



RESOURCE GUIDE

For families, from families

Children's[®]
MINNESOTA
The Kid Experts[®]

Family Advisory Council

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FOREWORD

The Children’s Minnesota Family Advisory Council created this guide to help patient families through their health care journeys. It includes resources and tips that Family Advisory Council members found helpful during the time they spent with their children at Children’s Minnesota.

Additional resources that may be helpful:

- childrensMN.org
- Children’s Minnesota Family Resource Centers
 - St. Paul: 651-220-6368, River Tower 3rd floor, Suite 3107
 - Minneapolis: 612-813-6816, 2nd floor, across from the Welcome Center
- Children’s Minnesota Welcome Book for important information about resources and amenities:
 - St. Paul: childrensMN.org/welcomebookstpaul
 - Minneapolis: childrensMN.org/welcomebookmpls

You can also ask your care team on an inpatient unit for a printed copy of the Welcome Book.

- Children’s Minnesota education materials about specific diagnoses and other health and parenting topics: childrensMN.org/educationmaterials
- Children’s Minnesota care specialties and condition-specific resources: childrensMN.org/specialties

Families as Partners

The families who created this resource guide served on the Family Advisory Council, one of several pathways for family involvement within the Families as Partners Program. To learn more about the many ways we collaborate with patient families through this program, and how you can get involved, visit childrensMN.org/familiesaspartners or contact Tessa Billman, Families as Partners program manager, at 612-813-7407 or tessa.billman@childrensMN.org.

Youth Advisory Council

The Youth Advisory Council is a dedicated group of patients and siblings of patients, ages 10 to 18, who offer practical ideas for how to help improve the Children’s Minnesota experience for children and teens. To learn more about the Youth Advisory Council, visit childrensMN.org/youthadvisorycouncil or contact child life at:

Minneapolis: 612-813-6259

St. Paul: 651-220-6465

Patient- and family-centered care

Families are valued members of the patient care team. Patient- and family-centered care (PFCC) is working “with” patients and families rather than doing “to” or “for” them. Patient- and family-centered care leads to better health outcomes and an improved patient and family experience of care.

Core concepts of PFCC:

- **Respect and dignity.** Health care practitioners listen to and honor the patient family’s perspectives and choices.
- **Information sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.
- **Participation.** Patients and families are encouraged to participate in care and decision-making at the level they choose.
- **Collaboration.** Patients, families, health care practitioners and health care leaders collaborate in the delivery of care.



Credit: Institute for Patient- and Family-Centered Care®

ADVOCATE FOR YOUR CHILD

As members of the Family Advisory Council at Children’s Minnesota, we understand how challenging and overwhelming it can be to navigate the pediatric health care system. We offer the following suggestions to help you navigate this experience and meet the needs of your child and your family, while focusing on patient- and family-centered care principles of respect and dignity, information sharing, participation and collaboration.

- **Get involved:** Take an active part in your child’s care discussion and decisions. Ask questions, seek clarity and share your insights and observations. You are a crucial member of the care team and your input matters because you know your child best.
- **Be proactive:** Communicate your child’s needs, preferences and concerns to the care team. Share important information like allergies, sensitivities and any changes in symptoms. Effective communication helps customize care plans for your child.
- **Work as a team:** Develop a strong relationship with your child’s health care providers. Establish open lines of communication, trust and mutual respect. Identify the main contact person for updates, questions and concerns.
- **Gain knowledge:** Educate yourself about your child’s medical condition. Learn about the diagnosis, treatment options, potential complications and available support services. This knowledge empowers you to make informed decisions based on evidence-based research. Additional resources can be found at childrensMN.org/educationmaterials or health.state.mn.us/diseases.
- **Stay organized:** Keep organized and up-to-date medical records for your child. Keep track of test results, medication lists, treatment plans and changes in their condition. This documentation helps you understand and communicate their medical history. Utilize the MyChildren’s online portal and refer to the “tips for organizing your child’s health information” at the end of this guide.

Remember, every child and family’s situation is unique. The following guide provides general suggestions and resources you can use to meet your unique needs.

How to address concerns

At Children’s Minnesota, we take great pride in the care we provide for our patients and their families. Whenever you have questions, concerns, comments or something that needs to be addressed immediately, the first person to talk with is your child’s physician, nurse or another member of the health care team.

You may also talk with the following people here at Children’s Minnesota:

Manager or director

Your child’s nurse or unit operations coordinator will help you contact this person.

Family liaison

To file a complaint or grievance.

All Children’s Minnesota sites:

612-813-7393

Email: familyliaison@childrensMN.org

Hospital nursing supervisor

For urgent matters during evening, overnight and weekend hours.

Minneapolis: 612-813-6833

St. Paul: 651-220-8460

PATIENT AND FAMILY RIGHTS

Privacy officer

For concerns about your medical information privacy rights.

All Children's Minnesota sites:

952-992-5470 or 1-866-225-3251

Email: privacy.officer@childrensMN.org

Social work department

For emotional support, mental health concerns, resource connection, information or assistance about protective services for children or vulnerable adults.

Minneapolis: 612-813-6138

St. Paul: 651-220-6479

Office of Ethics

For consultation if you are facing difficult health care decisions.

All Children's Minnesota sites:

612-813-6159

Email: ethics@childrensMN.org

You may also file a grievance with regulatory agencies:

Office of Health Facility Complaints

P.O. Box 64970

St. Paul, MN 55164-0970

651-201-4200 or 800-369-7994

Email: health.ohfc-complaints@state.mn.us

Board of Medical Practice

335 Randolph Ave., Suite 140

St. Paul, MN 55102

612-617-2130 or 800-657-3709

Email: Medical.Board@state.mn.us

The Joint Commission

Office of Quality and Patient Safety

One Renaissance Boulevard

Oakbrook Terrace, IL 60181

www.jointcommission.org

Ombudsman for Public Managed Health Care Programs

P.O. Box 64249
St. Paul, MN 55164-0249
651-431-2660 or 800-657-3729
Email: Dhsombudsman.smhcp@state.mn.us

If you have concerns about your medical information privacy rights, you may contact:

Office for Civil Rights

U.S. Department of Health and Human Services
233 N. Michigan Ave., Suite 240
Chicago, IL 60601
800-368-1019 TDD: 800-537-7697
www.hhs.gov/ocr

ADVOCACY RESOURCES

Patient Bill of Rights

Where can I learn more about my child's rights in the hospital?

Every child and family has rights and responsibilities. The Minnesota Patients' Bill of Rights is posted throughout the hospital for your review. You may also ask your nurse or the front desk for a copy of any of these brochures: "Notice of Privacy Practices," "Patient Rights and Responsibilities," and "Patients' Bill of Rights." Family liaisons at Children's Minnesota can help answer any questions you may have. Contact them at 612-813-7393 or email familyliaison@childrensMN.org.

Advocacy involvement

Where can I learn more about developing advocacy skills and influencing public policy?

Partners in Policymaking® is a leadership training program for parents of young children with disabilities and adults with disabilities. Through informative and interactive sessions, Partners in Policymaking® teaches leadership skills and the process of developing positive partnerships with elected officials and other policymakers who make decisions about the services that you and/or your family use. To learn more, visit mn.gov/mnddc/partnersinpolicymaking/.

Where can I get involved with legislative initiatives important to Children's Minnesota?

Get the latest information on policies that impact children's health and we will alert you when there is an opportunity to contact your legislators on various issues or engage at a community event. To learn more, visit childrensMN.org/advocacy.

RESOURCES AT CHILDREN'S MINNESOTA

A hospitalization is often an emotional and stressful time. It can feel overwhelming when your child is sick or injured. It can have a significant impact on you, your child and your family. Most families need help navigating the challenges they are faced with while in the hospital. There are many resources available at Children's Minnesota that can help during this difficult journey.

STARTING POINTS

Family resource centers

The family resource centers are available for business services, access to information about resources and amenities, snacks and beverages and more.

Minneapolis

Great Clips Family Resource Center
Hospital, floor 2 (across from the Welcome Center)
Monday–Friday: 9 a.m.–3 p.m.
612-813-6816

St. Paul

Family Resource Center
River Tower, floor 3, suite 3107
Monday–Friday: 9 a.m.–3 p.m.
651-220-6368

Social work

Children's Minnesota clinical social workers understand that a hospital visit can be stressful and that medical issues affect other areas of family life. They are available to help you and your child adjust to a new diagnosis and connect you to resources at Children's Minnesota and in the community. Social workers can also help you with transportation, parking, lodging, meals and many other community resources.

Call the numbers below or ask your care team to connect you with a social worker.

Minneapolis: 612-813-6138
St. Paul: 651-220-6479

Interpreter services

Interpreters are available 24 hours a day, seven days a week. Interpreters are free of charge. Ask your child's care team for an interpreter.

- In-person Hmong, Karen, Somali and Spanish interpreters are on staff at Children's Minnesota.
- In-person, video and phone interpreters are available for spoken languages and American Sign Language (ASL).
- ASL and video interpreters, TTYs and other services are available to deaf and hard-of-hearing persons. Contact the deaf and hard-of-hearing communications coordinator at 612-813-5826 (voice/TTY).

Financial counseling

For in-person financial counseling help, please visit one of the welcome centers on the Minneapolis or St. Paul campus to get directions to the financial counseling office. Learn more at childrensmn.org/financialmatters.

You may be eligible for financial assistance if you are uninsured or having problems paying your bill. Children's Minnesota offers:

- Assistance in identifying additional insurance options.
- Free care, or care at a substantial discount, to uninsured individuals based on family income.

Phone: 612-813-6432, Fax: 612-813-6429

Mailing address:

Children's Minnesota Financial Counseling

Mail Stop 17-750

2545 Chicago Avenue South

Minneapolis, MN 55404

CARE AND TREATMENT RESOURCES

Child life

Medical procedures and hospitalizations are stressful events in the lives of children and their families. The Children's Minnesota child life team uses play, creative arts, recreation and teaching techniques to help patients and their families cope with the fear and anxiety they may be feeling. The child life professionals at Children's Minnesota are trained specialists and members of your child's health care team. They work with you and your child to help relieve stress and to help you feel more in control of the situation.

Examples of some things child life specialists do include:

- Explain a diagnosis or treatment in words that your child can understand.
- Use play activities to help your child understand medical procedures.
- Allow your child to express feelings and ask questions.
- Provide your child with knowledge and effective coping strategies before and after a procedure.
- Provide support to siblings, including support groups, sibling playrooms, and creative expression playroom support, arts and crafts projects and more.

Call the numbers below or ask your care team to connect you with a child life specialist.

Minneapolis: 612-813-6259

St. Paul: 651-220-6465

Music therapy

Music therapists at Children’s Minnesota are trained to use music to facilitate movement and physical rehabilitation, engage patients and families in their treatment and provide an outlet for creative and emotional expression. Music therapy is provided through the child life department.

Call the numbers below or ask your care team to connect you with a child life specialist.

Minneapolis: 612-813-7394

St. Paul: 651-220-6465

Care conference

A care conference is a collaborative meeting that brings together the patient and/or patient’s family, nurses, physicians and other medical and non-medical professionals on your child’s care team. Any patient or family can request a care conference at any time. If you’d like to schedule a care conference, contact a social worker. To help make the care conference effective, write down questions and discuss them with the social worker ahead of time. Doing so will ensure that the correct people are in attendance to answer your questions.

Ethics consultation

Ethical questions around the care of patients can be difficult to resolve. Children’s Minnesota has a clinical ethics consultation service that is available 24/7 to help with these situations. You, and any member of the clinical team, can call an ethics consultation for any ethical issue. Sometimes you may not know if you need ethics consultation. If something “just doesn’t feel right,” call one of the consultants to talk about it.

Ask your care team for an ethics consultation or contact the ethics department at 612-813-6159 or ethics@childrensMN.org.

Pain and palliative care

The interdisciplinary pain and palliative care team is dedicated to improving the quality of life for the children we serve because we know that when pain and other symptoms are well controlled, children heal faster and do better. The pain and palliative care team will help ease your child’s pain and symptoms by combining symptom management medications and non-medicinal strategies such as aromatherapy and breathing techniques.

Ask your care team about a pain and palliative care consultation or call the Minneapolis clinic (outpatient) at 612-813-7888.

Integrative medicine

The integrative medicine program combines the best of complementary and conventional medical therapies to develop holistic solutions for children with chronic illness, acute and chronic pain, side effects from medical treatments, and emotional challenges such as depression and anxiety. Our approach is not meant to replace traditional treatments, but rather to enhance them. Available on weekdays, techniques and therapies include aromatherapy, biofeedback, clinical hypnosis, herbs and supplements, reflexology and more.

Ask your care team about integrative medicine or call the Minneapolis clinic at 612-813-7888.

OTHER INPATIENT RESOURCES

Geek Squad®

Geek Squad® precincts at both the Minneapolis and St. Paul campuses provide consulting and service support to patients and families. Expert Geek Squad® agents are available to assist with computers, tablets, DVD players, gaming systems, cameras, cell phones and other consumer technology devices — with all services provided at no cost to patients and their immediate families.

When you stop by the Geek Squad®, you'll stand outside of the precinct and the Geek Squad® agent will help you from there. You can also arrange for a Geek Squad® agent to come to your child's room for technology assistance.

Minneapolis

Children's Minnesota Specialty Center (CSC), floor 2
612-813-6760

St. Paul

River Tower, floor 3
651-220-7010

Children's Book Nook

Books for patients of all ages are available through Children's Book Nook. Volunteers make book cart rounds to the units. Families may also get books by visiting the family resource centers in Minneapolis and St. Paul.

Dining options

For the latest information about inpatient dining options for patients and families, check with your bedside nurse or unit coordinator or contact the Family Resource Center (see above).

Healthcare Legal Partnership

We recognize there are many factors beyond medical care that influence good health. Unresolved social needs such as denial of public benefits, substandard housing conditions, threats of eviction, disconnected utilities and concerns for personal security often have both a health and legal connection. In response, Children's Minnesota's Healthcare Legal Partnership supports two attorneys based on our St. Paul and Minneapolis hospital campuses. These dedicated lawyers collaborate with health care teams and families to identify, prevent and remedy health-harming factors that are rooted in legal problems.

Note: A referral from a designated Children's Minnesota staff member is required for Healthcare Legal Partnership services and eligibility requirements apply.

Sibling play areas

Minneapolis

Sibling Play Area

Hospital, floor 2 (near the Welcome Center)

Hours may vary. Please call 612-813-7051 to confirm.

- Monday–Friday: 9:30 a.m.–noon; 2 p.m.–5 p.m.
- Families can play together in the space until 5 p.m. We ask that parents and caregivers pick up siblings that were dropped off by 4:30 p.m.

The Sibling Play Area is a creative space specially designed for patients and their families. The staff works closely with child life specialists, the Family Resource Center and volunteers to create a supportive environment where children feel welcome to play. The Sibling Play Area includes:

- Therapeutic art and imaginative play areas.
- Outdoor play deck (weather permitting).
- Children’s library.
- Musical instruments, electronic game systems.

St. Paul

Child Life Zone

River Tower, floor 3

Hours may vary. Please call 651-220-9663 to confirm.

- Monday–Friday: 10 a.m.–noon, 2 p.m.–5 p.m. Families can play together in the space during these hours. Siblings can be dropped off Monday–Friday: 10 a.m.–noon.
- Saturday: closed.
- Sunday: 1–5 p.m.

The Child Life Zone is a therapeutic play area inside the hospital where patients and their families can play, learn, laugh and relax. The Child Life Zone includes:

- Expressive arts and crafts center.
- Microsoft media wall with a multitude of gaming options.
- Star Studio performance space with a music recording studio.
- Classic games like air hockey, pinball and a photo booth.
- 3D printer and interactive robots.
- Imaginative play materials.

Visits from special guests, including sports and entertainment personalities, artists, master gardeners, PAWH volunteer animals, Minnesota Zoo and more.

Star Studio

Minneapolis

Hospital, floor 1 (near the main entrance and Welcome Center)

St. Paul

River Tower, floor 2 (inside the Child Life Zone)

Star Studio is Children's Minnesota's very own in-house TV studio that provides positive, memorable experiences for patients and families as an alternative to mainstream and commercial entertainment. Star Studio produces several live, interactive shows that allow patients and families to participate through the telephone in their room or in the studio spaces on both the Minneapolis and St. Paul hospital campuses.

Patients and families can watch live shows:

- From the TV in their hospital room. Play along and hear yourself on TV by calling 5-5020 from any hospital phone during a live show.
- At the studio during live shows.
- On the website.

Go to starstudioMN.org for show schedules.

Healing gardens

Outdoor gardens provide healing green spaces for play, stress reduction and quiet reflection for patients and their families.

Minneapolis

Children's Minnesota – Minneapolis features a 24,000 square foot healing garden available for patients and families, staff and community members. Surrounded by a grove of aspen trees, the garden is available year-round and features walking paths, benches for resting, native plantings and five original granite sculptures created by Minnesota artists Dan and Lee Ross.

The Minneapolis healing garden is located outside the entrance of Children's Minnesota Specialty Center on the corner of Chicago Avenue and 26th Street.

St. Paul

Children's Minnesota – St. Paul features a 6,000 square foot rooftop garden — the Children's Hospital Association (CHA) Storyland Garden — available spring through fall for patients, families, visitors and staff. Check out the great view of the James J. Hill house, Cathedral of St. Paul and Mississippi River bluffs. You might even see a helicopter take off or land. Features include a fish water fountain, a scooter path, bronze sculptures and a 5-circuit labyrinth. Artistic play sculptures, pathways and the labyrinth promote physical rehabilitation by offering opportunities for movement and can also be used for meditative reflection. Soft music and an array of natural Minnesota plants and grasses create a peaceful atmosphere where visitors can relax, eat and socialize. Outlets are located throughout the garden for patient equipment, phone or laptop charging.

The CHA Storyland Garden is located on the rooftop access through Sky Tower on the 4th floor.

Spiritual care

Chaplains at Children’s Minnesota support the special spiritual needs of patients and families. Chaplains, who specialize in pediatric hospital ministry, visit persons from all faith traditions. They can facilitate connections with your home clergy and faith community or with local religious resources that match your faith and spiritual practice. Chaplains routinely visit patient care areas and can be contacted directly or through hospital staff. To contact an on-call chaplain, dial “0” from a Children’s Minnesota phone and ask for the on-call chaplain.

Interfaith Chapel

The Interfaith Chapel is available for any family of any faith and spiritual practice 24 hours a day, seven days a week.

Minneapolis

Hospital, floor 1 (near the lobby and Starz Café)
612-813-6253

St. Paul

River Tower, floor 3 (near the Family Resource Center and Child Life Zone)
651-220-6369

Bereavement services

The death of a child is both heartbreaking and life-changing. Children’s Minnesota offers programs intended to give comfort and support to affected families during the first year and beyond, including support groups, grief education programs, grief-related events and referrals to grief resources in the community.

Support groups provide a safe space where family members can talk about their child and connect and share support with others who have experienced a similar loss. Grief education programs offer families the opportunity to learn, explore and gain understanding about a variety of grief topics. Grief-related events offer families the chance to participate in a gathering where their child and other children will be remembered.

These programs offer reassurance that grief is a normal reaction to the deep and profound loss experienced when a child dies and provide an opportunity for emotional connection during a time when many families describe feelings of isolation. Additionally, each setting is designed to be comfortable and safe, allowing a space where powerful emotions can be experienced and released. All services are free of charge and open to all families.

To learn more, visit childrensMN.org/bereavement-services or call the bereavement coordinator at 612-813-7216.

Ronald McDonald House

Children's Minnesota partners with Ronald McDonald House Charities, Upper Midwest to provide lodging and other services to families with hospitalized children in the Minneapolis and St. Paul hospitals.

Ronald McDonald House, Children's Minnesota – Minneapolis

This beautiful and spacious House is located on the third floor of the hospital and is the largest in-hospital facility in the Upper Midwest. Serving families with children receiving treatment in intensive care units, the House offers families a place to rest and regroup just steps away from their child. Unique to this in-hospital program, there is no mileage requirement for families to access services at Ronald McDonald House.

Features of the Ronald McDonald House include:

- 15 private rooms (including two suites), each with its own bathroom, TV and phone.
- Private nap and shower rooms for day use.
- Home-cooked dinners every night and brunch on Saturday and Sunday, all purchased, prepared and served by Cooks for Kids volunteers.
- A help-yourself pantry for making breakfast, lunch and snacks.
- Free Wi-Fi.
- A relaxing lounge with a TV, fireplace and reading materials.
- Laundry facilities.
- An exercise area, computer lounge and patio.
- A sense of community and support for all families.

Who is eligible?

The House serves families with children receiving treatment in intensive care units.

- Day use is automatically granted to all families of patients in CVCC, ICC, NICU and PICU. Check with your unit social worker to see if you qualify.
- Overnight sleeping rooms can be requested by families and are coordinated through social work.

For questions about access and use, please talk with your child's unit-based social worker or call the social work department at 612-813-6138.

Ronald McDonald Family Room, Children's Minnesota — St. Paul

The Ronald McDonald Family Room is located on the third floor of River Tower. Serving families with hospitalized children, the House offers families a place to rest and regroup just steps away from their child.

Features of the Ronald McDonald Family Room include:

- Four private rooms, each with its own bathroom, TV and phone.
- Private nap and shower rooms for day use.
- Home-cooked dinners on weeknights with brunch and/or dinner on Saturday and Sunday, all purchased, prepared and served by Cooks for Kids volunteers.
- A well-stocked food pantry for a quick snack or meal.
- A relaxing lounge with a TV, fireplace and reading materials.
- Exercise equipment.
- Laundry facilities.
- Coffee and tea available at no charge.
- Sense of community and support for all families.

Who is eligible?

The Ronald McDonald Family Room serves families with children receiving treatment in intensive care units.

- Day use is automatically granted to all families of admitted patients that have spent at least one night in the hospital. To get started, have a family member stop by the Ronald McDonald Family Room and complete a short registration form.
- Overnight sleeping rooms can be requested by families and are coordinated through social work with priority given to families with a critically ill or injured child.

For questions about access and use, please talk with your child's unit-based social worker or call the social work department at 651-220-6479.

TIPS FOR WELL-BEING

While your child is in the hospital

For families,
from families

Having a child in the hospital is stressful. It is easy to put your own well-being as a last priority, but keeping yourself healthy helps you be your best for your child. Families and caregivers of children who have been hospitalized at Children's Minnesota put together these tips to help you maintain your well-being.

BE YOUR CHILD'S ADVOCATE.

You are your child's champion. You know better than anyone what your child needs. Trust your inner voice and ask questions. Use the communication board in your child's hospital room to write down all of your questions.

EAT, SLEEP, BREATHE AND BE ACTIVE.

Go for a walk every day to get fresh air and sunshine. Slow your breathing to keep calm. Take 10 slow, deep breaths to slow your heart rate, relax your body, and your mind. Feed your body healthy foods to keep it energized. Connect with the Family Resource Center or speak with a social worker for resources to help you maintain basic needs for your well-being.

BE COMFORTABLE.

The hospital environment can be cold and dry. Drink plenty of water to stay hydrated and healthy. Ask your child's nurse for a warm blanket, or bring one from home, to stay cozy in the cooler environment. You can get personal care items, such as toothpaste, shampoo, body wash and shaving cream at the Family Resource Center. Ask your nurse or the Welcome Center for these items if you are unable to go to the Family Resource Center.

ASK FOR HELP. ALLOW HELP. PRIORITIZE.

It can be difficult to ask for help. Be willing to ask for help and to accept help. Make a list of things you need help with, such as delivering meals, laundry or cleaning, or taking care of other children while you are at the hospital. Deal with only the things that must be taken care of right now and let the rest go for now.

ASK FOR CREDIBLE RESOURCES REGARDING YOUR CHILD'S CONDITION.

Your child's care team and staff at the Family Resource Center can provide credible resources if you would like to do further research. It is always okay to ask questions or request more information about your child's condition.

CONNECT WITH PEOPLE WHO CAN BE SUPPORTIVE.

Call a family member, a friend, or ask your child's care team to speak with spiritual care resources or a social worker. There is always someone to help you.

COMMUNICATE EFFICIENTLY.

CaringBridge and social media can reach a large audience with one post. You can reduce the amount of communication you send out and still keep people informed and connected to what is going on with your child. Contact the Geek Squad® for help using these tools.

WHATEVER YOU ARE FEELING, IT'S OK.

Remember the chaos, the grief, and the rollercoaster of emotions are normal. Having a child hospitalized can be a very challenging and emotional time.

COUNSELING CAN HELP YOU PROCESS YOUR EMOTIONS.

Your emotional well-being is important. Talking with a therapist can help you work through your concerns, sort out your emotions, and minimize your stress. See the list of mental health resources on page 19. If you need help connecting to these resources, ask your child's care team to connect you with a social worker.

UTILIZE THE FAMILY RESOURCE CENTER AND THE FAMILY RESOURCE GUIDE.

Staff at the Family Resource Center can help you navigate the many resources and amenities available to you and your family. They can also give you a For Families, From Families Resource Guide, created by Children's Minnesota Family Advisory Council to help other patient families through their health care journey — including tips for organizing your child's health information.

MENTAL HEALTH RESOURCES

Children’s Minnesota mental health services

Children’s Minnesota offers a range of outpatient and acute mental health services for children and adolescents. To learn more, please visit childrensMN.org/mentalhealth or ask your child’s care team to help connect you with a social worker to discuss which program(s) may be a good fit for your child’s needs.

988 Suicide and Crisis Lifeline

Call or text 988
988lifeline.org

The 988 Suicide and Crisis Lifeline provides free and confidential emotional support to people in suicidal or emotional crisis 24 hours per day, 7 days a week in the United States.

Trans Lifeline

877-565-8860
translifeline.org

The Trans Lifeline offers emotional and financial support to trans people in crisis.

Center for Grief, Loss and Transition

651-641-0177
www.griefloss.org

Specialized therapy and education to help adults, children, teens, couples and families in their journeys with grief, trauma and life transitions.

Minnesota Teen Mental Health Directory

612-334-5970
www.mnteenmentalhealth.org

Mental health tools and resources for teens, including an updated list of resources for BIPOC and LGBTQ+ youth.

Minnesota Warmline

651-288-0400 or text “Support” to 85511

The Minnesota Warmline provides peer support and a connection with others. It is intended for those who need support but are not experiencing a mental health crisis or emergency.

National Alliance on Mental Illness (NAMI) Minnesota

651-645-2948 or toll free 1-888-NAMI-Helps (1-888-626-4435)

www.namimn.org

NAMI crisis resources

Education, support and advocacy for children and adults with mental illness and their families — including a Parent Warmline. Many parents feel isolated and overwhelmed by their child’s behaviors or mental illnesses and don’t know where to start or to whom they can talk. If you feel this way and don’t have time to attend support groups or classes, or even make a phone call, email Parent Warmline at parent.resources@namimn.org to connect with a parent peer specialist. Parent peer specialists will assist with finding resources, answers to questions and support networks.

Pregnancy and Postpartum Support MN

612-787-7776

www.ppsupportmn.org

Services, information and resources, including a Helpline and online support groups, to promote emotional well-being for new families.

Psychology Today

www.psychologytoday.com

A comprehensive directory of therapists, psychiatrists and treatment facilities searchable by location — as well as information on mental health, family life, child development and parenting.

RECLAIM

www.reclaim.care

RECLAIM’s mission is to increase access to mental health care so queer and trans youth may reclaim their lives from oppression in all its forms.

Walk-in Counseling Center

612-870-0565

www.walkin.org

Free, short-term mental health counseling to address issues of depression, anxiety, chemical abuse/dependency, trauma, domestic violence and a variety of other emotional and interpersonal concerns. As needed, referrals are made to other organizations for additional services, including longer-term care and support.

FINANCIAL RESOURCES

I'm confused when it comes to all the information that my insurance company is sending me. Is there anywhere I can get an explanation of what all this means?

Insurance frequently used terms

Deductible: The amount you pay for health care services each year before the health plan begins to pay for covered medical services.

Coinsurance: The percentage of covered health care costs that you pay (or your health plan pays) after reaching your deductible. Example: 80%/20%, where the plan pays 80% and you pay 20%.

Out-of-pocket maximum: The most you will pay in deductible and coinsurance (and copays, if any) for covered services in a year.

Allowed amount: The dollar amount that a health plan determines is an appropriate charge for a medical service it covers.

Claim: Information from a health care provider that says health care services were provided.

Explanation of benefits: An explanation from your insurance company about how your claim was processed. This is not a bill.

Network: The hospitals, doctors and other medical professionals who sign a contract with a health plan to provide care for its members. Also referred to as participating or in-network providers.

Covered services: Services that your health plan considers "medically necessary" and therefore eligible for coverage under your plan. If there is ANY question about whether a service is eligible for coverage under your plan, call the customer service number on the back of your insurance card.

Provider: A doctor, clinic or hospital. It can also mean other care facilities or professionals, such as physician's assistants, chiropractors, etc.

If you have any questions, call the phone number on the back of your insurance card. Customer service can tell you if specific services are covered, if providers are in or out of your network, how close you are to your deductible and out-of-pocket maximum and answer any other questions you have about your health plan coverage.

Financial counseling for families

I am really worried that our medical bills are going to put a strain on our finances. Where can I go for help?

Financial counselors at Children's Minnesota provide a "one-stop-shop" for families who need financial support for medical purposes. Appointments are preferable; however, there is also staff available to help with immediate needs. Families may be eligible for benefits depending on their income level.

Services include:

- Assistance with questions regarding SSI (Supplemental Security Income), billing statements and online payments through Children’s Minnesota website.
- Assistance in applying for programs such as Medical Assistance (MA), TEFRA, Children’s Minnesota financial assistance discounts, spend down and Emergency Medical Assistance.

If you have questions about qualifying, or need assistance with the application process, call financial counseling at 612-813-6432. For more information about billing and insurance, visit childrensMN.org/billingandinsurance.

Other helpful links and phone numbers for financial services

Bridge to Benefits

mn.bridgetobenefits.org

Bridge to Benefits is a multi-state project of Children’s Defense Fund Minnesota that aims to improve the well-being of families and individuals by linking them to public work support programs and tax credits.

Disability Linkage Line

1-866-333-2466

www.minnesotahelp.info

The Disability Link section of MinnesotaHelp.info® makes it easier for people with disabilities to explore options and make decisions about services, benefits, employment, health care and more.

MNsure

651-539-2099 or 855-366-7873

www.mnsure.org

MNsure is Minnesota’s health insurance marketplace where individuals and families can shop, compare and choose health insurance coverage that meets their needs. MNsure is the only place you can apply for financial help to lower the cost of your monthly insurance premium and out-of-pocket costs.

Supplemental Security Income (SSI)

www.disabilityapplicationhelp.org

Or, call Children’s Minnesota financial counseling at 612-813-6432 to obtain the number for your local SSI office. SSI is a need-based program that pays monthly benefits to disabled adults and children who have limited income and resources.

TEFRA

1-866-333-2466

www.mn.gov/dhs (search: TEFRA)

TEFRA (Tax Equity and Fiscal Responsibility Act) provides Medical Assistance (MA) benefits for children with disabilities who do not otherwise qualify for MA due to their parents' income being above MA program limits. TEFRA funds disability programs, services and therapies that private insurance often does not cover or only partially covers.

HealthWell Foundation

www.healthwellfoundation.org

HealthWell Foundation's mission is to "reduce financial barriers to care for underinsured patients with chronic or life-altering diseases." The foundation provides financial assistance to help with medical expenses like copays for prescription drugs, health insurance premiums, deductibles and coinsurance, pediatric treatment costs and travel costs.

PAN Foundation

www.panfoundation.org

The PAN Foundation's mission is to "help underinsured people with life-threatening, chronic and rare diseases get the medications and treatment they need by assisting with their out-of-pocket costs."

COMMUNITY RESOURCES

The Arc Greater Twin Cities

952-920-0855

www.arcgreatertwincities.org

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities, actively supporting them and their families in a lifetime of full inclusion and participation in their communities. Services include information and advocacy, workshops and forums, sibling programs, abuse prevention and awareness, health care access, networking groups and lifetime assistance programs.

Brighter Days Family Grief Center

952-303-3873

www.brighterdaysgriefcenter.org

Brighter Days is a family-focused grief center that provides free resources and services to children, young adults and adults grieving the terminal diagnosis or death of a family member.

Family Tree Clinic

612-473-0800

www.familytreeclinic.org

The Family Tree Clinic offers a network and legal help for queer and trans people, LGBTQ+ transitioning services, sexual health care for teens and young adults.

Family Voices of Minnesota and CONNECTED program

1-866-334-844 or 612-440-1609

www.familyvoicesofminnesota.org

Family Voices of Minnesota is a non-profit, parent-run organization that serves families of children and youth with special health care needs and disabilities. Family Voices of Minnesota helps families advocate for their children by assisting them in accessing needed services or navigating systems of care.

CONNECTED is a free statewide parent-to-parent peer support program provided by Family Voices of Minnesota for families whose children have chronic or complex special health care needs or disabilities.

Help Me Grow

1-866-693-4769

www.helpmegrowmn.org

Minnesota's early intervention system, Help Me Grow, includes two programs for eligible children:

- **Minnesota's Help Me Grow: Infant and Toddler Intervention** services are provided for eligible children birth through two years of age who may be experiencing delays in their development for several reasons, including special health conditions.

- **Minnesota’s Help Me Grow: Preschool Special Education** provides services based on the needs of preschool children who meet state eligibility criteria for developmental delay or other disabilities and who are experiencing challenges in their learning and development. Children may be eligible if they are not able to learn, speak or play like other children who are the same age.

Minnesota children eligible for Help Me Grow can receive services in their home, childcare setting or school. Help Me Grow services meet each child’s individual needs and are free to eligible families regardless of income or immigrant status.

Early childhood specialists will work with eligible children and families to plan the services and support they need, which may include:

- Special instruction and other services, such as speech, physical and occupational therapy;
- Ideas about ways that a family can support their child’s development at home;
- Connections to community services and programs.

Legal Aid

Legal Aid assists families with critical civil issues including safety, shelter, income or health.

Free, high-quality legal help for low-income individuals and families is available through the following agencies:

- Southern Minnesota Regional Legal Services (SMRLS) 1-888-574-2954 or www.smrls.org, serving people in southeast Minnesota, southwest Minnesota and the east metro.
- Mid-Minnesota Legal Aid (MMLA) www.mylegalaid.org, serving Minnesotans in the 20 counties of central Minnesota, including Hennepin, from offices in Minneapolis, St. Cloud and Willmar.

Minnesota Children and Youth with Special Health Needs (MCYSHN)

651-201-3650 or toll free 1-800-728-5420

www.health.state.mn.us/cyshn

Information and resources, including a link to MCYSHN Navigator, a tool that helps connect families of children with special health needs to local community services. If you are seeking help and don’t know where to start, the Navigator can help you figure out what kind of help you may need.

Minnesota Disability Law Center (MDLC)

612-334-5970

www.lawhelpmn.org

As part of Legal Aid, the Minnesota Disability Law Center (MDLC) addresses the unique legal needs of Minnesotans with disabilities. MDLC provides free civil legal assistance to individuals with disabilities statewide on legal issues related to their disabilities. *MDLC does not generally provide assistance with divorce, child custody or personal injury cases.*

MN Adopt

612-861-7115

www.mnadopt.org

Information, resources, education, public awareness and support for adoptive, kinship and foster families.

PACER Center

952-838-9000

www.pacer.org

PACER Center is a parent training and information center for families of children and youth with disabilities and special health needs from birth through 21 years old. Located in Minneapolis, it serves families across the nation, as well as those in Minnesota. Parents can find publications, workshops and other resources to help make decisions about advocacy, education, vocational training, employment, long-term hospitalizations that have impacted your child's education and other services for children with disabilities and special health needs.

Parent Aware

888-291-9811

www.parentaware.org

Tools and information to help families find the best quality child care and early education for their children.

Red Tree House

www.redtreehouse.org

Red Tree House provides financial support for children with special needs and medical challenges.

TIGERRS

www.tigerrs.org

Transgender, Intersex, Gender-Expansive Revolutionary Resources and Services

United Way 2-1-1

Dial 2-1-1 or call toll free 1-800-543-7709

www.211unitedway.org

Free, confidential information about health, housing, jobs, schools, money, family, community resources, support services and more.

FAMILY FAVORITE WEBSITES

CaringBridge

www.caringbridge.org

Create a personal, private, secure website to easily share updates and receive strength, love and support during a health journey.

CareCalendar

www.carecalendar.org

A web-based system to organize meals and other help for families during a time of illness or life-changing event, such as the birth of a baby or death of a family member.

Children and Youth with Special Health Needs Navigator

www.kidsnavigator.minnesotahelp.info

Helps connect families with local community services from prenatal care to programs for young adults. If you are seeking help and don't know where to start, the Navigator can help you figure out what kind of help you may need.

Children's Health Network

www.childrenshealthnetwork.org

Health information for families, kids and teens.

Children's Minnesota Patient Family Education Materials

childrensMN.org/educationmaterials

Information provided by Children's Minnesota on a broad range of medical conditions, procedures, first aid and more.

Courageous Parents Network

www.courageousparentsnetwork.org

Supports parents of children living with serious illness with the tools and virtual support they need to cope and adapt during their child's illness journey.

HealthyChildren.org

www.healthychildren.org

A parenting and child health website powered by the American Academy of Pediatricians.

HopeKids

www.hopekids.org

Ongoing events and activities and a powerful, unique support community for families who have a child with a life-threatening medical condition.

KidsHealth

www.kidshealth.org

Doctor-reviewed information for parents, kids and teens about health, behavior, emotions and growth and development.

Lotsa Helping Hands

www.lotsahelpinghands.com

A free and private community website to organize family and friends during times of need.

Make-A-Wish America

www.wish.org

Grants the wish of a child diagnosed with a life-threatening medical condition.

Meal Train

www.mealtrain.com

Organize meals for a friend after a birth, surgery or illness.

MedlinePlus

www.medlineplus.gov

The National Institutes of Health's website for patients and their families. Produced by the National Library of Medicine, it provides reliable, up-to-date information about diseases, conditions and wellness issues in a language you can understand.

National Childhood Traumatic Stress Network

www.nctsn.org

Provides information and resources for parents, adoptive parents, foster parents, grandparents, caregivers and all others who care for children and teens who are recovering from traumatic events.

Sesame Street in Communities

www.sesamestreetincommunities.org/topics

Resources to help kids with social-emotional skills and school readiness.

Sibling Support Project

www.siblingsupport.org

Provides information about workshops and support for brothers and sisters of people who have special health, developmental or mental health concerns. The website includes a state-by-state "Find a SibShop Near You" function.

Wishes and More

www.wishesandmore.org

Enhances the life of a child fighting a terminal or life-threatening condition by providing extraordinary experiences including wishes, scholarships, memorials and more.

TIPS FOR ORGANIZING YOUR CHILD'S HEALTH INFORMATION

Whether you organize your child's medical documents and information electronically or in paper files, here are some tips you may find useful:

- For medical appointments, write a list of questions in advance that you would like to ask. Also write down important points while at the appointment and ask for a visit summary after the appointment.
- For paperwork, keep the following documents: lab results, test results, insurance documents, medications, visit notes, hospitalization records, discharge papers, immunizations, therapies, school information and other resources. Check with a social worker or case manager about obtaining a portable organizer for these documents.
- For computer storage, create a separate folder in your document library and create sub-folders for your categories. Categories could be the same as mentioned above.
- MyChildren's is an online resource offered by Children's Minnesota to give you secure access to parts of your medical record on your computer or phone, including immediate access to lab results, immunizations and more.

To enroll in MyChildren's, ask the front desk staff in your clinic or the Patient Registration staff on an inpatient unit. You can also enroll remotely by calling health information management, 612-813-6216. Patients under 18 must have their parent/legal guardian request a MyChildren's account. Visit childrensMN.org/MyChildrens for more information.

- For labs and other important test results, record them in a spreadsheet to track changes in your child's values.
- Sign up for a Medical ID System program. These services provide medical Identification and online medical information storage so your health care provider can access important medical information.
- Keep all Medical Assistance and Department of Human Services documents for a minimum of five years.
- Medical Records - It is your right to request copies of your child's medical records so you can keep them for your use. Visit the Health Information Management (HIM) office.

Minneapolis

Hours: Monday–Friday; 8 a.m.–4:30 p.m.

HIM is located in the basement of the hospital directly across from the elevators.

St. Paul

Hours: Monday–Friday; 8 a.m.–4:30 p.m.

HIM is located on the first floor of the Garden View Medical Building between the coffee cart and Red Ramp elevators.

Note: processing of requests can take up to five working days.

MEDICAL INFORMATION FORMS

childrensMN.org/medicalforms

Designed by the Family Advisory Council, these forms can help organize and track your child's medical information and can help you communicate information and care instructions to your child's care providers. You can fill in the blanks on these forms directly on your computer and print, or you can print them off and fill them in manually.

Forms included:

- Care contacts
- Patient contact and insurance information
- Diagnosis information
- Medication schedule — English, Hmong, Somali, Spanish
- Medication history
- Medical procedures/surgeries/tests
- Comfort plan
- Durable medical equipment: communications/orthotics
- Durable medical equipment: endocrine/hearing/vision
- Durable medical equipment: intravenous/cardiac/neurological
- Durable medical equipment: pulmonary and ENT
- Durable medical equipment: nutrition and feeding
- Durable medical equipment: equipment

Care contact information

Child's name _____ Date of birth _____

Specialty	Name	Clinic/Hospital	Address	Phone number	Email/fax	Last seen	Next seen
Common specialty examples: Dentist, Orthodontist, Eye, ENT, Pharmacy, GI Specialist, Psych Services, Cardiologist, Neurologist, Primary Pediatrician, School Coordinator, Social Worker, Case Manager, Home Care							

Patient contact and insurance information

Patient

Name: _____ Preferred name: _____
Address: _____
Date of birth: _____ Medical record number _____
First language: _____ Other languages spoken: _____

Parent/guardian

Name: _____ Relationship to child: _____
Address: _____
Telephone: First _____ Other _____ Other _____
First language: _____ Other languages spoken: _____

Parent/Guardian

Name: _____ Relationship to child: _____
Address: _____
Telephone: First _____ Other _____ Other _____
First language: _____ Other languages spoken: _____

Insurance information

Complete information below or attach a copy of the front and back of your insurance card here.

Name of Insurance: _____
Telephone : _____
Group # _____ Subscriber ID# _____
Subscriber (Name of policy holder) _____

Diagnosis information

Child's name _____ Date of birth _____

Diagnosis:	Abbreviation:
Date of diagnosis:	Diagnosed by:
Diagnosed at (hospital/clinic/healthcare system):	
Treatment (course of action):	

Diagnosis:	Abbreviation:
Date of diagnosis:	Diagnosed by:
Diagnosed at (hospital/clinic/healthcare system):	
Treatment (course of action):	

Diagnosis:	Abbreviation:
Date of diagnosis:	Diagnosed by:
Diagnosed at (hospital/clinic/healthcare system):	
Treatment (course of action):	

Today's schedule for _____'s medicine



Time of day	Medicine	Dose	Comments (with/without food, drug cautions)
<i>Example</i> 8 a.m.	<i>Example</i> Amoxicillin	<i>Example</i> 5ml	<i>Example</i> With food - breakfast

Current medication and medication history



for: _____

Known medication allergies: _____

Pharmacy Name: _____ Phone: _____

Fax: _____

Brand name	Generic name	Dose (how much)	Route (how given)	Frequency (how often)	Date Started	Date stopped
					/ /	/ /
Reason (why given)	Who prescribed	Where purchased (pharmacy, specialty pharmacy, home service)		Comments		

Brand name	Generic name	Dose (how much)	Route (how given)	Frequency (how often)	Date Started	Date stopped
					/ /	/ /
Reason (why given)	Who prescribed	Where purchased (pharmacy, specialty pharmacy, home service)		Comments		

Brand name	Generic name	Dose (how much)	Route (how given)	Frequency (how often)	Date Started	Date stopped
					/ /	/ /
Reason (why given)	Who prescribed	Where purchased (pharmacy, specialty pharmacy, home service)		Comments		

Medical procedures/surgeries/tests

Child's name _____ Date of birth _____

Please complete the information below. Remember to include any and all procedures that may have included sedation.

Name of procedure/surgery/test:	Date performed:
Performed at (hospital/clinic):	Performed by:
Dates of hospitalization (if applicable):	
Anesthesia/special considerations:	
Other notes:	

Name of procedure/surgery/test:	Date performed:
Performed at (hospital/clinic):	Performed by:
Dates of hospitalization (if applicable):	
Anesthesia/special considerations:	
Other notes:	

Name of procedure/surgery/test:	Date performed:
Performed at (hospital/clinic):	Performed by:
Dates of hospitalization (if applicable):	
Anesthesia/special considerations:	
Other notes:	

Comfort plan for: _____

These are things that help comfort my child (please check all that apply)

Environment; my child likes:

- quiet warm low/lights soft/quiet voices
 busy cool bright/sunny
 other _____

We know children do better when prepared ahead of time, but what and when you tell them, depends on your child.

My child likes information:

- far ahead to be ready just before something happens all the details keep it short
 with repetition once is enough limited choices
 choices are confusing, please just give clear instructions count or warn don't count, just do it
 other _____

Comfort positioning for procedures; my child likes:

- family member cuddling or swaddling (babies only)
 sitting up, with family member close by sitting up, by themselves
 lying down, with family member close by lying down, by themselves
 holding my (or family member's) hand other _____
 please ask each time, it depends on the day or situation

Comfort items/distraction; my child likes:

- Music:** toys singing headphones
Conversation: questions stories books
Comfort Object: blanket favorite toy/object _____
Relaxation: bubbles pin wheels deep breathing imagery
 biofeedback self hypnosis meditation/prayer warm pack
 heated blanket ice or cool pack massage healing touch
 acupressure squeeze toy /stress ball aroma therapy _____
Screens: video game TV/movie phone app/game
 computer favorite movie/game _____

Please do not try to distract, it helps them to watch what you are doing

For Babies:

- sucrose
- breast feeding
- skin to skin (Kangaroo care)
- rocking
- pacifier
- swaddling
- other _____

My child is also:

- sensitive to sounds
- sensitive to touch
- sensitive to scents
- limited in what they hear
- limited in what they see
- upset by too many people in the room

Please Do: _____

Please Don't: _____

Durable medical equipment
Intravenous/Cardiac/Neurological

Intravenous

Notes:

Type of line: _____
 Date placed: _____
 Port Date placed: _____

Infusion pump
 Rate: _____ Volume: _____
 TPN

Prescribing physician: _____

Infusion equipment and supply company: _____

Subq supplies: _____

Cardiac

Pacemaker
 Settings: _____ Type: _____
 Date placed: _____

Defibrillator
 Settings: _____ Type: _____

Holter monitor
 Settings: _____ Type: _____
 Date placed: _____

Prescribing physician: _____

Equipment/supply company: _____

Neurological

Baclofen pump
 Date placed: _____ Settings: _____

VP Shunt
 Date placed: _____ Settings: _____
 Programmable Nonprogrammable

Vegus nerve stimulator
 Settings: _____

Continuous positive motion (CPM)
 Settings: _____

Prescribing physician: _____

Equipment/supply company: _____

Children's[®]
MINNESOTA

The Kid Experts[®]
Family Advisory Council