

# RESOURCE GUIDE

For families, from families



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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 at Children’s Minnesota with their children.

## Additional resources that may be helpful:

- [www.childrensMN.org](http://www.childrensMN.org)
- Children’s 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](http://childrensMN.org/welcomebookstpaul)
  - Minneapolis: [childrensMN.org/welcomebookmpls](http://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](http://childrensMN.org/educationmaterials)
- Children’s Minnesota care specialties and condition-specific resources: [childrensMN.org/specialties](http://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](http://childrensMN.org/familiesaspartners) or contact Tessa Billman, patient- and family-centered care coordinator, at 612-813-7407 or [tessa.billman@childrensMN.org](mailto: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](http://childrensMN.org/youthadvisorycouncil) or contact child life at:

Minneapolis: 612-813-6259  
St. Paul: 651-220-6465



# RESOURCES AT CHILDREN'S MINNESOTA

## Family resource center

Minneapolis Great Clips Family Resource Center  
2nd floor, across from the Welcome Center  
612-813-6816

St. Paul Family Resource Center  
3rd Floor, River Tower, Suite 3107  
651-220-6368

*Is there a place where I can take a break from my child's bedside and catch up with everything that is going on in life outside the hospital?*

The family resource center is available to help "lighten the load" for you during your visit to Children's Minnesota. Whether you are looking for information about your child's diagnosis, need to catch up on work, or just want to relax with a cup of coffee and a magazine, the resource center provides a comfortable, quiet place to spend time.

The resource center library offers a large selection of books, brochures and videos on health and parenting topics. Reference/research assistance is available. Staff can also help you locate information about resources available through community-based agencies and organizations.

A variety of complimentary amenities are offered to help you relax, rejuvenate and keep your life going whether you are at Children's for hospital or clinic visits, including computers, wireless Internet access, phone charging stations, fax, photocopier, notary, beverages and breakfast snacks, leisure reading materials and more. To learn more, visit [childrensMN.org/familyresourcecenters](http://childrensMN.org/familyresourcecenters) or call the phone numbers listed above.

## Bereavement services

612-813-7216

*I feel alone and overwhelmed as I face life without my child. What support is available to help me and my family during this time of grief?*

The death of a child is both heart-breaking and life-changing. Children's Minnesota offers programs intended to give comfort and support to families during the first year and beyond. 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 some 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.

Grief education programs, support groups, and grief events all offer reassurance that grief is a normal reaction to the deep and profound loss experienced when a child dies. These programs 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. To learn more, visit [childrensMN.org/bereavementservices](http://childrensMN.org/bereavementservices)

## Care conferences

*There are several people involved in my child's care. With specialists rounding at different times and needing to consult with one another, it's sometimes hard for me to get my questions answered. I'm not always able to be present at rounds or at the bedside. Is it possible to have a meeting where everyone is in the same place at the same time?*

A care conference is a collaborative meeting that brings together the patient family, nurses, physicians and other care team members involved in your child's health care. Any patient or patient family can request a care conference at any time. If you'd like to schedule a care conference, contact your social worker to determine a date and time. To help make the care conference effective, it is recommended you 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.

## Child life

Minneapolis: 612-813-6259

St. Paul: 651-220-6465

*My child is confused and frightened in the hospital. Is there anyone at Children's who can help my child cope?*

We recognize that 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 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.

## Children's libraries

Minneapolis: 2nd Floor, inside the Sibling Play Area  
612-813-6816

St. Paul: River Tower, 3rd Floor, inside the Child Life Zone  
651-220-6368

*Does the hospital have books my child can borrow to help take their mind off being in the hospital?*

Books for patients of all ages are available through the Children's Library. Volunteers make book cart rounds to inpatient units so children can check out books without leaving their rooms. You can also call the library on either campus to request books. Reading is a great way to pass time in the hospital. Books can also help your child understand and adjust to the hospital experience. Please ask library or child life staff for recommendations.

## Ethics consultation

612-813-6169  
ethics@childrensMN.org

*The proposed treatment for my child is not consistent with my personal beliefs. What should I do?*

Ethical questions around the care of patients can be difficult to resolve. Children's 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 to you about it.

## Healing gardens

*We have been in the hospital for several days. My child and I could really use some fresh air and a change of scenery. Is there any place we can go outside while at the hospital?*

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

Minneapolis: The Healing Garden - outside the entrance of Children's Specialty Center on the corner of Chicago Avenue and 26th Street.

St. Paul: Children's Hospital Association Storyland Garden - rooftop garden access through Sky Tower, 4th floor, adjacent to the Pediatric Intensive Care Unit.

## Health Legal Partnership\*

*I have concerns about non-medical issues that are impacting my family's health and well-being. What resources can assist me?*

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 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.

***\*A referral from a designated Children’s staff member is required for Healthcare Legal Partnership services and eligibility requirements apply.***

## **Interfaith chapels**

Minneapolis: 1st floor, near the lobby and Starz Café

St. Paul: River Tower, 3rd floor, near the Family Resource Center and Child Life Zone

*Is there a quiet place to reflect?*

Children’s interfaith chapels are available for prayer, meditation and reflection. The chapels are open to members of all faith traditions as well as those with no faith tradition. There are sacred texts from a variety of religions available in the chapels as well as prayer rugs. Spiritual care staff will help patient families find the spiritual resources needed for their faith tradition if they are not currently on hand. The chapels are open 24 hours-a-day for patients and families.

## **Integrative medicine**

Minneapolis and St Paul: 612-813-7888 or Toll-Free 800-938-0301

*Are there any alternative treatments we could try to help our child feel more comfortable?*

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. Techniques and therapies include aromatherapy, biofeedback, clinical hypnosis, herbs and supplements, reflexology, massage therapy and more.

## **Interpreter services**

Interpreter services: 612-813-7600

Spanish family language line: 612-813-7500

Somali family language line: 612-813-2020

### **English *How do I request an interpreter?***

Children’s provides interpreters for their patients and families. Any patient registration representative or your child’s nurse can help you with these services at your request. Professional interpreters in all languages and American Sign Language (ASL) are always available at no charge to you.

### **Spanish *Necesito un intérprete en español:***

El hospital Children’s proporciona intérpretes a los pacientes y sus familias. Solicítelo a través de la Representante de registro de pacientes o con la enfermera de su niño (a). Tenemos intérpretes profesionales en todos los idiomas y sin costo alguno, incluyendo Lenguaje de Señas Americano (ASL).

### **Somali Sidee u waydiistaa turjubaan:**

Isbitaalka Caruurtu wuxuu u diyaariyay turjubaano buukanada iyo qoysaska. Waydii wakiilka xafiiska diiwaan galinta ama kalkaalisada. Turjubaano xirfad u leh dhamaan luuqadaha iyo tan dhagoolayaasha baa mar walba diyaar ah, kharashna aan kuugu fadhiyin.

## **Music therapy**

*My child might benefit from a motivating, creative activity while in the hospital. They enjoy music. Is there any way to incorporate that into the care plan?*

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. Talk with your child’s care team if you think your child may benefit from music therapy.

## **Pain and palliative care — Children’s Comfort Promise**

### **Pain Program**

Minneapolis and St. Paul Hospitals (inpatient): 651-220-5400

Minneapolis Clinic (outpatient): 612-813-7888

### **Palliative Care**

Minneapolis and St Paul Hospitals (inpatient): 612-813-7888

Minneapolis Clinic (outpatient): 612-813-7888

*It is so upsetting to hear my child crying in pain. I feel helpless. Is there anyone here at Children’s who can help treat that pain?*

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. Staff or family members can request a pain or palliative care consult any time they have concerns about their child’s level of comfort. The pain and palliative care team will help ease your child’s pain and symptoms by combining state-of-the-art pain medications and non-medicinal strategies such as massage therapy, aromatherapy and breathing techniques.

## **Comfort Promise**

We’ve made a promise to our patients — we call it Children’s Comfort Promise. It means we will do everything possible to help prevent and treat pain. Evidence supports that if we follow four steps children will have less pain with needle procedures.

1. Numb the skin
2. Sugar water or breastfeeding (for babies 12 months or younger)
3. Comfort positioning
4. Distraction

To learn more about what is possible, go to [childrensMN.org/comfortpromise](http://childrensMN.org/comfortpromise)



## Sibling play area

Minneapolis: Hospital, 2nd floor, Suite 2100  
612-813-7051

St. Paul: Child Life Zone, River Tower, 3rd floor, Suite 3100  
651-220-9663

*My other children sometimes get restless while visiting their sibling in the hospital. Is there a place they could go to play and relax?*

Check-in childcare is available for brothers and sisters of patients receiving care at Children's clinics or hospitals. Children must be 2 years or older and free of cold, flu, or other symptoms of illness. For more information about hours, activities and guidelines, please call the numbers listed above.

## Social work

Minneapolis: 612-813-6138

St. Paul: 651-220-6479

*I feel overwhelmed and confused by the health care system. I have questions about how all this works. Is there anyone at Children's who can help answer my many questions?*

Children's 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. You can ask your care team to connect you with a social worker, or call the phone numbers above.

## Spiritual care

Minneapolis: 612-813-6253

St. Paul: 651-220-6369

*I wish I had someone to talk to. Is there anyone at Children's who can help me find peace and comfort at this time when my life feels upside down?*

Children's chaplains are clergy who are specially trained to work in the hospital. They work with families and children from all faith traditions, no matter where they are in their faith journey. Families with hospitalized children often face unique and difficult questions, emotions and decisions. Chaplains are available to provide comfort and support to children, families and staff. Sensitivity to various religious affiliations is assured. Some of their spiritual care services include prayers, rituals, sacraments and assistance with questions of meaning, hope and suffering. They can offer a hand to hold or a shoulder to cry on. The hospital chaplains can also share in moments of thanksgiving or celebration.

## Star studio

612-813-5888

childrensMNstarstudio.org

*My child is tired of watching the same shows on television. Is there another option for entertainment while at the hospital?*

Star Studio is Children'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.

## FAMILY WELL-BEING

### Tips for well-being while your child is in the hospital

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 Family Resource Center 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 community based mental health resources on page 12. If you need help connecting to these resources, ask your child's care team to connect you with a social worker.

# MENTAL HEALTH RESOURCES

## Center for Grief, Loss and Transition

651-641-0177

[www.griefloss.org](http://www.griefloss.org)

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

## NAMI Minnesota

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

Suicide Prevention and Support 1-800-273-TALK (8255)

<https://namimn.org>

Crisis Resources: <https://namimn.org/support/resources/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 and classes or even make a phone call, email Parent Warmline at NAMI Minnesota to connect with a parent peer specialist: <https://namimn.org/support/resources/helpline-parent-warmline/>. 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](http://www.ppsupportmn.org)

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

## Psychology Today

[www.psychologytoday.com](http://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.

## Walk-in Counseling Center

612-870-0565

<https://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 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 website

- Assistance in applying for programs such as Medical Assistance (MA), TEFRA, Children’s 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](http://childrensMN.org/billingandinsurance)

## Other helpful links and phone numbers for financial services

### Bridge to benefits

[mn.bridgetobenefits.org](http://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/SpecialTopics/PeopleWithDisabilities](http://www.minnesotahelp.info/SpecialTopics/PeopleWithDisabilities)

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](http://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/SSD-Form/Contact\\_Us.aspx](http://www.disabilityapplicationhelp.org/SSD-Form/Contact_Us.aspx) or call Children’s Financial Counseling, 612-813-6432 to obtain the number for your local SSI office.

SSI, or Supplemental Security Income, 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

Disability Hub MN - <https://mn.gov/dhs/people-we-serve/people-with-disabilities/health-care/health-care-programs/programs-and-services/ma-tefra.jsp>

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. Parents pay a monthly fee based on the Adjusted Gross Income (AGI) from their most recent federal tax return in order for their children to access services and supports through MA.

# RESOURCES IN THE COMMUNITY

## The Arc Greater Twin Cities

952-920- 0855

[www.arcgreatertwincities.org](http://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 program.

## Family Voices of Minnesota and CONNECTED

1-866-334-8444

[www.familyvoicesofminnesota.org](http://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 educates and empowers families by helping them access needed services or navigate systems of care. CONNECTED is a free state-wide parent-to-parent peer support program provided by Family Voices of Minnesota for families whose children have chronic or complex special healthcare needs or disabilities.

## Help Me Grow

1-866-693-4769

[www.helpmegrowmn.org](http://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

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](http://www.smrls.org), serving people in southeast Minnesota, southwest Minnesota and the east metro.
- Mid-Minnesota Legal Aid (MMLA) [www.mylegalaid.org](http://www.mylegalaid.org) serving Minnesotans in the 20 counties of central Minnesota, including Hennepin, from offices in Minneapolis, St. Cloud and Willmar.

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

## Minnesota Children and Youth with Special Health Needs (MCYSHN)

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

<https://www.health.state.mn.us/people/childreneyouth/cyshn/family.html>

Information and resources, including a link to CYSHN 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

612-334-5970

[www.lawhelpmn.org](http://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](http://www.mnadopt.org)

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

## PACER Center

952-838- 9000

[www.pacer.org](http://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 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](http://www.ParentAware.org)

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

## **United Way 2-1-1**

Dial 2-1-1 or call toll free 1-800-543-7709 [www.211unitedway.org](http://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](http://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](http://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/](http://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](http://www.childrenshealthnetwork.org)

Health information for families, kids and teens.

## **Children's Minnesota Patient Family Education Materials**

[childrensMN.org/educationmaterials](http://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](http://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](http://www.healthychildren.org)

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

## **HopeKids**

[www.hopekids.org](http://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](http://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](http://www.lotsahelpinghands.com)

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

## **Make-A-Wish America**

[www.wish.org](http://www.wish.org)

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

## **Meal Train**

<https://www.mealtrain.com/>

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

## **MedlinePlus**

[www.medlineplus.gov](http://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](http://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**

<https://sesamestreetincommunities.org/topics/>

Resources to help kids (and parents!) with what matters most in young lives: health and wellness, social-emotional skills, and school readiness.

## **Sibling Support Project**

[www.siblingsupport.org](http://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](http://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](http://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](http://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
<b>Common specialty examples:</b> 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 \_\_\_\_\_

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

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

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



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



Sij hawm rau Hnub no \_\_\_\_\_ cov tshuaj



Sij hawm rau hnub	<i>Piv txwv</i> Amoxicillin	Tshuaj	Npaum li cas <i>Piv txwv</i> 5ml	Kev taw qhia (nrog/tsis nrog zaub mov, tshuaj ceev faj) <i>Piv txwv</i> Nrog zaub mov – plus tshais





# Daawo Qaadashada \_\_\_\_\_ ee Maanta



Wakhtiga Maanta	Daawadda	Tirada Daawada	Faalo (cunto ku qaatay/kuma qaadan, digniinta daawada)
<i>Tusaale</i> 8 subaxnimo	<i>Tusaale</i> Amoxicillin	<i>Tusaale</i> 5 ml	<i>Tusaale</i> Cunto ku qaatay - Quraac



**Horario para la medicina de:** \_\_\_\_\_



Hora	Medicina	Dosis	Comentarios (en ayunas o con alimento, precauciones)
<i>Ejemplo</i> 8 a.m.	<i>Ejemplo</i> Amoxicillin	<i>Ejemplo</i> 5 ml	<i>Ejemplo</i> Con un alimento – en el desayuno



# 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.

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

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

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





**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:** \_\_\_\_\_

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**Please Don't:** \_\_\_\_\_

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Durable medical equipment  
Pulmonary/ENT

Pulmonary/ENT

Notes:

Nebulizer  
 Portable Date issued: \_\_\_\_\_  
 Standard Date issued: \_\_\_\_\_

Oximeter  
 Portable Date issued: \_\_\_\_\_  
 Owned  Rented  
 Stationary Date issued: \_\_\_\_\_  
 Owned  Rented  
Setting  
HR low: \_\_\_\_\_ High: \_\_\_\_\_  
O2 Stat low: \_\_\_\_\_ High: \_\_\_\_\_

CPAP  BIPAP  MR850  Other  
Type: \_\_\_\_\_ Date issued: \_\_\_\_\_  
Settings: \_\_\_\_\_  
 Owned  Rented

Vent  
Type: \_\_\_\_\_ Date issued: \_\_\_\_\_  
Settings: \_\_\_\_\_

Trach  Cuffed  Uncuffed  
Type: \_\_\_\_\_ Date placed: \_\_\_\_\_  
Size: \_\_\_\_\_

Suction  
 Portable Date issued: \_\_\_\_\_  
 Owned  Rented  
 Stationary Date issued: \_\_\_\_\_  
 Owned  Rented

Humidifier  
Date issued: \_\_\_\_\_  
 Owned  Rented

Cough assist machine  
Date issued: \_\_\_\_\_  
 Owned  Rented

Prescribing physician: \_\_\_\_\_

DME/supply company: \_\_\_\_\_

Secondary company: \_\_\_\_\_

Notes section with 20 horizontal lines for writing.









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MINNESOTA

[childrensMN.org](http://childrensMN.org)