well as end of life care, medical liaison services, advocacy and connection to community support, special event programming and ongoing bereavement support.

Contact info

(207) 396-7565 (office) ; (207) 396-7922 (direct line with confidential voicemail)

Rett's Roost

The mission of Rett's Roost is to be a source of hope and healing for families impacted by childhood cancer and child loss, offering holistic retreats and meaningful gatherings that create connection while honoring the process of grief and the power of love. The free, immersive retreats provide a safe and compassionate space for families to connect, heal, and process their grief or celebrate survival. For families facing the end-of-life of their child or those in mourning, they offer a certified death doula and one-on-one or family grief support.

Contact info

www.rettstroost.org;(508)813-9222

Complementary /Integrative services**Maine Music & Health**

Organization founded by Kate Beever who is a board-certified music therapist .She provides music therapy, direct care and training for adults and children with cancer, brain injury, and developmental disabilities. Music therapy addresses cognitive, physical, social, and emotional goals through evidence-based musical interventions and instrumental improvisation. Kate Beever has additional trainings in Neurologic MT, Guided Imagery, and Drum Circle Facilitation. She sees patients in hospitals and in her Brunswick office, and works with palliative care teams to offer bereavement counseling, heartbeat recordings, and ceremonial music.

Contact info

Kate@mainemusicandhealth.com;(207)233-8734

Find additional music therapists throughout the state at

<https://www.mainemusictherapy.com>"

Education**Grahamtastic Connection**

Provides free technology for children with illnesses - a great resource for families who are trying to keep up with schoolwork.

Contact Info

<https://www.grahamtastic.org/>

Morrison Center

Provides comprehensive services to children and adults with intellectual and developmental disabilities.Services include residential care for children and adults;a preschool for children referred to them by CDS, a K-12 special purpose school;case management services for children and adults, shared living option, adult day programming.

Contact info

Amy Whitmore, Director of development and campus initiatives,
awhitmore@morrison-maine.org; (207)838-2177

Emergency Services

Maine EMS

EMS-C program-focuses on betterment of care for children under 18-data reporting and analysis of EMS interaction with pediatric patients, review and update protocols of care for EMS providers statewide, improve education for EMS providers across the state, improve the safety and effective transport of pediatric patients to hospitals, healthcare facilities and interfacility.

Contact info

Marc Minkler, EMS for children (207)626-3860

Equipment supplies and services**Caring Resources for Living**

501(c)3 nonprofit founded by Tracy Libby whose mission is to meet the urgent and unmet needs of children with life threatening medical conditions. CRL works on a referral basis with the child's medical team (RN, OT, PT, case manager, physician). CRL provides equipment and services that are needed to improve the quality of life but which may not be provided by insurance or other social service agencies.

Contact info

[Www.crlmaine.org](http://www.crlmaine.org)

Robbie Foundation

Scarborough based non-profit founded by Robbies parents, Lynn and Robert Gierie, serving Maine children with developmental disabilities ages birth to 20 years old. They help children and families by funding adaptive equipment, assistive technology, and therapy treatment not covered by insurance.

Contact info

<https://robbiefoundation.com> or email at: helpachild@robbiefoundation.com

Spurwink All-Tech

Nonprofit that supports the identification and utilization of technology that enables individuals to lead a full and independent life by providing assistive technology and augmentative and alternative communication services to children with disabilities.

Contact info

Alltechinfo@spurwink.org;(207)871-1200 ext3322

Financial support**Alpha-One**

Financial support programs for adaptive equipment and adaptive transportation.

Contact info

[Www.Alphaonenow.org](http://www.Alphaonenow.org)

Mes Papillons Foundation

This organization's mission is to provide financial assistance to children with rare diseases (e.g., listed on the NORD database) to help them gain access to medical equipment that is not covered by insurance.

Contact info

Www.mespapillons.org

Medical care/Home healthcare/Hospice

Andwell Health Partners

Provides skilled home health with a dedicated pediatric team that includes RN, PT, OT, ST, and SW staff. Maternal child health care spans the continuum of preventative and high risk obstetrics. Perinatal and pediatric hospice with current care is available and has a freestanding 14 bed hospice house in Auburn that provides general inpatient care to hospice patients of all ages. Androscoggin home health and hospice serves nine counties in central and western Maine.

Contact info

Laura Bachelder, Clinical Manager of Pediatrics. Cell (207)330-9431; office-(207)795-9383; laura.bachelder@androscoggin.org

For referrals, call Patient Services Center at (207)777-7740

BBCH program for Children with Medical Complexity

<https://www.mainehealth.org/barbara-bush-childrens-hospital/care-services/pediatric-medical-complexity>

Contact info

207-662-5143

CorHealth

Provides pediatric block time nursing for those under 21 who have a variety of medical complexities; Pediatric personal care services for those under 21 who have needs in assistance with activities of daily living; Targeted Case Management services for those under age 21 who need assistance in getting connected with resources from housing, food, medical, educational, etc; Section 28 Rehabilitative and Community Support Service skill-building program for children under age 21.

Contact info

(207)347-6106 ; fax (207)347-6113

Home Hope & Healing

Specializes in 1:1 nursing service to individuals with medically fragile health conditions. The nursing team has expertise in caring for pediatric clients who require care for: tracheostomy tubes, gastric and jejunostomy tubes, management of mechanical ventilation/respiratory support, seizure disorders and skilled medical needs in the school setting. Care is provided in partnership with the client's physician and is based on a care plan that is developed

together with the client and family, while considering the needs, strengths, and goals of the family unit. The team is experienced in assisting families to navigate the complexities of caring for a loved one in the home setting.

Contact info

207-250-0636

Maine General Health

Pediatric palliative care-inpatient,outpatient clinic,home visits-NP and LCSW visits

Contact info

Susan Folk NP (207)621-8890;susan.folk@mainegeneral.org and Gina Mosca

LCSW(207)621-8890;Gina.Mosca@mainegeneral.org.

Northern Light Home Health and Hospice

Provides post-acute pediatric home care nursing and therapy (PT, OT, SW) services north of Augusta from their Waterville, Ellsworth, Bangor, Presque Isle and Fort Kent offices. They also have limited but growing coverage for Cumberland and York counties from their So. Portland office.

Contact info

Referrals Can be made by calling 1-800-757-3326. Website is

<https://northernlighthealth.org/Homecare-Hospice> .

OMT Resources

Portland Osteopathic Children's Clinic

Contact info

www.portlandocc.org

PACT team

The Pediatric Advanced Care Team (PACT) is a specialty group at Maine Medical Center who have advanced training in pediatric palliative care. Pediatric palliative care is specialized medical care intended to provide an extra layer of support and improve quality of life for infants, children, young adults with complex, chronic or serious illness and their families. The team includes a physician, nurse practitioner and social worker who are available to collaborate with a child's existing care team and focuses on aspects of their care that impacts a child's quality of life. PACT offers expertise in the areas of pain and symptom management, communication within the child's care team, continuity across medical settings and support around identifying additional resources in the community. PACT provides inpatient consultation if a child is hospitalized at Barbara Bush Children's Hospital, outpatient consultation/follow up at the MMC palliative care clinic or through telehealth. Patients are able to receive support from PACT with a child's care centered within any medical system or medical group across Maine.

Contact info

Referrals can be placed by a child's PCP or specialty provider by calling 207-396-7606.

Additional private duty nursing: Maxim, Skilled Care Solutions and Home Hope Healing

Recreation

Adaptive recreation-Special surfers; Maine Adaptive(variety of sports throughout the year); **Portland Wheelers**(cycling)

Spiritual support

Spiritual care-MMC, Barbara Bush Children's Hospital

Provides spiritual care, emotional support and family support to patients, family and staff in the hospital

Contact info

MMC (207)662-1265

State Resources

Early Intervention for ME

Responsible to provide early intervention (birth-2 years old) and special education and related services (age3-5) to children with developmental delays and disabilities .Early intervention teams from CDS sites support the child, family and caregivers in increasing the child's engagement, independence and social relationships within the context of everyday routines and activities.

Contact info

(207)624-6660

146 State House Station, Augusta, ME 04333

Help Me Grow Maine

Help Me Grow (HMG) Maine is a free service available to children up to eight years of age and their families. Help Me Grow Maine connects you to information and services about child development and community resources. In partnership with 2-1-1 Maine, any parent, caregiver, or provider can call for support. The Help Me Grow team will listen, link you to services, and supply ongoing support when needed.

Contact info

If you know a family who may need support, please refer with their permission by dialing (207) 624-7969

Maine CDC

Newborn Screening Program

Newborn Bloodspot, Newborn Hearing and Genetic Services

Contact info

Newborn Bloodspot-Ann Watson,(207)287-8188,anne.watson@maine.gov

Newborn Hearing-Ann Banger,(207)287-8427,ann.banger@maine.gov

Children and Youth with Specific Healthcare Needs

<https://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/>

There a General Contract Request Form on the website that families can fill out and someone from the team will contact the family.

There are also virtual monthly webinars on different topics and the recordings are available...

<https://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/training-gallery/index.html>

Healthcare Coordinator

The CYSHN Care Coordinator is responsible for promoting the health of children and youth with specific healthcare needs through state-wide initiatives and collaborations. The goal is to assist families and providers in finding services that will help the child or youth acquire optimal health, development, well-being, and the best quality of life. This service is available to families of children from birth to age 21 who have, or are at risk for, chronic medical conditions, behavioral and emotional conditions. The Healthcare coordinator can assist with insurance appeals, application processes, advocacy, navigation of healthcare systems, referrals, finding resources, and connecting families to other support systems and services.

Contact info-Healthcare Coordinator

MCH.CDC@maine.gov

(207)287-5753

Support for families and child**Babygirl Foundation**

Babygirl Foundation is a Maine based nonprofit ,founded by Tammy and Dave Dube in honor of their daughter Addison, that supplies parents with necessities such shampoo, toothpaste, blankets, phone chargers etc while they are at the BBCH.These supplies are located in “parents closets “ in several units of BBCH and the ER.Staff at the hospital help the families with accessing these supplies.

Contact info

info@babygirlfoundation.org;207-229-3497

Bittersweet End-of-Life Doula Care

Providing in-person and virtual pediatric end-of-life doula support, guidance in difficult conversations, and in-depth grief support for parents and primary caregivers who have lost a child to any illness (including mental illness) or accident. Beecher Grogan received her end-of-life doula training through the University of Vermont, is a bereaved parent of 18 years, and was the co-founder and Executive Director of the childhood cancer charity Lucy's Love Bus for 18 years.

Contact Info

www.BeecherGrogan.com

(207) 502-4470

LittleRiverBeech@gmail.com

Blooming Violette

Blooming Violette empowers families raising children with special needs through comprehensive support and connection. The organization provides dedicated advocacy to help families navigate complex systems, curate essential resources tailored to a family's unique journey, and foster meaningful community connections with other families who understand your experiences. Blooming Violette will help with educational processes, finding specialized services, and provide a supportive community that celebrates every milestone achieved by the child.

Contact info

courtney@bloomingviolet.org;(207)577-6275

Camp Sunshine

Camp Sunshine provides retreat and respite for children with life-threatening illnesses and their families at its beautiful campus on Maine's Sebago Lake. Camp Sunshine offers year round programs, free of charge to families. Families can attend medically supported illness-specific, mixed diagnosis, or bereavement sessions throughout the year. Camp sessions are supported by volunteers and staff. These sessions create community for families and provide opportunities for peer to peer support in a unique lakeside setting.

Contact Info

Stephanie Feyler / Vice President Program Operations & New Business Development

Email: sfeyler@campsunshine.org

Telephone: (207)655-3800

Tricia Burrell,RN,BSN,CEN

Email pburrell@campsunshine.org

Telephone:(207)655-3825

Center for Grieving Children/Tender Living Care

Supports children and their families through 2 community peer support programs:Tender Living Care groups when someone in the family has a serious, life limiting illness;and bereavement groups when a child has experienced the death of someone close to them.Written resources and phone support are also available.These programs are offered at no cost for as long as families need them.

Contact info

Main phone line(207)775-5216

Clarion Hotel

<https://clarionportlandme.com/>

Discount available for patients having surgery at Maine Medical Center or medical appointments through MaineHealth....Call for current rate: (207)774-5611

Courageous Parents Network

Courageous Parents Network (CPN) is a nonprofit organization and a digital web, (mobile app) platform designed to support families of seriously ill children and the clinicians who care for them. All of this content is offered free of charge, 24/7, and is easily accessible on all devices (computer, phone, tablet). There are videos (featuring mostly families & some clinicians), downloadable guides, curated pathways and blogs. They also sponsor virtual events monthly and offer newsletters with the latest assets featured.

Contact info

[Https://courageousparentsnetwork.org](https://courageousparentsnetwork.org)

DASi-Discussion about serious illness

Conversation guide that can be used by health care providers to facilitate a discussion with a child or family of a child with serious illness to learn about their goals, hopes, fear, sources of strength, trade offs, etc with an effort to provide support to the family as they proceed in caring for their child.

Contact info

Chris Bennett MD, retired pediatrician (207)415-5927, cbennett327@gmail.com

Inn Along the Way

Inn located in Damariscotta offering respite to caregivers, as well as a peaceful place to stay with a seriously ill child. Those who are caregivers are offered reduced rate lodging. Located on Chapman farm.

Contact info

(207)751-6261, or (207)682-0118, info@innalongtheway.org

Madeline's Mission, Rising Hope for Healing

Madeline's Mission supports families grieving the loss of a child or baby through peer support and referrals to counseling and memorial items. It has a children's memorial garden in Brunswick, ME, and helps funeral homes and hospitals, equipping them with Cuddle Cots and bereavement kits to best support grieving families.

Contact info

Madelinemission.org; info@madelinemission.org

Maine Hands and Voices

Parent led organization that provides support to children who are deaf or hard of hearing. They answer questions, provide parent to parent support and offer opportunities to meet other families with children who are deaf or hard of hearing.

Contact info

Www.mainehandsandvoices.org,Facebook-www.facebook.com/mainehandsandvoices or email at mainehandy@gmail.com

MaineHealth Findhelp

This is an online directory that lists free or reduced cost services like medical care, food, housing, and more.

You just enter your zip code and find the category of services or goods you are looking for.

Contact info

<https://mainehealth.findhelp.com/>

Maine Parent Federation

Family organization which is granted and assists families of children with disabilities and/or special health care needs navigate and access all systems of care. All services are free of charge to families and there is no qualifying criteria to access the services.

Maine Parent Federation hosts monthly peer support groups for parents and caregivers of children with complex medical needs providing a safe and confidential space to connect, give and receive empathy, share resources and provide encouragement to others who share common life experiences of medical caregiving. In addition, Maine Parent Federation's Family Support Navigator program has been expanded to provide one to one support to families by navigators that have been trained in additional systems of care including palliative care support.

Contact info

(207)588-1933 or (800)870-7746;parentconnect@mpf.org

Parents

Jen and Craig Messinger-parents of Ryan, diagnosed with Menkes Disease who died at a young age. They helped develop a class to educate first responders about pediatric chronic care emergencies. They have served on several parent support group committees and panels. They are eager to provide support to others.

Contact info

Craig(207)712-9776;Jen(207)655-6311, (207)330-0729

Pine Tree Society

Provides a variety of resources for children with developmental disabilities-communication, summer camp, case management.

Contact info

[Www.pinetreesociety.org](http://Www.pinetreesociety.org;);(207)443-3341

Ronald Mc Donald House Charities of Maine

Ronald Mc Donald House Charities of Maine provides comfort for the families of pediatric patients and supports programs that directly improve the health and wellbeing of all children. Free lodging, meals, and support are provided in our 14-room Bangor House and our 34-room Portland House. Additional services for snacks, respite, showering, and laundry are offered in our Family Rooms at Northern Light Eastern Maine Medical Center and Barbara Bush Children's Hospital, Maine Medical Center.

Contact info

Whitney Linscott, hmbangor@rmhcmaine.org, or Will Groves, himportland@rmhcmaine.org. Visit www.rmhcmaine.org.

211

A Maine-based helpline that is available 24 hours a day, seven days a week. 211 Maine is a free, confidential program that helps people find local services and resources that help them stay healthy, safe, and independent. This includes but is not limited to heating assistance, food resources, support groups, case management, and more.

Contact info

Dial 211 (or 1-866-811-5695)

Text your zip code to 898-211

Visit www.211Maine.org

Email info@211maine.org

Transportation

Modivcare-Available to Mainecare recipients

Provides transportation, free access to bus or rail transit, and mileage reimbursement. Lodging and meal assistance are also available for certain visit types (out of state, overnight trips, 250+ miles away). When booking the reservation, mention that you are also looking for meals and lodging assistance. Of note, out of state trips require a 7 day advance notice.

To set up an account or login to an existing account: <https://member.modivcare.com/en/login>

MAINE REGIONS

Region 1:

(Patten, Danforth, & Aroostook County)

1-855-608-5174

Region 2:

(Washington & Hancock Counties)

1-855-608-5176

Region 6:

(Cumberland County - NOTE: Brunswick & Harpswell Excluded)

1-855-608-5178

Region 7:

(Androscoggin, Franklin & Oxford County)

1-855-608-5180

Region 8:

(York County, Brownfield, Denmark, Fryeburg, Hiram, Porter Lovell, Stoneham, Stow, Sweden cities in Oxford County)
1-877-659-1302

Penquis

MaineCare Covered Transportation

Penquis Transportation Brokerage coordinates all rides for MaineCare appointments in the Penobscot, Piscataquis, Kennebec, and Somerset counties. We utilize the Lynx Mobility Services, volunteer drivers, taxi services, the Community Connector, and offer reimbursement for friends and family.

For general questions regarding MaineCare Covered transportation, such as scheduling, cancellations and reimbursements, in Penobscot and Piscataquis County call 207-974-2420 or 1-855-437-5883

For general questions regarding MaineCare covered trips for Kennebec and Somerset including scheduling, cancellations and reimbursements call: 207-973-3605 or 1-844-736-7847 .

Meal and lodging assistance may be available for certain appointments- inquire upon booking transportation.

Any questions, please contact

Chris Bennett, cbennett327@gmail.com, (207)415-5927 or

Janet Duncan, swiss80@gmail.com, (978)302-3681

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