

Our Impact Year ending 30 April 2023



About us

We support children with cancer and life-challenging conditions, and their families, helping them to cope more easily whatever the outcome. Working across London, Surrey and Sussex, we partner with ten local hospitals who refer families to us following their child's diagnosis.

Why families need our support

150 children are diagnosed with cancer in England monthly, with around 10 of these in London, Surrey and Sussex*. A further 9000 children are diagnosed with a life-challenging condition (eg. congenital, neurological, respiratory) in England,** resulting in hundreds more families in our geographical catchment area learning that their child is seriously ill.

The impact of a diagnosis of cancer or a life-challenging condition is devastating and wide-ranging for children, young people and their families and carers.

Whilst the sick child does receive appropriate medical care and treatments, their wider needs – and those of their family - are often neglected.

An NHS in crisis

is resulting in many families struggling to access appropriate support, *"the NHS is a minefield"*, raising issues around long waiting lists and lack of mental health therapies.

80%

of parents said their child experienced a moderate to severe impact on their emotional and mental wellbeing, participation in social activities and schooling.

94%

of parents said their mental wellbeing is negatively impacted, and wanted emotional support, with common feelings being 'terrified', 'stressed', 'helpless' and 'alone'.

*CRUK

** University of York 2020

How childhood illness affects mental health



We felt lost and lonely. Our life, as we'd planned it, had been stolen from us.



We're utterly heartbroken... A life ahead wondering what could have been, a life I didn't choose and a life that I don't want.



We're devastated, overwhelmed with grief, frightened, frustrated. Everything's a battle.



Our son felt sad and alone...we've been plucked out of our lives and put in this alien world.

Research suggests that helping families to cope with these stressful experiences should be a priority during treatment yet, strained for time and resources, support provided on the NHS does not meet the needs of the whole family, or is not easily available at the right time. Our NHS hospital partners benefit from our presence too.



Momentum Family Support Workers help enhance the level of support available for families... freeing up nursing staff to concentrate on clinical duties.

The paediatric team are so grateful for this additional support which has greatly enhanced the care experience for children."

Louise, CEO, Royal Surrey NHS Foundation Trust

Cost of living crisis

In October we asked families with children undergoing treatment to tell us about the impact of the cost of living crisis. Whilst like many of us they were already seeing large increases in monthly expenditure, they reported further that vital expenses like travel costs to hospital, and food and parking whilst there, exacerbated the situation. We also saw a noticeable decline in emotional and mental wellbeing across the board.

65% of parents reported a significant or severe impact on their emotional and mental wellbeing.



I've had to go back to work part time...which means leaving Lily in hospital by herself.

Family life

When your child is seriously ill and your new 'normal' involves long hospital stays, isolation and tough treatment, little treats and being able to get away to exhale can make all the difference....

100% of parents cited being able to afford any family treats will be impacted by cost of living.



We are having to take overtime shifts at work which is cutting into our family time and we're having to sacrifice trips and holidays desperately needed as we just don't have the money.



We are struggling hugely, so not putting any heating on at all at the moment which is horrible as we're home pretty much 24/7.

How we supported children and their families

Family Support Workers

From the moment a family is referred to us from one of our local hospital partners, they are allocated a Family Support Worker who assesses their individual needs in order to offer personally tailored emotional and practical support, both in hospital and at home, when it's needed most.



1500

Children, siblings and parents

300

Families whose child is undergoing treatment

140

bereaved families



I didn't realise the impact Momentum would have on our journey and my ability to cope. There are still moments of sheer disbelief and shock, but they are always there to give us support and keep us strong.



With friends and family, you sometimes need to filter what you're saying as you don't want to shock or upset them, but I feel like I can just open the floodgates and tell my Family Support Worker everything. She helps me feel hopeful and strong; like I can do this.



She connected immediately with C, with her huge smile and words of support. It was like a ray of sunshine emerging from behind the dark cloud.

Hospital partnerships

We are unique in providing support to families when their child is in hospital and also back home. We have partnerships with 10 local NHS hospitals who refer families to us, and our Family Support Workers spend time every week on their children's wards making a positive difference:

- **East Surrey Hospital (Redhill)**
- **Epsom Hospital**
- **Kingston Hospital**
- **Royal Marsden Hospital (Sutton)**
- **Royal Alexandra Children's Hospital (Brighton)**
- **Royal Surrey County Hospital (Guildford)**
- **St. George's Hospital (London)**
- **St. Peter's Hospital (Chertsey)**
- **St. Richard's Hospital (Chichester)**
- **Worthing Hospital**

We also improve the hospital experience, through arranging entertainment and massage therapy, and transforming hospital spaces with child-friendly designs.



Sky's story

Sky, was diagnosed with a brain tumour at 16-months-old. Her tumour had spread within the brain and she quickly underwent a huge operation at St George's Hospital, Tooting, to remove as much as possible. The surgery was frightening enough but when she then developed meningitis and sepsis, her family found themselves in the middle of a very dark and scary time.



Mum, Emily, says, "Sky spent a long time in intensive care after the operation. Momentum came to see us every few days, which was a lifeline to us at what was the worst time of our lives."

Looking back, being able to talk to someone about what was happening and how we were feeling really helped us process the situation.

Following multiple tests post surgery, her tumour was diagnosed as a Medulloblastoma (MBEN), requiring a 37-week-course of chemotherapy, some of which was given directly into her brain.

"Sky has benefitted hugely from regular Family Support Worker visits and the charity have given her some magical experiences too, such as meeting a real life 'Elsa', which she loved.

"Having one person assigned to you gives you a sense of consistency and allows you to build a relationship. They've been with us through all the ups and downs especially as you can feel like you're in a very lonely environment."



I still feel a huge sense of relief when our Momentum Family Support Worker walks through the door.

Respite Services

Our three holiday homes and Thames riverboat give families the chance to spend precious time together away from the stresses of hospital visits and treatment. This year, we've also introduced Overnight Stays on our riverboat, which have proved extremely popular with children and parents alike!

69 boat trips
benefitting
320 individuals

172
respite holidays
benefitting
744 individuals

30
Volunteer
skippers/deckhands
helping to run
boat trips

“It was great for F to have such a special day out on the boat with her sisters after all the intense treatment and the surgery she has been through over the past months; it really was her first proper family day out for many months.

“After almost a year of intensive treatment with long hospital stays and painful side effects, we could finally relax a bit and enjoy family time. V's first words when we got there were 'nurses will not find us here!' Having endured weekly blood tests, it meant so much for him to be able to take a break.

“The respite break, away from hospitals and treatment, helped us all reconnect – the siblings could just be 'normal' children together and my husband and I recharged our batteries which was invaluable.

100%
of families report that a
respite break improved
their mental wellbeing
and their ability to cope,
and helped them to
create memories

Mental health therapies

When a child is diagnosed, they can often struggle to deal with the emotional and physical changes they suddenly face, causing a decline in their mental wellbeing. Equally, sibling and parent mental health can be severely affected, impacting schooling, work, finances and relationships.

We offer a range of age-appropriate therapies for the whole family. For younger children, we use creative therapy - music, art and play - to encourage them to communicate how they feel, when traditional talking therapies are not appropriate. For older children and parents, we offer specialist counselling and psychotherapy, providing strategies to help them cope more easily. Hour-long sessions are led by one of our accredited therapists, with individuals on average having a course of six sessions.



443

Counselling
sessions

461

Creative therapy
sessions

“We are so thankful for A’s music therapy. It enabled him to talk about his seizures and epilepsy, he also opened up about his lack of confidence in his own abilities and his learning. Thank you for giving him this opportunity to talk, play and shine through the medium of music.

“The sessions have been absolutely invaluable to me. When I first started I did not believe I needed to talk to anyone and thought I was coping just fine. However, after only a few minutes of the first session I realised that I desperately needed to discuss the trauma of my son’s diagnosis and address how I actually felt.

Special treats and experiences

When a family’s new normal involves hospital stays and gruelling treatment, we try to offer moments of delight with special treats and experiences. From doorstep owl and Santa visits, to coffee mornings bringing parents and children together with others going through similar situations, **we've arranged hundreds of magic moments.**



Our Impact Survey Findings

In January we sent out a survey to the families we support, to gather their feedback on our support and services. Families placed the direct contact they received from their Momentum Family Support Worker as the most impactful of our support offerings, thanks to our ability to offer a personalised support pathway for every family member.

This tailored care has:

- improved emotional wellbeing of **95% of parents and 80% of children.**
- improved participation in social and leisure activities for **66% of families.**
- enabled access to professional emotional support and practical information for **72% families.**

As part of our ongoing commitment to improving our evaluation, we have also launched a new internal Outcomes monitoring tool. This will help us to measure detailed outcomes for each family even more effectively, to identify areas that have improved for them or areas where more support might be beneficial.

Funding our work – looking ahead

We receive no statutory income and rely entirely on voluntary donations. For the coming year we need to raise £1.1 million to carry out our charitable activities and meet our annual objectives.

We're seeking funding for a range of projects and services, including our Family Support Workers and tailored support package, our respite breaks and mental health therapy programmes.



**Our goal is simple;
to ensure no family has
to cope alone**