



Children's Hospice Association Scotland

Sharing the Caring

# The CHAS Model of Palliative Care







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## Introduction

The Children's Hospice Association Scotland (CHAS) is a Scottish charity that provides the only hospice services in Scotland for children and young people with life-limiting conditions.

A children's hospice offers professional care, practical help and emotional support to the whole family usually from the day of acceptance, to the death of their child, and beyond.

CHAS runs two children's hospices - Rachel House in Kinross and Robin House in Balloch. Both hospices are purpose-built and each can provide ongoing support for up to 200 families across Scotland each year. At any one time, the hospices can each accommodate up to eight children or young people and their families.

CHAS also runs the CHAS at Home service which offers support to families referred to the hospices by providing a care service to families in their own homes when they need it most.

The range of services CHAS provides are free to children, young people and families who need them.





# Referral process

Anyone can refer a child or young person to CHAS, providing it has been discussed and agreed by their family. Referral for hospice care should also be discussed with a child or young person's key worker and other health professionals who are providing care and advice to the family.

Children and young people with the following groups of conditions can be referred to CHAS, as described by ACT (2009)\*:

## Category

### one

Life-threatening conditions for which curative treatment may be feasible but can fail, eg cancer, irreversible organ failures of heart, liver and kidney.

## Category

### two

Conditions where premature death is inevitable, but long periods of intensive treatment aims to prolong life, eg Duchenne muscular dystrophy and cystic fibrosis.

## Category

### three

Progressive conditions without curative treatment options. Treatment may extend for many years, but it is exclusively palliative, eg Batten disease and mucopolysaccharidoses.

## Category

### four

Irreversible non-progressive conditions causing severe disability leading to a likelihood of premature death, eg severe cerebral palsy, brain and spinal cord injuries.

Ordinarily a referral should be made using a CHAS referral form, which is available on the CHAS website at [www.chas.org.uk](http://www.chas.org.uk). This information is then assessed and further information gathered. Often a home visit is made allowing an opportunity for a family to meet some of the CHAS team, and for CHAS staff to assess the referral. If the assessment indicates that a referral is not appropriate, hospice staff will sensitively discuss this with the original referrer. If the referral is an emergency, it should be made by telephone to the appropriate hospice and followed by a written communication.

Children and young people can be referred and accepted for care at Rachel House or Robin House whilst their treatment is still active. The hospice team will support the child and family with symptom management and emotional support as a transition to palliative care becomes appropriate.

\* ACT (2009), *A guide to the development of Children's Palliative Care Services (Third Edition)*, ACT.

## Following acceptance to CHAS

CHAS understands that for many families the decision to accept that treatment is no longer working for their child is not easy. For that reason, the hospices create a 'home from home' environment for all children, young people and their families, following the child or young person's home routine during their stay at the hospice. This not only provides a sense of continuity and stability, but it also forms a trusting relationship between families and staff.

A key worker is assigned to each family, who keeps in regular contact with the family between short planned breaks. The key worker also arranges emergency admissions, helps direct the family to members of the team when problems or issues arise, and works with professionals in the community.

## Sustainable medical care

CHAS has a full time Medical Director with a specialist qualification in palliative care for children and young people.

The Medical Director leads a small team of part time doctors working in both hospices who are able to review and prescribe medications, and assess and manage children and young people with varying symptoms. This includes those requiring end of life care. NHS 24 currently provides some out-of-hours care to children and young people staying in the hospices for short planned breaks if an emergency arises.

The team of doctors also works closely with other medical practitioners involved in a child or young person's care outside the hospice. They ensure that a smooth transition of care is possible between home or hospital, and the hospice.



# Services offered by CHAS:

## 1. Short planned breaks

Caring for a child or young person with a life-limiting condition can place extreme demands on parents, physically and emotionally, as they often become the primary carers.

A key role of Rachel House and Robin House is to provide short planned breaks which enables the whole family to stay together in a 'home from home' environment. The multi-professional team provides complex care alongside play and activities for the ill child. Siblings are able to benefit from inclusion in activities and quality time with their parents, who in turn are able to talk, have time together and benefit from uninterrupted sleep.

The whole family can enjoy prepared meals, and the environment created by staff and volunteers is homely and relaxing. Families meet others in similar situations, and this is invaluable for parents and children alike.

Short planned breaks for a child or young person without their parents are also provided. For some young people, it allows an element of independence and gives parents time to catch up on things at home.

Short planned breaks allow families to plan ahead, and enables CHAS staff and volunteers to build relationships with all family members. This enables effective and ongoing support.



## 2. Outreach services/CHAS at Home

There are times when families require support outwith the hospices. CHAS offers a flexible outreach service encompassing:

- Home support provided by members of the CHAS at Home team includes:
  - nursing care of the ill child or young person;
  - support to siblings, including play and activities;
  - end of life care; and
  - helping young people to access activities in their local community.
- Social work advice and support and, when appropriate, advocacy
- Bereavement support

In all these situations, staff assess the needs of the child or young person and family to ensure the support offered is appropriate and complements any other provision.

## 3. Emergency admission

Emergency admissions to the hospices are arranged in times of special need and may be as a result of any of the following situations:

- A sudden change in a child or young person's condition requiring admission for symptom management
- At the end stages of life, coming in from home or hospital
- A period of parental or sibling illness
- Parents feeling overwhelmed by the enormity of the situation
- A breakdown in a locally provided home care package
- An assessment by other professionals of urgent family need.



## 4. End of life care

CHAS staff are very sensitive to the needs of the children, young people and their families during end of life care. Discussions and appropriate recording of individual needs and wishes in relation to end of life care will be planned with the child and family and shared, with their consent, with other professionals involved.

Children, young people and families can receive end of life advice and support from CHAS at any point following their acceptance for palliative care at Rachel House or Robin House.

Some families may wish to stay at the hospice during the last few days or weeks of their child's life. When this happens, CHAS staff will listen to the needs of the child and family and provide support, working closely with other professionals involved in hospital or community teams.

When a child or young person dies in Rachel House or Robin House they usually remain in their room for a few hours and, after discussions with their family, the child will be moved into the Rainbow Room. This is a special bereavement room for the child, away from the main hub of the hospice to allow greater privacy. It has a small lounge attached to allow parents to be near their child, plan for the funeral, and allow bereavement support to begin.

It is also possible for children and young people to be moved into the Rainbow Room if they die either at home or in hospital.

If a family wish to remain at home, CHAS staff are able to support them while working closely with their local children's community nurses, GPs and other members of the team.

## 5. Bereavement support

Families caring for children and young people with life-limiting conditions have to live with the knowledge of what is to come, and some describe bereavement as beginning when their child's diagnosis is made.

The death of a child has a significant impact emotionally and physically for parents and siblings, and a complex range of issues affect each family's response. CHAS provides bereavement support in a flexible way, responding to the needs of individual families. Led by the senior social workers in Rachel House and Robin House, support is provided by staff and specially trained volunteers and offers:

- One to one support for parents and siblings
- Group support for family members, adults and children
- Informal visits for family members to visit the hospices to talk with staff
- Annual remembering day services
- Telephone befriending service
- Short bereavement programmes aimed at increasing the resilience of children, and assisting parents in coping with their loss.

## 6. Information and advice

Parents, children and young people or professionals seeking information and advice from CHAS can access this at any time by telephone. A core team of nurses and support workers staff the hospices 24 hours a day. During the day this extends to the social workers, physiotherapists, chaplains, activities and medical teams.





## Further Information

Hopefully this has given you an insight into the care and support offered by CHAS. If you have any further questions or queries, please don't hesitate to get in touch with the Directors of Care at either Rachel House or Robin House:

- Rachel House in Kinross – 01577 865777
- Robin House in Balloch – 01389 722055

There is also further information on the CHAS website at [www.chas.org.uk](http://www.chas.org.uk)





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