

## Children's Hospice South West

# Statement of Purpose



# Part 1

## Statement of purpose, Health and Social Care Act 2008, Regulation 12, schedule 3

The provider's business contact details, including address for service of notices and other documents, in accordance with Sections 93 and 94 of the Health and Social Care Act 2008

1. Provider's name and legal status	
Full name	Children's Hospice South West
CQC provider ID	1-101728853
Legal status	Organisation

2. Providers address, including for service of notices and other documents	
Business address	Little Bridge House
Town/city	Redlands Road, Fremington
County	Barnstaple, North Devon
Post code	EX31 2PZ
Business telephone (care)	01271 321999
E-mail address	Claire.kilbey@chsw.org.uk

CQC service user bands	
The children and young people that use our hospices have:	
Physical disabilities	✓
Sensory Impairment	✓
Learning difficulties or autistic disorders	✓
Children and young people aged	0 – 21 years

The CQC service type provided at all our locations	
Hospice Services	✓
Regulated activities at all our locations	
Treatment of disease, disorder or injury	✓



## Part 2

**Our Purpose** is to make the most of short and precious lives and to put babies, children, young people and their families at the centre of all we do.

CHSW is a regional service and provides care to children and families in Cornwall and the Isles of Scilly; Devon, Plymouth and Torbay; Somerset; North Somerset; Bristol; Bath and North East Somerset; South Gloucestershire and West Wiltshire.

We operate three hospices; Little Bridge House in North Devon, Charlton Farm in North Somerset and Little Harbour in mid Cornwall. These services are offered on referral from the NHS, Social Services, direct family referral and other organisations and individuals.

CHSW cares for children and young people of all ages, from newborns to teenagers and can continue to care for some very poorly young people who are in the end stages of their life. Most of our children and families will receive services from us for up to 10 years, although some journeys are sadly shorter.

We are dedicated to making the most of short and precious lives through the provision of the best possible hospice care for children and young people with life-limiting conditions. The care offered at each of our three hospices is not just about medical and nursing support for sick children but also enriching lives of the children and their whole family.

**Our Ethos** is to ensure that everyone (Trustees, staff and volunteers) places children, young people and their families at the centre of the organisation.

In order to achieve this, everyone will be expected to promote a strong, caring, community environment characterised by a culture of sensitivity, trust, consideration and respect for others.

**Our Vision** is to provide high quality care services to every child and young person on the South West who may not live to their 18<sup>th</sup> birthday.

We are truly committed to looking at how we can continue to meet the needs of our children and families, through the enhancement of our services, while ensuring they remain sustainable for the future. Our vision is to be fit for the future by continuing to:

- Strive to provide the highest level of care, clinical expertise and enrichment opportunities for children who are expected to die in childhood.
- Continue to provide holistic care that meets the needs of all family members.
- Maximise our services to as many families as possible in ways they want and in partnership with others.
- Promoting the needs of children with life-limiting conditions both regionally and nationally.
- Share our expertise widely through the provision of education.

## Part 3



### Our Care and Services

Our service is provided by our multi-disciplinary Care Team, who have been specially selected to help enrich the lives of all the children and young people we care for. We are truly committed to looking at how we can continue to meet the needs of our children, young people and their families, through the enhancement of our services, while ensuring they remain sustainable for the future. At CHSW, we believe in 'Time to Care' and as a standard provide every child or young person with one-to-one care; giving families confidence to take a break from care duties and concentrate on being a family. We have several children or young people who require 2 staff (and a small number of children or young people benefit from 3 Care Team members) allocated to them to ensure their needs are met safely and effectively. These children and young people may have behaviour challenges, require ventilation or susceptible to a high number of seizures.

CHSW Care Team comprises of registered nurses, doctors, carers, psychologists and music therapists; supported by a wider team of administrators, kitchen, housekeeping and facilities personnel. All staff are suitably qualified and are recruited using "safer recruitment" guidelines. Staff undertake a comprehensive induction programme. Core skills, continuous professional development and advanced training needs are met through internal and external training and education resources. Support and supervision to promote health and wellbeing and prevent burn out are provided to cover different needs.

We are committed to ensuring that the voice of the child is heard and ensure that children are involved in as much of the decision making regarding their life, personal care and treatment as they wish. We develop personalised care plans with the child where possible, and their family. We work in partnership with families and ensure time is given to discuss treatment and care; provided with information and choices; and all care provided should take into account their preferences and wishes.

CHSW recognises it is part of a wider network of services providing care and support to children and families. CHSW is committed to working in partnership with other professionals, services and agencies, whether statutory or voluntary, involved in the care of children in order to optimise the support which can be. CHSW aims to support the development of children's palliative care knowledge and skills in the wider community through the provision of education and participation in relevant networks and forums. This means that children and families in the South West benefit by receiving safe and coordinated care, treatment and support from organisations who are working collaboratively and who are supporting each other in the development of specialist knowledge and skills to enhance the care of children and families.

## Our Hospice Bases

Our three purpose-built hospice bases are something we are really proud of and have been specially designed to meet the needs of the children and families.



### Registered Manager's Details

<b>Name of Hospice</b> <b>Location number 1-118646474</b>	Little Bridge House
<b>Address</b>	Redlands Road, Fremington, Barnstaple, North Devon
<b>Postcode</b>	EX31 2PZ
<b>Telephone (care)</b>	01271 321999
<b>E-mail</b>	Lisa.kliem@chsw.org.uk
<b>Registered Manager ID</b>	CON1-20395180795



### Registered Manager's Details

<b>Name of Hospice</b> <b>Location number 1-118646507</b>	Charlton Farm
<b>Address</b>	Charlton Drive, Wraxall, North Somerset
<b>Postcode</b>	BS48 1PE
<b>Telephone (care)</b>	01275 866611
<b>E-mail</b>	Karen.greaves@chsw.org.uk
<b>Registered Manager ID</b>	CON1-11872107794



### Registered Manager’s Details

<b>Name of Hospice</b>	Little Harbour
<b>Location number 1-341388066</b>	
<b>Address</b>	Porthpean Road, Porthpean, St. Austell, Cornwall
<b>Postcode</b>	PL26 6AZ
<b>Telephone (care)</b>	01726 871811
<b>E-mail</b>	Sam.hurse@chsw.org.uk
<b>Registered Manager ID</b>	CON1-12408265351

### All our hospice bases provide:

- Safe, supportive and welcoming environment for the whole family
- Sensory Rooms
- Music Therapy
- Hydrotherapy Pool
- Messy Play and Games Room
- Sensory Gardens
- Specialist Outdoor Play Equipment
- Indoor Soft Play
- Psychology Services

Comprehensive provision has been made to meet the health and care needs of the referred child:

- All children’s accommodation/facilities are on the 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 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.
- Medicine cabinets in children's rooms for named child medicine.
- Stock medications and oxygen therapy.
- A range of electric beds, cots and specialist pressure relieving mattresses.
- Access to essential medical devices and equipment, such as suction machines; syringe drivers; oxygen saturation monitors, feeding pumps and blood glucose monitors.

## Types of care

**Hospice stay** - CHSW offers a supportive and relaxed environment where children and young people living with life-limiting conditions and their families can take a short break away from home to build resilience and recharge their batteries or for a specific clinical or welfare reason. Many of our children and young people come and stay with family members, usually parents and siblings but sometimes the referred child or young person visit on their own to allow the rest of the family time together.

Many of the children and young people who use our service are medically extremely complex (for example, including: tracheostomy ventilated; complex seizures and complex feeding regimes). It is paramount that both their nursing and medical needs are met to a meticulously high standard and that they are supported, in a less clinical environment, to have fun and make the most of the hospice facilities and opportunities. These stays give our team moments to build supportive and trusting relationships with the family.

It is often during these hospice stays that opportunities arise for key conversations; for example, sitting down with a family over lunch or in the garden can often result in conversations that are much more challenging.

**Step-down stays from hospital** - Where a child or young person has had a significant hospital or if they have never been home before, or there has been a significant re-orientation of direction of care), then we do our best to accommodate step down stays for families to regain their confidence in providing care before returning home.

**Day care** - This is either used to introduce children, young people and their families to our services or to support children, young people and their families with discrete needs, such as specialist equipment for bathing, access to specialist services, for example, hydrotherapy and Music Therapy, on an outpatient basis for specific care such as symptom management, administration of intravenous medication, assessment of care needs or simply for social support.

**Medical care** - From a medical perspective, our team are increasingly involved in the care of children and young people on our caseload, wherever their care is being delivered (such as in reach to hospital, advice regarding symptom control during hospital stays, attendance at key care planning discussions and leadership of advance care planning discussions when required). We are also increasingly contacted by local Neonatal and Paediatric Teams from around the region for advice about symptom management and advance care planning for antenatal referrals, babies, children and young people. For children and young people known to us who are dying in hospital or at home (and who do not wish to transfer to the hospice at that time), we provide medical advice to the hospital or Community Teams.

**Symptom control** - These admissions are for overnight stays and day visits, to support specialist medical and nursing provision, to help manage a child's symptoms. Frequently, these admissions support acute hospital discharge or facilitate admission avoidance. This alleviates pressure on acute services and allows the child or young person and family to be cared for in an out of hospital environment. Our Medical Team liaise with hospital and community specialist teams as required, to ensure care remains as 'joined up' as possible.

**Keeping in touch** - In between hospice stays, our Care Teams are in frequent contact with children and families, by e-mail, telephone, virtually and visits to the home.

**In-reach** - Our Care Teams work closely with acute teams and support children and families during their stays in hospital.

**Home visits** - Our staff may undertake a visit to the child's home for a number of reasons; to keep in touch to assess how the child and family are getting on, prior to a hospice stay to update a care plan, familiarise themselves with a new piece of equipment or check the child has all the right medications for their stay. CHSW care staff may provide direct care in the child's home for a couple of hours or a full shift; this might be just the CHSW team or with a partner provider. For some children, care at end-of-life care can be provided in their own home (working with partner providers).

**End of life care** - For children and young people living with life-limiting conditions, there are important decisions to be made along the way. Our teams work closely with Hospital Teams, participate in multi-disciplinary meetings and meet individually with families to support key discussions, including symptom planning and advance care planning. Families known to us (including those referred urgently) can stay at the hospice for the duration of their child's end of life care. They may come to us from home or from an acute setting, either via their own transport or via a medical transport team if they are less stable or receiving ongoing intensive treatment (for example, ventilation) at the point of transfer. The length of end of life provision varies hugely, from a few hours to several weeks. Our teams work holistically with the child or young person and family during that time to make the most of memory making opportunities, to ensure the child or young person remains comfortable and to meet the needs of the whole family.

**Bereavement care** - After a child or young person has died, we can, if the family wish, care for the child or young person and the family in the hospice for up to 7 days. We call this Starborn care, describing the special room where this care is provided. This can be for families where the child or young person has died in the hospice and also for families known to us, when their child has died elsewhere. During these stays, our team support the family in registering the death and arranging a funeral as well as support for parents and siblings. Time in Starborn for families and siblings enables us to support memory making and starting their bereavement journey.

**Sibling support** - Siblings also have a long and sometimes difficult journey alongside their brother or sister. We provide dedicated support to siblings who may feel isolated, scared or confused. We provide the opportunity for them to meet other siblings and seek support through play, sharing some memorable times and having some fun too, through a range of special activities.