



**Chestnut  
Tree House**

The children's hospice for Sussex

# A Guide



{ Children's  
Hospice Care }

## Who we are

Chestnut Tree House is the only children's hospice in Sussex and cares for local children and young people – from birth to 19 years of age – with progressive life-limiting and life-threatening illnesses such as Muscular Dystrophy, Spinal Muscular Atrophy, multiple disabilities, cancer and progressive genetic disorders. Sadly, children affected by these conditions will probably die before they reach adulthood. There are potentially 400 families with life-limited children in Sussex alone.

Completed in 2003, the hospice provides a 'home from home' environment with ten special bedrooms for children who come for overnight respite care, plus eight family rooms, a wet and dry play area, computer and music rooms, a multi sensory room and hydrotherapy pool. The house is set in wonderful gardens within an area of outstanding natural beauty.

### A helping hand

Caring for a sick child can raise all sorts of practical, physical and emotional issues, which affect not only the child, but their loved ones too. Chestnut Tree House aims to help tackle these issues,

by providing 'holistic' care for the whole family, offering practical and emotional support, expert advice and dedicated care.

Above all, Chestnut Tree House is a safe haven where families can have some quality time together, enjoying enriching experiences and the chance to live life to the full in a very special place.

### Relying on kindness

The hospice costs approximately £2 million per year to run. Families are not charged for their care and the hospice receives very little government funding so it relies almost entirely on the generosity, help and support of the people of Sussex.



## What we do

### Overnight respite care

We have six bedrooms where we provide care for our younger children – from newborns to 12-year olds. Each room is decorated to appeal to children and has a range of entertainment and special equipment.

Our Young Adults' Wing consists of four bedrooms and the 'Common Room', all designed to appeal to the young people we support. We understand that older children need their own space and facilities to help foster their own identity and independence.

We have eight family bedrooms with en-suite facilities, plus a fully adapted bathroom equipped for disabled use. Families have their own lounges and kitchenette, as well as the superb decked balcony overlooking the garden. A stay at Chestnut Tree House gives them the opportunity to rest and relax in the knowledge that our Care Team is looking after their child downstairs.

### Community care

Our Community Team is the first point of contact for families wanting to use Chestnut Tree House and

provides a vital link between families and the hospice.

The Community Team offer assessment, specialist advice, support, liaison and teaching. A team of specially trained staff visit families in their own homes to care for the sick child or young person. This enables parents to take a much-needed break – to pop out to the shops, go to the hairdressers, have a meal or a trip to the cinema. It also means that parents can spend time with brothers or sisters who often get forgotten and need time and attention from their parents.

The community staff not only provide respite care but organise fun activities for children, young people, brothers and sisters in the house and day trips to exciting places – from crafts and cooking to singing or just having a good time.

### End of life care

When a child or young person dies, families are offered the use of the bereavement suite, 'Stars'. There is a cool room where their child can remain for a period of time. Support is offered whilst planning a funeral and in saying their goodbyes.

# Who can use Chestnut Tree House?

Children with a wide range of conditions or illnesses could use the hospice. Usually, these are children defined as having life-limiting or life-threatening conditions or potentially life-threatening disabilities.

## What is a life-limiting condition?

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some conditions cause progressive deterioration resulting in the child or young person becoming increasingly dependent on their parents or carers.

### Group 1

Life threatening conditions for which curative treatment may be feasible but can fail, e.g. cancer and irreversible organ failure (children



in remission are not included), where access to palliative care services may be necessary when treatment fails. Children in long term remission or following successful curative treatment are not included. (Examples: cancer, irreversible organ failures of heart, liver, kidney.)

### Group 2

Conditions where premature death is possible, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. (Examples: cystic fibrosis, muscular dystrophy).

### Group 3

Conditions with severe disability leading to susceptibility to health complications and likelihood of premature death.

### Group 4

Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. (Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury.)

The Care Team includes GPs, nurses and care support workers, supported by a range of professional and administrative staff and volunteers. Support is provided in the form of respite care in the house or at home, together with telephone advice and support.

Our multi-disciplinary and multi-skilled approach recognises the individual physical, emotional, spiritual and social needs of each child and young person, and their families. The focus is to ensure that the children and young people at the hospice have the opportunities and experiences that they might otherwise not have had.



## We provide:

- Initial assessments of children on referral, to facilitate a seamless referral process.
- The provision of specialist advice about treatment, medication and medical conditions.
- Support for families, children, and young people following diagnosis and throughout the disease process.
- Nursing care, practical and emotional support in the family's home.
- Regular planned respite sessions at home.
- Access to emergency respite care in crisis situations where possible.
- Liaison with other professionals and referral to specialist services where required.
- Supporting and assisting families to ensure their views are heard.
- Teaching, supervision and support for parents, colleagues and other professionals.
- 24 hour support for children requiring care in the terminal stages of their illness in conjunction with other healthcare professionals.
- Bereavement support for families and carers.
- Referral to formal bereavement support if necessary.
- Chaplaincy and spiritual support.
- Remembrance services.

## Who can make a referral to Chestnut Tree House?

Anyone can refer a child or young person so long as it has been discussed with the families first. Families can also refer themselves

Permission is sought from the parent(s) or carer(s) to request medical information from their GP or paediatrician. A home visit from a member of the Community Team may then be arranged to discuss the referral further and establish the level of support required.

Referrals are discussed monthly with the Clinical Nurse Manager, Community Team Leader, Medical Advisor and GP. All families accepted are subject to an annual review.

We work closely with other professionals, agencies and services involved in providing child and

family care. Our codes of practice regarding confidentiality and Data Protection are the same as those for statutory sector services, and we have the same requirements for ensuring human resource management policies and procedures are in place for the safe recruitment of staff.

The services we provide are subject to the Care Standards Act 2000 and to close external scrutiny, inspection and regulation by the Healthcare Commission. Chestnut Tree House Children's Hospice has a clinical governance framework in place. We also work in partnership with other providers.

If you wish to discuss a referral or to receive more information about our services, please contact us.





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