

CHILDREN'S HOSPICE SOUTH WEST: LOCAL OFFER

1. WHAT DOES CHILDREN'S HOSPICE SOUTH WEST DO?

Our main purpose is to provide hospice care for children with life limiting/life threatening conditions and their families across the South West of England.

Our service is unique in that we offer care to both the child and also to their family. At Children's Hospice South West we understand that the whole family is affected when there is a life limited child within the household and so the whole family needs care and support. Families of children with life limiting/life threatening conditions tell us that they are often overwhelmed by: the challenge of caring for their children; the complexities of juggling numerous professionals, services and appointments; the difficulties of maintaining family life and employment; and a sense of isolation.

The most important message we need to get across to families who may need hospice care is that many of the families who use our service wish they had started to use the service sooner. Many families are fearful at the thought of a hospice, but when they arrive find it is not at all like they expected:

'Like everyone thinks, there'll just be an awful lot of very ill children and it would be quite a depressing, sad place and of course it was nothing like that - it was an amazing place and the children were all happy'

'You walk in and you get this sense of peace, I don't know how they do it. I don't know how the people that build these places make it, and it's got such a lovely atmosphere. I expected to see ill children and it isn't like that at all'

The children themselves, and their brothers and sisters, quickly find they feel completely at home:

'I think it's good because it is big, cosy and friendly'

'It feels like a second home to me, I've made a second family'

We hope the information provided here will help families who need hospice care feel more comfortable about using our service.

What do we offer?

Children's Hospice South West provides a range of services at all of our hospice locations:

- Planned hospice care: this is short break (respite) care for the whole family, (providing specialist care for the child and support for the rest of the family) which is pre booked in advance.
- Unplanned hospice care: Emergency and/or end of life care for the child and support for the family which is not pre booked in advance but arranged when the need arises.
- Access to medical care and advice at the hospice 24hrs/365 days a year.

- Ongoing contact with families by phone and e mail to provide advice and support by a named 'contact' from the Care Team, including some outreach support through occasional home visits.
- 24/7 telephone advice and support.
- Sibling service - a dedicated service established to meet the specific needs of brothers and sisters.
- Bereavement support for the whole family following the death of a child.

The services we provide are largely delivered within our hospices, however, we also offer some outreach support into the community.

How does hospice care help?

Hospice care helps by providing the family with:

- comfortable and family friendly accommodation in a beautiful setting;
- relief from the day to day responsibility of care;
- expert care for their sick child;
- support for the whole family, including siblings;
- chance to enjoy a whole range of fun and exciting activities and opportunities;
- friendship and companionship both from the Care Team and also the other children and families who use the service.

This means that families feel supported, refreshed and enabled to continue to care for their life limited child at home and the child's needs are assessed and reviewed by doctors and nurses who specialise in children's palliative care.

What surprises most children and families, who may be initially fearful and reluctant to use a hospice, is that our hospices are full of fun, life and laughter. When we ask children to write down the three words they would use to describe the hospice, the top word used is 'fun'. Families say they love the fact that their children are seen first and foremost as children and that so much effort is put into making sure they make the most of every day. Brothers and sisters get to join in with lots of fun activities at the hospice, enjoy an interesting array of visitors - such as circus performers; animals from local zoos; artists, bands and Forest Schools; and to join outings and day trips to lots of local attractions. Parents enjoy the rare luxury of taking it easy, catching up on sleep, being able to recharge their batteries.

'My brother goes there for respite care. He gets looked after by a nurse 24/7. My Mum and Dad don't have to look after him so they get to catch up on sleep and go out on their own. I get looked after too, by sibling workers. They take us out to places and do amazing things I could never do. It's the best place on earth'

'When I think of Charlton Farm my face blows up and I crack a giant smile. No place could make you feel so special and wanted and belonging. Without Charlton Farm my family would be stuck, no breaks and unable to do certain things. Charlton Farm has inspired me so much, growing up, knowing not to complain about not getting a new pair of shoes because people out there are fighting for their life. I would love to work in a place like this. Outstanding. You see things through a different light.'

2. WHAT AREA DOES CHILDREN'S HOSPICE SOUTH WEST COVER AND WHERE ARE OUR HOSPICES LOCATED?

Children's Hospice South West is a regional service and provides hospice care to children and families who live in the South West of England. This includes Cornwall and the Isles of Scilly; Devon, Plymouth and Torbay; Somerset; North Somerset; Bristol; Bath and North East Somerset; South Gloucestershire and West Wiltshire.

Children's Hospice South West has three hospices:

- **Charlton Farm** located in Wraxall, North Somerset;
- **Little Bridge House** located near Barnstaple, North Devon;
- **Little Harbour** located near St. Austell, Cornwall.

Each of our hospices provide the same range of services, however Little Bridge House and Charlton Farm are 8 bedded hospices and Little Harbour is a slightly smaller facility with 6 beds

3. WHO DOES CHILDREN'S HOSPICE SOUTH WEST PROVIDE FOR?

Children's Hospice South West is set up specifically to meet the needs of children with life limiting or life threatening conditions who are not expected to live into adulthood.

This means that not all children with disabilities will be eligible for children's hospice care, but all children with a life limiting or life threatening condition who are not expected to live into adulthood will be eligible - whatever their diagnosis. We care for children with a wide range of different conditions and with both physical and learning disabilities and our hospices are staffed and equipped to care for children with very complex and/or continuing health care needs.

Children's Hospice South West is able to care for children ages 0 - 21 years, although at the age of 18, (if a young person is expected to survive beyond the age of 21 years) we work with the young person, their family, and other agencies to put in place transition arrangements to other services which will be more suitable for a young adult by the age of 21.

4. HOW CAN I START USING CHILDREN'S HOSPICE SOUTH WEST?

Referrals to Children's Hospice South West can be made by anyone: professionals who work with the family; the family themselves; or relatives and friends of the family. We

do ask that the family are aware that the referral is being made and are in agreement with this as we will make direct contact with the family once a referral is received.

There are no waiting lists for our service. At the end of the referral process, if a child is suitable for hospice care, they can start using our service right away. Two or three members of the Care Team will be allocated to be their 'contacts' and will start the process of getting to know the child and family and helping them make the most of our service. Due to the fact that families book short breaks in advance, it may not be possible for a child and their family to come and stay immediately, but a day visit can usually be arranged.

Children's Hospice South West makes no charge to the children and families who use our service. At the moment children's hospice care is not identified as a service which can be funded by your personal budget if you have one.

5. HOW ARE DECISIONS MADE ABOUT WHO CAN USE CHILDREN'S HOSPICE SOUTH WEST?

As soon as we receive a referral, we write to the family and ask for permission to proceed with the referral. If the family consent to this, we ask them to provide us with details of both a GP and a Consultant Paediatrician involved in the care of their child who we can contact to assess the suitability of referral for hospice care. It is these doctors, who already know your child and are familiar with their condition, who help us understand whether your child is not expected to survive into adulthood.

Once we have received information from the child's GP and Consultant Paediatrician, our referral committee, (which is made up of the Medical Director and Head of Care at each hospice and other experienced hospice nursing and medical staff) is able to assess the suitability of the referral. This is not always an immediately straightforward decision and in some cases we advise a home visit so that an experienced member of our referral committee can come and review your child at home.

We write to the family and the referrer to explain the referral decision. If the family is not happy with the decision, they can request a review of this decision and, in these situations, the referral is reviewed by the referral committee at one of the other CHSW hospices.

There are occasions when a child is not deemed suitable for hospice care, but subsequently their health deteriorates and, in these circumstances, we are able to consider a re-referral for a child at a later date.

6. HOW DOES CHILDREN'S HOSPICE SOUTH WEST COMMUNICATE WITH SERVICE USERS AND INVOLVE THEM IN DECISION MAKING/PLANNING?

We have a range of information leaflets available for children and families. Some of these are sent to the family at home, and others are available, (like Family Information Folders) in the family accommodation at the hospice. Some leaflets explain the service we offer in general, others cover a specific topic, such as explaining to families the information we hold about them, what it is used for and how it is stored or providing information about the way we manage a child's medicines at the hospice.

We communicate regularly with families who use our hospices. Each child and family is allocated two or three members of the Care Team who act as 'contacts' for the family. These 'contacts' keep in touch on a regular basis with children and families by phone, e mail, and through home visits. Their role is to get to know each child and family very well and help them make the most of our service by supporting them in booking stays at the hospice and making sure that we respond to their particular requests and needs when staying at our hospices.

We always write to families to confirm any booked visit with them and then telephone them a day or two before the visit to confirm details and special requests regarding their visit. On a child's first visit to one of our hospices we complete a comprehensive care plan with the help of the child and their family. Our aim is to replicate the care each child receives at home and to follow their usual routine of care and respond to each child's choices and preferences. This care plan is then reviewed and updated with the child and family at each subsequent visit so that they are closely involved in the plan of care for their child and all decisions which need to be made.

These extracts from the Care Quality Commission inspection reports of two of our hospices illustrates the extent to which children and families are involved in care planning and decision making:

CQC report (Dec 2013) for Charlton Farm:

'We saw that care plans were person centred and were signed by the parents and where possible the child or young person'.

CQC report (Jan 2014) for Little Harbour:

'We were provided with examples of how parents were consulted about the treatment and care of their child. Records we looked at showed there was also day to day contact with parents to inform and update them about their children's treatment and care'.

'We were provided with examples of when young people had been consulted regarding their wishes about specific aspects of their care and noted their views, preferences and choices had been respected whenever possible'.

Once a year we review each child and family who uses our service. The 'contacts' for the family ask for their views and thoughts so that they can be contributed to the

review and we also write to the child's GP and Consultant Paediatrician for up to date information about each child. We write to each family following this review and let them know the outcome of the review in terms of their use of our service. For some children/young people, for example those who are now over the age of 18 or those where their health is improving, we may need to suggest a reduction in service use and moving towards deferral from the service if children's hospice care is no longer felt suitable. In these circumstances staff at the hospice will assist families in identifying alternative provision and support.

We are very interested in how children and families feel about the service we provide and find out informally through conversations we hold on a daily basis, but also through feedback forms, user satisfaction surveys, and user groups. We give each child and family who uses our service a leaflet entitled: 'We want to know how we are doing' and this explains that we are very keen to understand how they feel about our service, both good and bad, and how we collect their feedback and views and encouraging them to take part. This leaflet also gives clear details about how to make a complaint if the child or family wish to.

We always endeavour to communicate with the children who use our service in their preferred way, some of our Care Team are able to sign and we also make use of specialist technology, such as iPad's and iPod's. Where children have very specialised communication systems we may have to arrange training for our staff, but are always happy to work with schools and Speech and Language Therapists to assist us with this.

We have access to interpreters for those children and families for whom their first language is not English.

7. ARE CHILDREN'S HOSPICE SOUTH WEST'S SERVICES FULLY ACCESSIBLE?

Our hospices have been designed to: feel warm and welcoming; offer a range of exciting opportunities and facilities; include clinical equipment and facilities to meet the needs of children with complex needs, including technology-dependent children; and to be fully accessible

At each of our hospices we have:

- A range of brightly decorated single bedrooms for the sick children.
- Comfortable and spacious family accommodation for other family members, accessible by lift if needed at two of our hospices, or with some family accommodation accessible on the ground floor at the third hospice.
- Play and recreational needs are catered for with a: Messy Play Room for art and craft activities; wide variety of play and recreational equipment suitable for all ages; family activities room, including state of the art computer facilities; soft play area; and outdoor play areas in a large garden.
- Sensory provision is made for those with sensory impairment, including: a multi-sensory room; sensory garden; and extensive range of sensory equipment.

- Music therapy is offered at each of our hospices by a qualified music therapist, but there is also a wide range of musical instruments available and the Care Team offer music and singing activities as part of the range of opportunities for the children to enjoy.
- A Jacuzzi or spa pool is available for both fun water activities for the whole family, but also for the therapeutic benefits for the children.
- Provision and space has been made for peace, prayer and spiritual reflection in a multi faith room and a suite of rooms is available where families, and their friends and relatives, can be supported in the immediate period following their child's death.

Comprehensive provision is also made in our children's hospices to meet the health and care needs of the children/young people with disabilities:

- All children's accommodation/facilities on fully accessible ground floor.
- Low windows and under floor heating in all children's areas.
- Intercoms in all children's bedrooms to allow close monitoring of their condition.
- Emergency call bells in all areas of the house,
- Resuscitation equipment to fully meet the basic life support needs of infants, children and adults in an emergency.
- Wide range of moving and handling equipment, including built in hoists.
- Assisted bathroom and wide range of bathing aids.
- Separate pharmacy and medicine cabinets in children's rooms.
- A range of electric beds, cots and specialist mattresses.
- Access to oxygen via oxygen concentrators, oxygen cylinders, and for named children, liquid oxygen
- Access to essential clinical equipment, such as suction machines; syringe drivers; oxygen saturation monitors, blood glucose monitors and others.

Children are cared for on a one to one care ratio, this means that the activities that they take part in can be tailored to their personal preferences and choices and they can be supported to take part in any activities they wish.

8. WHAT TRAINING DO CHILDREN'S HOSPICE SOUTH WEST STAFF HAVE IN SUPPORTING CHILDREN AND YOUNG PEOPLE WITH SPECIAL EDUCATIONAL NEEDS AND DISABILITIES?

The services we provide are delivered by a multi-disciplinary team which includes children's nurses, doctors, therapists, social workers, chaplains, carers, teachers and play staff. This means that CHSW is well placed to meet both the specific physical and clinical needs of the children, (including their physical disability; learning difficulties and sensory impairment) but also the wider holistic needs of both the child and their family, including their social, emotional, spiritual and play and educational needs.

All new staff are provided with a one month induction programme to equip them with the knowledge and skills required to deliver children's hospice care and they work a 6 month probationary period during which their suitability for their role is determined. After this, all care staff receive mandatory training on a yearly basis in: safeguarding children and vulnerable adults; moving and handling; fire safety; resuscitation; and infection control.

The Care Teams at our hospices are also supported by Practice Educators who deliver an ongoing programme of training and development throughout the year, with sessions on a wide range of relevant topics being delivered at monthly Care Team meetings and during the annual Training and Review week each January.

9. WHO CAN I CONTACT FOR FURTHER INFORMATION ABOUT CHILDREN'S HOSPICE SOUTH WEST?

Children's Hospice South West welcomes enquiries. If you wish to discuss referring a child for hospice care, please phone and speak with the Head of Care or a member of the Care Management Team at the hospice local to you.

Charlton Farm, (North Somerset) Head of Care: **Nicola Orchard** - 01275 866611
Little Bridge House, (North Devon) Head of Care: **Tracy Freame** - 01271 321999
Little Harbour, (St. Austell) Head of Care: **Tamsin Lewis** - 01726 65555.

During the referral process, your first point of contact will be the Head of Care as above. Once accepted and using one of our hospices, your first point of contact will either be your named 'contacts' on the Care Team or the Head of Care. If you are worried about something, there are a number of people who can help. If you have issues regarding the service, you can discuss this with the Head of Care. If you are worried about your child's health or symptoms, then you can discuss this with the Medical Director or one of the children's hospice doctors. For support with other matters you can speak with your 'contacts', if they are unable to help they will be able to direct you to someone else who can.