

# Will you be there?

What Julia's House offers is unlike any traditional hospice and every part of our service is completely free to our families. However, because our model of care is so flexible and not tied to a location or timetable, it attracts less NHS funding. In a world of shrinking social care budgets, frequent respite is seen as a lower priority.

The average adult hospice receives 30% government funding, the average children's hospice 22%. Julia's House receives just 5%, making it one of the worse-funded hospices in the UK.

Public donation and fundraising accounts for 95% of our income. This extraordinary care only happens because of the kindness and generosity of the community we serve.

Last year it cost £4.3million to provide our care and support to 166 families registered across Dorset and Wiltshire. More than 80% of this was bespoke regular respite care and 64% of these sessions were in family homes or out and about in the local community, taking a child swimming or to Brownies, for instance.

Latest figures show that 76% of the children receiving community care from Julia's House need two care team members, making them among the most fragile children we support. And this demand is growing.

We want to be there for every parent relying on us for this vital lifeline of community care, but we need your help.

**Support a child in Dorset or Wiltshire with all their community respite needs for a year:**

**£5,300** Provides a Dorset youngster like Adam, with all the community respite sessions they need to be able to take part in clubs like Scouts for a whole year. To be able to make friends, have fun, just like any other 12 year old boy.

**£7,200** Will provide a year's worth of community respite sessions for a Wiltshire child like Carmela, who uses the time to go horseriding with her carers. Sessions full of laughter that also help her failing body to stay stronger through exercise.

**Support two families for a year:**

**£12,500** Will provide two families with all their home based respite for a year, bringing care they can trust, play and complementary therapies to their door, whenever they need it. The freedom of being able to take a break from reality, even for a short time.

**Support our whole community respite service for a month:**

**£25,000** Funds 100 community respite sessions in Wiltshire, enabling our nurses, carers and therapists to support families where ever and whenever they need them for a whole month.

**£30,500** Funds 122 community respite sessions in Dorset, providing exhausted families with all the flexible, bespoke care they need at home or out and about, for a whole month.

**Be there for our families month in, month out:**

**£1,000** a year (£84 a month via direct debit) funds an hour of community respite for a family every month for a whole year. Your regular donation means regular comfort and care, care that will mean the world to a family whose world has been turned upside down.



# Julia's House isn't just a place... it's wherever parents need us

**Julia's House cares for babies, children and teenagers with life-shortening or life-threatening conditions and provides support for the whole family. No parent expects to live longer than their child, but for many of the families we support, this is the reality. Julia's House exists for these families.**

Each life-limited child is unique; no two have the same combination of circumstances. They suffer from a broad spectrum of conditions, each carrying with it the threat of premature death.

Some children may only need our help short-term until the life-threatening nature of their condition improves. Others have long-term or degenerative illnesses and may be with us for many years. Children may also be referred in the final stages of life, such as those with terminal cancer, and need intensive round-the-clock care in the last few weeks or days.

Many parents can find themselves giving up careers to become carers, swapping financial security for

fear about the future and ultimately becoming isolated and withdrawn as they are slowly consumed by the daily routine of keeping their child safe and alive.

The stress and exhaustion – the fear of not knowing what is going to happen to your child – is unimaginable. Without support, these families can quickly reach breaking point.

"People don't realise how intense it is having a child with a complex health condition. We don't have those little gaps that exist in normal families, like night times and when children amuse themselves, we just have a continual cycle of care."

*Louise, mum to Ella.*

"No-one will babysit once I have told them: 'If Jack has a seizure you need to call an ambulance immediately because if it's really severe he could die'. Not surprisingly people are too scared and back off, they don't want the responsibility"

**Hayley**  
Mum to Jack



# How does Julia's House help?

Every family's needs are different but the one need they all have in common is flexibility. When your life is tied to hospital appointments and care routines the last thing you want from a service that's meant to help you is rigidity.

That's why our families get an allocation of care hours – 200 a year – not a fixed timetable of sessions. Families are free to 'spend' them in any way they want – a few hours every week, regular days, now and again or perhaps a longer chunk of time once a fortnight or every month.

Only by offering a bespoke service can we expect to make a difference. By giving families choice we are providing a service that truly works for them.

We are reaching more families than ever as parents and healthcare professionals are becoming aware of just what we can offer, of the empowering, life-changing difference the right support can make in dark times when everything can feel like it is spiralling out of control.

This is reflected in the number of children being referred to us – it is on the rise across both counties, with 41 new children being accepted for care last

year. By 2022 we anticipate to be supporting 235 families – a 42% increase – reaching around 1000 beneficiaries.

One of the common misconceptions about Julia's House is that our service is confined to our hospice buildings, but we are not a hospital or a residential care centre.

More than 60% of the care we provide happens outside our hospices, in family homes and in the community. Mornings, daytimes, evenings, year-round – our care team is out and about in local neighbourhoods across both counties.

Last year Julia's House provided more than 2,600 of these community respite sessions – an average of 50 every week. This included nearly 1,200 sessions in Wiltshire, an increase of 65%.

Our care sessions happen at Scouts, Brownies, swimming, in the park, in the countryside, at the cinema, in the evenings while mum and dad go out, in the afternoon so a mum can get to a sibling's school play, at tea time so a family can enjoy a worry-free meal together. Anytime, anywhere.

## New Challenges

Advances in science mean that more children with life-limiting, complex medical conditions are being born and surviving longer. Nearly one in three of the children supported by Julia's House need two care team members to be present during their community sessions.

Only by providing this level of support and experience can families gain the confidence to leave their child and take a break.

"I was so glad that Bruce's Julia's House carers were with him when he had his first seizure. If I had been at home on my own I would have been very frightened. We can't just leave Bruce in

anybody's care. Scott and I need the confidence of knowing the person caring for Bruce will be able to handle a potentially scary situation."  
*Claire, mum to Bruce.*

Some children need two carers, some a nurse and a carer and for the most vulnerable children, two nurses. Only an experienced paediatric nurse has the expertise to care for a child on a ventilator, administer complicated medication, or differentiate between a mild clinical episode and complex seizure.

Even where parents have family and friends who are willing to help out, most don't feel able once



"Once a month we go somewhere as a family but William's nurse and carer come along too. That way we can enjoy a lovely, relaxing day together, knowing there are extra pairs of hands to help care for William"

**Tania**  
William's mum

they realise the enormity of the task. This is not babysitting, it's life support.

These more fragile children need intensive care and constant monitoring. Life-threatening situations can – and do – happen without warning.

Many of these children cannot travel, or if they do, they need two people travelling with them to keep them safe. Children can stop breathing or have a seizure on even the shortest journey.

For these families, care that comes to your doorstep, your community, isn't a luxury, it's a necessity and a critical part of their care package.

Julia's House is committed to constantly evolving its service so that, despite the logistical challenges of providing clinical care in any location and on demand, no family misses out.

Imagine the reassurance of having specialist care come to you, no matter where you live, no matter where you want it, even in the most remote rural communities – and not just that, an entire family support package too. That's what we do. Our families are in every corner of Dorset and Wiltshire and so are our hospices.

**Care without boundaries: care that's there, wherever there is.**