



MAKING MOMENTS COUNT  
FOR KIDS & FAMILIES

# Family Handbook and Home Guidelines Respite & Hospice Home for Kids

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# Welcome to the Crescent Cove Respite & Hospice Home for Kids!

Crescent Cove is only the third pediatric palliative care center in the United States. We offer palliative respite, hospice respite, and hospice end-of-life care. We are here to provide a place of compassionate, comprehensive, and family-centered care for your child and family.

Our Home is shared by many families, and as such, we ask those coming to the Home to please follow the guidelines provided in this handbook. This handbook and guidelines were created to assist our team in providing a respectful and compassionate place for all. If you have any questions, please remember we are here to help and are available to answer any questions you have. We will work to meet your needs and make your stay with us as comfortable as possible.

Statements in purple text are made for our families experiencing sacred end-of-life care. Most of these exceptions will be explored through a discussion with our social worker, nursing staff, or house manager. It is the expectation that other families respect the confidentiality and individualized goals of care for each child and family at Crescent Cove.

## Overview

### A Respectful Environment

Crescent Cove recognizes all people from all walks of life. Each family that enters our Home is treated with dignity, respect of beliefs, and welcomed without judgment. Crescent Cove is a haven where everyone can be his or her self in a safe environment. It is a Crescent Cove expectation that all who enter provide the same respect for others in the Home that we provide to you. Please honor each family's right to choose what is best for their child.

Our team is here to provide emotional, spiritual, and physical care and support to your family while supporting your child medically when appropriate. We will honor and respect your family's needs, traditions, and cultures. It is our promise to support your family's goals concerning the physical, emotional, and spiritual needs of your child, including his or her siblings.

### About our Team

We are staffed with a medical director, director of nursing, registered nurses, nursing assistants, social worker, administrative staff, and volunteers who have all received extensive training in caring for medically fragile children, as well as end of life care for children and families. They are a remarkable group of caregivers that are committed to providing quality compassionate care.

## Confidentiality

All of our staff and volunteers understand your right to privacy. We take confidentiality very seriously, and we make every effort to protect the personal and health care information of your child and your family. **It is the policy of Crescent Cove that we give information to two (2) primary caregivers during the child's stay. All personal child information given to visitors must be routed through those two individuals.**

We require all of our staff and volunteers to receive specific training in this area, and to sign a confidentiality agreement pledging not to discuss or release information, directly, or indirectly, regarding children and families, except when required in the performance of their duties.

We respectfully ask that you refrain from taking pictures at Crescent Cove that include other peoples' loved ones without their permission.

## Grievances/Concerns

Every family admitted to Crescent Cove receives a copy of the Hospice Bill of Rights. This document outlines your rights and also the grievance procedure. If you have questions or concerns about our services or the care you receive, you are encouraged to speak to a staff member.

## Contact Numbers

952.426.4711 x1 | Respite & Hospice Home Main Line

952.426.4711 x5 | Social Worker

952.426.4711 x6 | Volunteer Coordinator | House Manager

952.426.4711 x7 | Care Coordinator

952.426.4711 x8 | Director of Nursing

Our Care Team is committed to providing quality respite and end-of-life care. We are honored that you have chosen us to care for and support your family. Please ask us if you need anything.

## Donations and Gifts

Crescent Cove is currently funded through philanthropy, and accepts monetary donations and gift cards. Non-monetary donations need to be approved with our team. Please speak with a member of our team with any questions.

## Fees and Charges

It is thanks to the generosity of our donors that we can currently offer the Home at no cost to families. Crescent Cove is continuously working on a robust insurance reimbursement model to aid in supplementing the costs of providing palliative respite, hospice respite, and end-of-life care at our Respite & Hospice Home for Kids. For this reason, we request to make copies of your child's health insurance cards. In December 2020, we started accessing funding through the State of MN Medicaid Waiver program as a Home and Community-Based Provider. We work with families and county case managers together to determine eligibility and how waivers can support stays at Crescent Cove.

## The Home

### Our Hospice License

Our facility is licensed by the Minnesota Department of Health as a Residential Hospice under the Crescent Cove Respite & Hospice Home license.

### Building Access

Our facility is a locked facility. Families and volunteers are encouraged to enter the main entrance using the blue door. You can ring the doorbell and a Crescent Cove representative will give you access to enter.

Please see the visitor section below for more information on visitor badges, signing in/out, visiting hours, and visiting restrictions.

### Home Basics

#### Wi-Fi Access

Please use the networks of either **Crescent Cove-Guest** or **Crescent Cove-Guest 5G**. The password is located in each room.

#### Mail

Our mailing address for the Home is **4201 Bass Lake Rd, Brooklyn Center, MN 55429**. Please feel free to send mail to the Home for any kids staying at Crescent Cove. Outgoing mail can be left in the mailbox outside the Admin Office door.

### Our Rooms

Crescent Cove can accommodate up to six kids and one family overnight at any given time.

#### Family Suite

A family suite with a queen bed, sleeper-sofa, and a full bathroom is available for families. The care coordinator or social worker will advise the family if there is a suite available for them. Families have use of the Home's family suite if assigned, child's bedroom and bathroom, kitchen, dining room, sensory room, and great room, but will be respectful of the ongoing operations of the Home occurring on a daily basis. **Families staying for end-of-life care will have priority to use the family suite.** Staff must have the names of family members who stay overnight at Crescent Cove (limited to four per family). See visitors section for information on visitor badges as well as sign-in and sign-out procedures.

When there are special circumstances, we can suggest nearby hotels for extended family or visitors needing overnight accommodations.

### Great Room

The large room with comfortable seating is available to relax or visit with friends or family. An outside door to the patio offers seating to enjoy the view of the lake. Books are available throughout the Home, and activities are available upon request for patients and siblings.

### Multi-Sensory Wall

Please make sure to take the time to enjoy the many features of the multi-sensory wall located in the great room.

### Sensory Room

- Sensory-friendly toys are available for use. Please ask staff to assist you.
- All toys are sanitized in between uses. Please place any used toy in the “clean me” basket after using it to allow the room to be ready for the next family.

### Music/Art/Toy Room

- Musical instruments are available upon request. Please ask staff to assist you.
- Craft supplies are available to express yourself, create memories, or just have fun.
- Toys are available for play. Place used toys in the “clean me” basket before being used by another child.

### Recording Studio

This room is available for you and your family to enjoy. Prior to using any equipment in the recording studio, families should talk to staff on-site about usage.

### Spa Tub Room

- The therapy tub is for use by kids receiving care only.
  - A child can never be left alone in the spa bathroom. Please make sure that you or a staff member is with your child or young adult at all times.
- We encourage parents or caregivers who are staying at the Home to help with bath time.

## Overnight Guest Accommodations for Families

- Crescent Cove staff will make every effort to provide sleeping accommodations for parents/legal guardians.
- Due to limited space, we cannot accommodate extended family members or visitors overnight. The care coordinator, house manager, or social worker can assist families in identifying their options for sleeping accommodations outside of the Home.
- One parent/legal guardian may sleep in the child’s room at any given time. If there is adequate space, a second parent/legal guardian may also sleep in the room. If space is inadequate, guardians will be offered available sleep areas within the Home, if available.
- One family pass for building access is provided when using overnight accommodations. This pass will be documented on the admission and discharge checklists. The replacement cost for a pass not returned at discharge is \$10.
- When a child is a minor, non-related persons may not stay overnight in the same room.

Compassionate exceptions are made on an individual basis for situations involving exceptional circumstances and with the permission of the parent(s). Our Social Worker will assist staff in determining eligibility.

- Adult patients (18 or older) may have overnight adult visitors (18 and over), space and safety permitting.
- If there is a need for a sibling to stay overnight, the parent/adult caregivers should discuss this with a staff member (ie. Nurse, Social Worker, or House Manager) to determine feasibility. When staying overnight, an adult family member must attend to the sibling at all times.
- Linens are available including pillows, blankets, and towels for guests that are planning to stay overnight. There is a shower available for visitors.
- There is a public restroom next to the Clinical office for guests.
- Living spaces are to be shared by all kids and their guests including the kitchen, great room, dining room, sensory room, playroom, and the Grace Space. Please speak to any staff member if you have questions.

## Kitchen/Food

Crescent Cove provides daily meals for kids who eat solid food orally. Visiting family members and guests are welcome to Crescent Cove meals when provided. If your family does not prefer what Crescent Cove provides, you are welcome to purchase your own meals. The kitchen and dining room are available for everyone to use.

Exceptions regarding special meal requests and food items for sacred, end-of-life can be a discussion with the Care Team.

We follow the Minnesota Department of Health guidelines for kitchen safety. We ask your assistance in following these guidelines:

- Families may bring in personal food if they choose. It must be labeled with the child's name or room number and date, and if perishable, kept in the dining room refrigerator on a designated shelf. Nonperishable food items will be stored on the dining room snack counter in a bin labeled with the child's name. A small fridge is available in the family suite and Grace Space.
- Once food has been taken into a child's room, it cannot be returned to the dining room refrigerator.
- Families may help themselves to the available water, coffee, and snacks in the dining room and kitchen.
- Families may help themselves to leftover food items in the kitchen refrigerator and non-perishable food items in the dining room pantry at any time. No food will be allowed to leave the premises unless otherwise given by a staff member of Crescent Cove.
- Please be diligent about washing your hands before serving yourself or others.

## Hand Washing

Hand washing is the most important task to prevent the spread of infection. Please make a habit of washing your hands thoroughly upon arrival, before and after meals, and after contact with a contaminated source (e.g., diaper change, using the bathroom, blowing your nose, etc.). Please wash your hands or use hand sanitizer when you enter the Home and throughout your visit.

## Parking

We have a limited number of parking spaces for our families, team members, and visiting health care personnel. We encourage visitors to carpool when possible. If the parking lot is full, there is street parking one block west on June Ave. There are three designated family parking spots.

## Laundry

Crescent Cove staff will provide laundry services for kids only. Please make accommodations for doing any personal or visitor laundry off-site.

## Recycling

There are containers located underneath the microwave for recycling purposes. Large recycling receptacles are located outside in the front of the Home by the Admin Office. If you have questions, please talk to a member of our staff.

## Housekeeping

Volunteers are here to maintain and clean kids' rooms daily. However, we ask that any families on-site help with disposing of food and any soiled linens or diapers properly in provided containers. A thorough cleaning will be done daily/as needed.

## Lake Safety

Safety for kids and adults indoors and outdoors is a very high priority. Crescent Cove is located on Twin Lakes. When kids are outdoors, there **MUST** be an adult 18 years of age or older who is capable, assigned supervision, and willing and able to remain in this role supervising children until he/she returns inside. All children staying at Crescent Cove will be required to wear a life jacket when on the dock. Other children aged 10 and under who are visiting Crescent Cove must also wear a life jacket when they are on the dock. **Limit one wheelchair on the dock at a time.**

## Smoking or Illegal Substances

Smoking is not allowed in the facility or on the grounds. Crescent Cove is an illegal substance free campus. Persons who might have partaken of illegal substances prior to visiting Crescent Cove will be asked to leave.

If staff believes that a person shows signs of drug or alcohol impairment, appropriate authorities will



be contacted. Under no circumstances can there be any disruption to the care of our patients by family or friends who might have difficult behaviors due to inappropriate use of substances and alcohol.

## **Alcoholic Beverages**

Visitors are prohibited from consuming alcohol on the premises.

## **Weapons**

No weapons of any kind are allowed on the premises.

## **Valuables**

Crescent Cove is not responsible for any personal items brought to the Home. Upon admission and discharge, we will take an inventory of your child's belongings. We suggest you take all valuables home. If you bring in or remove any items, please notify a staff member for our records.

## Crescent Cove Children & Young Adults

### Children's Rooms

- Each child's bedroom has a:
  - Private bathroom equipped with a toilet and sink
  - A TV (with Roku) and radio
  - An age-appropriate bed with linens and pillows provided
- Each room has an outside door equipped with an alarm.
  - Our regulations and fire codes require that all kids' rooms remain unlocked from the inside at all times.
  - The outside doors are locked to maintain privacy and safety of all at the Home.
- We encourage you to bring personal items that would bring comfort such as photos, etc. (please label personal items with your child's name). Because of electrical wiring and oxygen systems that serve our Home, we ask that you do not make any nail holes to hang pictures. We have placed hangers in each room for you to hang personal art if you so desire.

### Supervision

It is our intent that kids are with a staff member, volunteer, or adult family member when the child is not in his/her room or the family suite. Nursing staff must have access to kids at all times.

Visitors may not visit a patient without permission of the legal guardian when the legal guardian is not present. We have a limited number of people that can visit without the presence of legal guardians. Those individuals will be chosen by the family and documented at the beginning of their stay at Crescent Cove.

The child's family is responsible for supervision of siblings and other guest children under the age of 18 at all times. With permission by nursing staff or caregiver, volunteers may play with the siblings for short periods of time. Parents are in-charge of supervision of siblings.

### Primary Caregiver Responsibilities

For Crescent Cove to be in compliance with our license, we must follow all physicians' orders. Therefore, it is important to review your child's orders with our Care Team, so any discrepancies between the child's providers' orders and the care provided at your home are resolved prior to admission at Crescent Cove.

We can only give the medications and feeding regimens as ordered by your child's provider. We will need an order not only for any prescription medications, but also all over-the-counter medications, such as vitamins, herbal remedies, dietary supplements, or creams/ointments that your child may need administered while under our care.

## Medications/Equipment/Medical Supplies

- Families must bring their child's current medications from home, as Crescent Cove does not provide medications, equipment, or medical supplies (except standing order meds).
  - A child's primary caregiver is responsible for supplying an adequate amount of all ordered medications, formulas, supplies, and equipment needed for the child's entire stay upon admission and/or plan to supplement the supply during his/her stay.
    - If any of the above are missing at the time of admission, the child's primary caregiver (or designee) must bring the item within 24 hours. If not delivered, there may be a medical need to transfer or discharge your child.
    - Any costs that may occur in obtaining missing items are the responsibility of the primary caregiver.
  - All medications need to be in the original, labeled container and will be examined by the admitting nurse. Please check for expiration dates, especially on rescue medications as medications that are rarely used may become unintentionally expired.
  - If families prefer to administer medications, these specifics will be included in the child's care plan.
  - All medications, when prescribed, are administered by one of Crescent Cove RN's and will be kept locked in the med room.
- Crescent Cove is not responsible for the payment of co-pays for medication refills during admission.
- In addition to any medications, supplies or products, due to allergies, Crescent Cove is offering only unscented generic soap/shampoo for all children. If a specific product (soap, shampoo, nail polish, creams, etc) is preferred, please send it along with their supplies for the duration of their stay.
- We also ask that parents please provide sunscreen and insect repellent for their child so the child can be taken outdoors in these elements.

## Checking Out

Children will be discharged by the nurse on-duty. The discharge process includes a review of your child's experience during his/her stay, along with any concerns or changes noted. The primary caregiver will be offered a written summary. The nurse will go over all the belongings and medications with you at the time of discharge.

When a child is leaving on an outing, a Child Outing Form must be completed. The child must return within 24 hours. Medications will be sent with the family along with a detailed explanation. It is the understanding that if a child does not return to Crescent Cove within the mutually agreed upon time, he/she may be discharged from Crescent Cove. It is also an understanding that Crescent Cove assumes no responsibility and is not liable while a child is not in our direct care.

A survey will be given to you upon check out and emailed after discharge, which may be mailed

back to Crescent Cove or completed online at your convenience. We encourage you to fill out the survey as your input is very important to us.

## Visitors

### Visiting Hours

Our facility has an open door policy. We welcome visitors to support and comfort families staying here at Crescent Cove. If visiting after 8pm please call the Home as evenings are our time to encourage healthy sleeping patterns.

### Visitor Guidelines

Any number of family and loved ones may visit the Home at any time, as long as they are with at least one of the two primary caregivers listed on admission. The primary caregiver may list up to four (4) preferred guests that can visit their child outside of that parameter. A preferred guest cannot receive medical information. If there is a request for more than four visitors/larger group, visits/parties must be pre-arranged with our Social Worker and/or House Manager regarding the specifics of the visit. Tours are arranged with the House Manager, and are expected to be guided by leadership.

For the safety of all kids and others, all of the doors are locked. Our security system at the front door allows us to view and speak with visitors before allowing them in. At times, we have volunteers or other Crescent Cove staff who may not recognize you and need to ask who you are visiting. We ask all visitors to sign-in so we are aware of who is in our building. If there is not someone available to let you in, please be patient as he/she is with a child and will be with you as soon as possible.

Visitors are not allowed in the Clinical Office due to confidential patient information stored in that area. Children may visit at any time, but must be supervised by an adult. They are welcome to go outside or anywhere on the grounds as long as an adult is with them.

### Balloons

Latex balloons can cause an allergic reaction for some people and can be a choking hazard. Therefore, we can only allow Mylar balloons in the Home. Mylar balloons are the shiny, metallic-type balloons usually found with a printed message or design on them.

### Pets

Only certified service/therapy animals are allowed in the Home with the supervision of their handler/owner.

Exceptions for sacred end-of-life can be a discussion with the Clinical Team. All animals must enter through exterior doors, and must stay in the child's individual room. Care of the animal is the sole responsibility of the child's responsible guardian. Crescent Cove employees will not be responsible for toileting, maintaining, or care of the animal. Crescent Cove staff retains the right to request that a

pet be removed from the Home if they believe it poses a health and/or safety issue.

## Parties

### Birthday Parties

Birthday parties are invited and encouraged at Crescent Cove during a scheduled respite stay. Parent/Legal Guardian is asked to provide decorations (no latex balloons) and any necessary food items with serving supplies (e.g. plates, napkins, cups). Parents/Legal Guardians are allowed to invite up to 15 guests to attend. Parties are limited to 2 hours.

Plan ahead by notifying the Care Coordinator or Social Worker of your hope to celebrate the birthday when scheduling the respite stay. At least four weeks' notice is preferred.

### Graduation Parties

When a child reaches 22 years of age, they will graduate from Crescent Cove. To celebrate this occasion, a party may be planned during his/her last respite stay. For this celebration, Crescent Cove will supply the food and decor. Parents/Legal Guardians are allowed to invite up to 15 guests to attend. Parties are limited to 2 hours.

Disclaimer: An end-of-life stay may change party arrangements.

## Infection Prevention and Control

Because infection prevention and control concerns affect the child, other children, and staff at Crescent Cove, the child's parents, visitors, employees, staff, and volunteers must adhere to all infection prevention and control requirements from the time of entry into the Home, during time with the child, and during time waiting or in transit to their child's room.

Visitors will be screened for infectious disease upon entry to the Home. Screening may find restrictions to be warranted.

- This may include:
  - Wearing protective equipment as recommended by infection control policies or by nursing staff;
  - Restriction to certain areas such as remaining in the child's room or outside the Home;
  - Limitation to common areas of the Home.
- Lack of compliance with infection prevention and control guidelines may lead to visitor behavior contracts or exclusion from visiting Crescent Cove. This applies to both parents and visitors.
- Required screening for entry into Crescent Cove may be applied to all parents and visitors at some times as decided by the Infection Control Committee to comply with infection prevention and control.
- Based on infectious disease status in the community, Crescent Cove may elect to restrict ALL general visitations to the facility as a whole, or to two, one or no parents as determined by the Director of Nursing or Medical Director.

- For the protection of kids, all family and visitors are asked not to visit if they have symptoms of cold, COVID-19, cough, flu, runny nose, sore throat, cold sores, vomiting, diarrhea, fever, rash, or skin infection.
- Parents/adult caregivers who have a contagious illness must consult with a doctor or nurse regarding precautions that they may be required to take.
- Additional screening, including screening for temperature, specific symptoms, exposures, or vaccine history, may be required in some circumstances.
- Immunization status and immune status may lead to exclusion from the Home in particular areas of the Home. The fact that parents/adult caregivers have conscientious objection to immunization, or that medical reasons for lack of immunization exist, does not override the requirement for immunization or immunity as decided by infection prevention and the medical leadership at Crescent Cove.
- Many of our kids have immune systems that are not strong enough to fight off infections. A simple cold can be life-threatening to some Crescent Cove kids.
- We are asking families to recognize that any illness that is contagious can be dangerous and possibly life threatening to the kids staying at Crescent Cove. For this reason, we ask that kids be free from any contagious illnesses while at Crescent Cove.

**If your child develops symptoms indicative of a contagious illness while at Crescent Cove, please understand that you will be asked to return to pick up your child. We will then work together to reschedule your stay for a time when your child is free from illness that can be spread to others.**