



Plugging the Gaps 2019

The critical role of social palliative care
in supporting families in need



Sebastian's Action Trust

Here for families of seriously-ill children.

Always.

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About us

From one little boy's special wish, great things have come.

Sebastian's Action Trust is a charity established in 2004 in accordance with the last wishes of our founder, Sebastian Gates, who wanted to reach beyond the limitations of his own lifetime and illness to help others. His desire to create a special place where families facing enormous challenges could come together for memory making, rest and relaxation in private, accessible and exclusive surroundings is the cornerstone upon which our family-focused yet child-centred model has evolved.

We provide emotional, social and practical care for life-limited and life-threatened children and their families. We offer a unique family respite care model at our flagship facility, The Bluebells, together with outreach and specialist support at our second centre, The Woodlands, that is aimed at reducing isolation, providing meaningful support and building resilience to help our beneficiaries face the uncertainties of the future.

At Sebastian's Action Trust, we passionately believe seriously-ill children should be able to enjoy quality time together with their families, never having to face life alone. Our vision is to ensure lives, however short, are lived to the full.

Sebastian's Action Trust has been here for the past 16 years ensuring that every one of the children, young people and families we support gets the best possible care. We remain present for families through the good days, the bad days and everything in between, remaining a constant in a world that presents endless challenges and uncertainties.



I am delighted to write a foreword to this report on the activities of Sebastian's Action Trust. This charity receives no public funds and is totally dependent on charitable donations. Over the 16 years since it was established, it has provided an increasing amount of essential family-focused and child-centred care to families living with a seriously-ill child.

I have been a paediatrician, and more specifically a paediatric oncologist, for over 30 years. I am only too aware of the many challenges that face a family when a child is diagnosed with a life-limiting or life-threatening condition. Although there have been significant medical advances which have resulted in improved survival rates in children's diseases, there are still many children who are not cured and there has been continued growth in the need for holistic support for them and their families.

This Trust provides a unique service to families living predominantly in the south east of England, by offering practical, emotional and social help which would otherwise be unavailable. This report highlights the services the charity provides which help families to try to live life to the full with a seriously-ill child despite all the associated daily practical, emotional, social and financial difficulties and demands. It demonstrates how in many situations the services provided fill in and complement the gaps between NHS care and palliative care. Sebastian's Action Trust is able to provide in-patient and day respite care for whole families at two dedicated facilities where there is a variety of specialist help available. From the point of diagnosis and for as long as it is needed, a comprehensive service provides emotional, social and practical care, both at these 'home from home' facilities and via an outreach service.

The personalised benefits of Sebastian's Action Trust for these children and their families are immense, as confirmed in this report. My patients and their families frequently update me on the hugely beneficial, and always professionally delivered, support which is given with so much care. Sebastian, who I treated as a patient and who sadly died in 2003 of a childhood cancer, had a wish at the end of his life that there could be a "happy house" for all families with an ill child. This wish has been more than achieved. For it to survive long term, consideration must be given to how it is funded and I hope that this report not only opens a dialogue around the importance of social palliative care as practised by organisations such as this, but also encourages a commitment to funding its delivery.

Dr Kate Wheeler

Consultant in Paediatric Oncology

Oxford Children's Hospital

Patron, Sebastian's Action Trust



Executive summary

- ◆ There are at least 49,000 children and young people under 19 years of age in the UK living with a life-limiting or life-threatening condition who may require palliative care services.
- ◆ Sebastian's Action Trust (SAT) complements existing medical services by offering a unique social palliative care package for children and young people. The charity offers family respite care along with outreach and specialist support. Its services are popular and highly-valued among eligible families; 97% of users report feeling happier after a respite break at SAT.
- ◆ Because of resource and funding constraints, many of the services provided by SAT are limited to families living in a defined geographical area. This contributes to the creation of a postcode lottery in social palliative care, whereby families in some parts of the UK are left with little or no support.
- ◆ Independent evaluation of its services demonstrates that the Trust enables families to cope more effectively, to maintain family stability and to reduce the likelihood of families finding themselves in crisis situations. This, in turn, reduces the likelihood that these families need to turn to social, health and mental health services for state-funded support. SAT interventions therefore create significant savings for the health and social care system in the region of £1.6m per year. It is simply impossible to assess the human and societal value of SAT's support to individual families and this report does not attempt to make this calculation.
- ◆ Currently only two organisations in the UK offer a service that befits the term social palliative care: Rainbow Trust Children's Charity and Sebastian's Action Trust. The model provided by Sebastian's Action Trust expands upon the practice of Rainbow Trust to include family respite breaks and specialist services delivering a comprehensive, cohesive and flexible approach.
- ◆ There is evidence that funding constraints in the hospice sector have led to some hospices' support being targeted only at immediate end-of-life care. This has created an even greater gap in service provision for those living with their child's terminal condition for an extended period. Families of children with life-limiting or life-threatening conditions, however, report needing support from the point of a child's diagnosis.
- ◆ SAT does not receive any statutory, NHS or local authority funding. It does not qualify for the current NHS England Grant to Children's Hospices, which is limited to clinical care providers. SAT services have only once, through a brief pilot project with Hampshire County Council in 2015, met the locally determined criteria for Short Break Services, for disabled children and their families, which local authorities have a statutory duty to provide. Looking ahead, its high quality services can only be maintained through sustainable and consistent income streams. There is a clear funding gap for social palliative care and increased statutory funding would help secure more comprehensive, sustainable and equitable delivery of these vital services.



Report recommendations

Recommendation 1:

More than one in five local authorities do not commission short breaks for children with life-limiting or life-threatening conditions. Clinical Commissioning Groups (CCGs) and local authority commissioners should fulfil their legal duty to fund short breaks for disabled children and their families, including respite care for the carers and families of children requiring palliative care. The creation of Integrated Care Systems should be used as an opportunity to embed and coordinate this duty across health and social care.

Recommendation 2:

Sebastian's Action Trust welcomes recent announcements from NHS England and the Government of increased funding to support hospices and palliative care services. However, we are concerned that this will not reach providers offering social palliative care for children and young people, such as Sebastian's Action Trust. NHS England and the Department of Health and Social Care should ensure that social palliative care providers can access these funds and consider targeting additional statutory funding at the social needs of children with life-limiting and life-threatening conditions and their families.

Recommendation 3:

A clear policy framework and integrated service model for children and young people's palliative care services should be developed by the Department of Health in conjunction with NHS England, the Department for Education and the Department for Communities and Local Government. Non-clinical social care and bereavement care, as well as the role of charities and voluntary organisations in delivering such services, should be explicitly included.



Our model of care

Sebastian's Action Trust offers emotional, social and practical care for life-limited and life-threatening children and their families. We provide family respite care at our flagship facility, The Bluebells, together with outreach and specialist support at our second centre, The Woodlands, that is aimed at reducing isolation, providing meaningful support and building resilience to help families face the uncertainties of the future.

The range of services we offer is shaped from what families tell us helps the most to meet their individual and collective needs, recognising that there are over 300 life-threatening conditions that will affect users' needs. We support the whole family as a unit and as individuals, including parents, the sick child, siblings, grandparents and carers. Support is offered at home, in hospital and in the community, as well as at our facilities in Hampshire and Berkshire.

The continuity of care we offer is tailored to the needs of the family and may include all, or some, of the following:

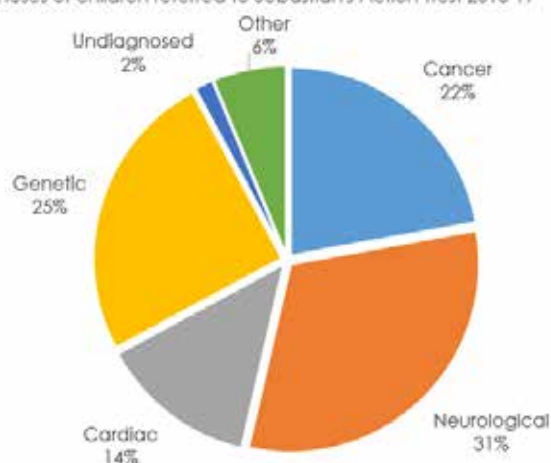
Breaks and day visits

We provide places and spaces where families can access time together, away from the stresses of hospital and home at our unique facilities, The Bluebells in Hampshire and The Woodlands in Berkshire.

"A break at The Bluebells has given us an opportunity to spend four days together as a family having a fun, relaxed time, away from our daily stress." (Parent)

Outreach family support

Diagnoses of children referred to Sebastian's Action Trust 2018-19



We aim to walk alongside families through the good days, the bad days and everything in between with assigned key workers who deliver support that is tailored to each family. From providing vital transport to hospital to caring for siblings or attending appointments, outreach workers become an indispensable source of support in extreme and fluctuating times. Following support, families with a child with a life-limiting condition feel more equipped, less anxious and more supported, enabling them to provide better care for their seriously-ill child.

"Having our outreach worker to talk to makes me feel less invisible. With every other service that we engage with, they are focused on the outcome for the child and the parents are almost an afterthought. SAT focuses on the family as a whole and [outreach worker] is the only person who asks how I am coping, both emotionally, physically and practically." (Parent)



Our model of care

Outreach child support

Our specialist workers are trained to provide a safe, fun and nurturing environment to help young people cope with the enormity of what is happening in their lives. Support is offered to the sick child and their siblings, who often struggle to understand the changes to their family dynamic and may need help to express their worries or frustrations. With tailored support, seriously-ill children and their siblings feel less isolated or angry and are generally able to find better coping strategies for facing the future.

"I'm not as stressed and can talk to someone who can help rather than lashing out." (Sibling)

Outreach finance and welfare

Knowing what you and your family need and what you are entitled to can feel overwhelming at the point of your child's diagnosis. Without guidance and signposting, parents often struggle to access the right support at the right time. Our specialist workers are trained to identify what is available and relevant to a family's situation. Through access to specialist financial support and advice, families obtain the specialist equipment, services and help considered essential to meet their challenging and changing needs.

"Life without Sebastian's Action Trust would be a lot harder. Fehmida has helped me with various forms applying for Disabled Living Allowance and Mobility Allowance and more importantly enabled us to have a mobility car. Some of the applications we need to complete are very complicated and if you don't word them correctly or write the right terminology, you probably won't be as successful in getting the help you really need. Fehmida is very friendly and knowledgeable and knows just what to say. She also helps coordinate letters I might need from doctors and other medical professionals for various benefit applications and takes a lot of our stress away. Knowing someone has the qualifications to help us means so much and gives us all terrific peace of mind." (Parent)

Outreach bereavement care

We understand that facing the death of a child is likely to be the hardest, loneliest and most painful ordeal a family will ever experience. We offer continuity of care from a child's diagnosis and where all curative options have been exhausted we continue to support families after the death of their child. Families accessing bereavement support develop better coping strategies that help them live with their loss and many feel connected to a community that understands through personal experience.

"You make the loneliest journey on earth more bearable" (Parent)

Events, activities and workshops

Families tell us that they often feel isolated by their child's condition. We create opportunities to connect families with others who walk in similar shoes so they can offer and receive peer support in the knowledge that they are with others who do understand.

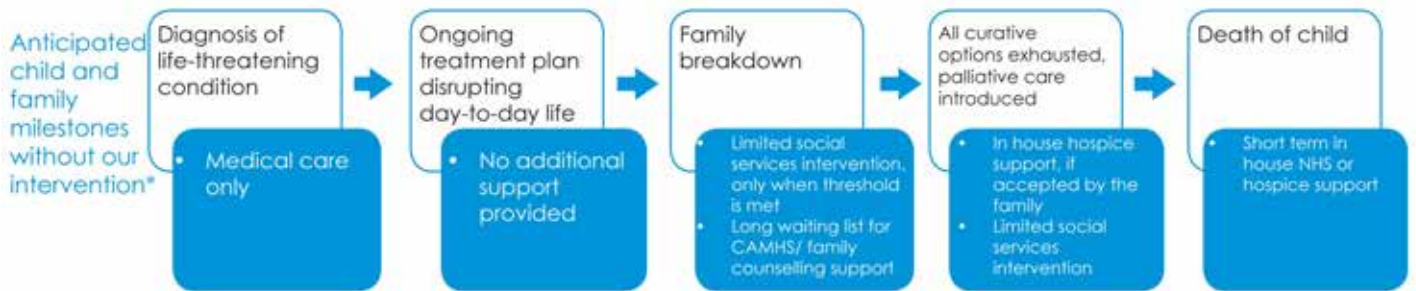
"It is nice to have the opportunity to connect with people whose normal is like mine." (Parent)



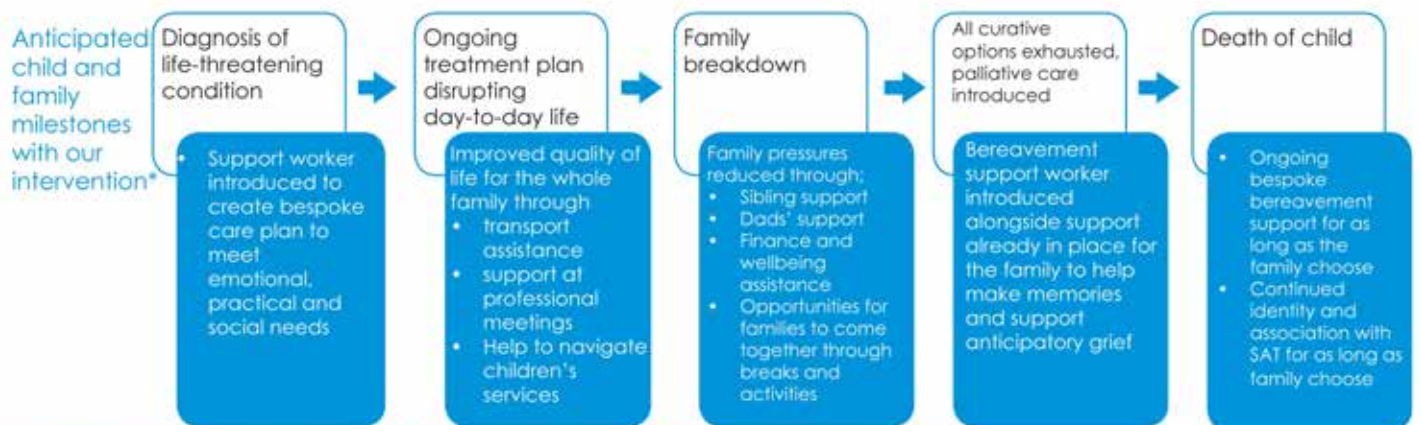
Our model of care

The following graph highlights the differences which exist for families supported by Sebastian's Action Trust as opposed to those who are not:

Without Sebastian's Action Trust



With Sebastian's Action Trust



* please note a timeline is not included due to variance of life expectancy short (weeks, months), medium (years), or long term (decade).



Meet the Folland family

“You feel so isolated when you're grieving”

Five months after Anna was born, her mum Kay started noticing her development wasn't at the stage it should be for her age. With five other children, Kay and Anna's dad, Johnny, knew something wasn't right – their youngest daughter was crying uncontrollably for hours at a time and had difficulty in smiling and lifting her head, which she had previously been able to do. Following various tests, it was discovered Anna had white matter on her brain and was diagnosed with Krabbe – a rare disease that results in progressive damage to the nervous system.

Anna's condition meant she would not live more than a couple of years and her family put all their efforts into caring for her, making sure they spent precious time together making memories. Anna's health slowly deteriorated, resulting in the loss of her sight; she was oxygen dependent 24-hours a day, fed via a tube and was gradually losing weight. During this time, Kay became an expert in her child's medical care, managing her pain relief and symptoms.

The family were introduced to Sebastian's Action Trust in March 2018. Paula, the family's outreach support worker, would regularly visit Kay to see how she was coping.

Anna sadly passed away surrounded by her beloved family on 28th October 2018.

Before she died, the family had enjoyed **respite breaks** at The Bluebells and Anna's **siblings** were encouraged to get involved in various activities. Encouraged by Paula, Kay and her family have also visited The Bluebells and The Woodlands for various **events and activities**.

“After Anna died, we stayed at a hospice in their cool room, so our family could have more time with Anna before her funeral. The Trust provided **transport** to take Anna from the hospice so we could be with Anna in the car rather than driving. I don't know any other charity that would do something like that. They also helped me **plan Anna's funeral** before she died, so I didn't have to worry as much about how I wanted it to be.”

The whole Folland family remains within our 'family of families' and **continues to receive support**. Brother Alfie, 5, is finding the death of his little sister particularly hard and has been receiving help from Trust **youth support worker**, Tracy, who regularly goes into his school to organise activities giving him an opportunity to talk about his feelings.

Kay said: “When Anna was poorly, there was a lot of uncertainty in his life. Alfie knows he feels so many emotions, but he's only 5 and doesn't know what these emotions mean. Tracy has made a massive difference and helped Alfie create a memory box. He is more able to express himself and we often talk about Anna.



“You feel so isolated when you're grieving. I'm the one looking after everyone, but to have someone to look after me, like everyone does at the Trust, means so much. When you know time is short, every day is precious. Paula was incredible in making sure I didn't feel like I was doing it on my own. She makes sure my whole family is looked after. The Trust is there for the whole family and I don't know what I would do without them.”

Setting the scene on need and funding

There is limited research to confirm the current position regarding the number of children living with life-limiting or life-threatening conditions. However, studies completed in 2012 revealed that at that time there were at least 49,000 children and young people under 19 years of age in the UK living with a life-limiting or life-threatening condition who may require palliative care services. More recent estimates in Scotland suggest an increase in prevalence; therefore it is likely that an increase throughout England and Wales would follow.

The excellent work of Rainbow Trust Children's Charity in producing the 'Hidden Savings' report of 2017 also concludes that 'the growth is linked to medical advances, which enable more premature babies to survive with complex medical conditions, and improved treatment and support which enables more children to live longer with their conditions'.

Who pays for support?

The funding system for providing children's palliative care is complex; it is expected to meet their health, social care and educational needs. NHS England has responsibility for commissioning the health care elements of paediatric palliative care, with non-specialist care needs being delivered either by statutory or voluntary sector providers through collaborative commissioning involving CCGs and local authorities. For organisations like Sebastian's Action Trust, the complexity of the funding system creates barriers to accessing recognition of the non-specialist but nevertheless vital care we deliver. At present, we overcome this through funds generated either through our own fundraising efforts, through grants or with corporate, trust and foundation partnerships but this alone is not sustainable; it makes planning for the future unreliable and creates an unhealthy dependence upon charitable giving.

With the variance in numbers affected across the country, coupled with a lack of uniformity in approach, a postcode lottery has evolved that has led to an inequitable system with inherent flaws impacting on children and their families. It is recognised that as this report is being written, NHS England together with NHS Improvement have outlined plans seeking to improve short and long term funding deficits, beginning with a review of CCG funding allocations to children's palliative care. This communication also commits to making available up to £7 million per year by 2023/24 to CCGs to increase their overall investment in children and young people's palliative care services. It is specified that this will apply to hospital, children's hospices and community services. Provider organisations are being urged to engage with local CCGs to help establish the baseline and to make a case for funding.

Whilst the recent communication is to be applauded it is imperative that CCGs recognise the importance, value and benefits of social palliative care, together with the role of emotional, social and practical support for families coping with a child's life-limiting or life-threatening condition.



How our services save money

Families with a life-limited child face a unique combination of challenges in addition to the medical needs of the child. Financially, families with a life-limited child are at higher risk of poverty due to the additional costs associated with the disability or condition, as well as a lower earning potential, as one parent usually gives up their job to care for the child.

The Trust's support provided via its finance and welfare services make the very complex system of benefits, grants and health and social care services accessible to parents. It offers families a tailored and individualised service that increases their economic wellbeing.

The Trust's services lead to direct and indirect savings to health and social care by providing transport, counselling and reducing the need for respite care. In addition, they help to prevent families from hitting rock bottom and needing crisis intervention either from mental health services and/or children's social services. The need for these services outstrips current provision. Sebastian's Action Trust improves the quality of life of families with life-limited children on many levels, stabilises families and supports their mental wellbeing. For families living with the unpredictability of a life-limiting condition, the possibility and availability of support is as important as the actual support they receive.

Against the backdrop of the Rainbow Trust's Hidden Savings Report (2017) we have been able to calculate the total direct and indirect savings as a result of the work of Sebastian's Action Trust (see right)

Service	Total Direct Savings	Total Indirect Savings	Total Direct and Indirect savings by service
Respite breaks and day visits	£136,500	£142,571	£279,071
Outreach	£87,212	£689,968	£777,180
Youth	£18,562	£99,892	£118,454
Finance and Welfare		£64,935	£64,935
Bereavement	£11,824	£332,652	£344,476
Total Savings			£1,584,116

“From a human and social standpoint, the benefits for the families go far beyond the cost savings to health and social care” - Dr Katrin Bain



Since 2004, Sebastian's Action Trust has continued to shape its range of services in response to listening to its users and seeking to address unmet needs. Whilst there is tremendous value in the anecdotal responses of beneficiaries to the work of the Trust, it was felt that in order to take the charity forward it was imperative that an external evaluation of services was commissioned to provide unbiased, qualitative and quantitative evidence of the impact of delivery together with a consideration of the situation that might arise if services were withdrawn.

One of the Trust's key objectives is campaigning for the rights and needs of its beneficiaries. It is implicit in commissioning the evaluations that follow that families who either perceive, or in reality do not have, the opportunity to speak openly about the challenges they face and their lived experiences are able to have both an individual and collective voice. It is also hoped that this body of work will inform the cohort of professionals working alongside life-limited and life-threatened children, together with prospective funders, of the importance and value of a holistic approach to social palliative care.

This report brings together the context of the Trust's services against the backdrop of what is available via other organisations and its place in delivering social palliative care that complements existing medical services. The term social palliative care has been defined by Rainbow Trust Children's Charity as 'the essential support that a family needs and may not recognise, alongside medical care to face each day as it comes'. Currently only two organisations in the UK offer a service that befits the term social palliative care: Rainbow Trust Children's Charity and Sebastian's Action Trust. The model provided by Sebastian's Action Trust expands upon the practice of Rainbow Trust to include family respite breaks and specialist services to provide a comprehensive, cohesive and flexible approach.

Our social palliative care model consists of six vital elements: respite breaks, outreach, child support, finance and welfare, bereavement and peer to peer support. External evaluations of five of these elements through 2018-19 have been completed by Dr Katrin Bain from Royal Holloway College, University of London. The sixth element of peer to peer support has been considered throughout the evaluations in respect of the activities, events and workshops the Trust organises to bring beneficiaries together. The evaluations have been conducted against the backdrop of the outcome measures associated with each project and aspect of service, together with providing an opportunity for user engagement and feedback.

At this point we would like to acknowledge and thank the National Lottery Community Fund for their generosity in sponsoring aspects of this report in respect of evaluating outreach support.



Evaluation one: Respite breaks

Executive summary

Within SAT, breaks at The Bluebells are referred to as respite breaks. While this is an accurate description and enables potential funders to easily understand the value of, and need for, Bluebells breaks, this is not the language families choose when talking about their experience at The Bluebells. The families talk about 'a holiday' or 'a getaway'.

Outside of The Bluebells most families are very aware of their 'otherness'. The Bluebells not only gives them facilities that are suitable and unavailable elsewhere, but also enables families to feel normal – something that they crave and appreciate. There are no stares, questions and judgements. Both the staff and other families at The Bluebells see past a wheelchair or feeding tube and not only accept everyone as they are, but also get to know the child as a person with individual interests. This goes for the supported child as well as for the siblings. The activities that the staff offer are tailored to the child's interests and abilities.

As a result of the setup, facilities and atmosphere, a stay at The Bluebells enables the families to switch off from the daily chores, therapies and organisation that comes from having a life-limited child and focus on having fun as a family and relaxing. In 2018/19 a total of 95 breaks were provided supporting 428 individuals. Families accessed The Bluebells from 20 counties across the UK.

The two apartments at The Bluebells can sleep up to 8 people each. Families get to choose who they would like to bring for the stay. This can be immediate family, extended family, friends or neighbours.

Bluebells breaks are free of charge for families, but a voluntary contribution of £100 is welcome. Roughly 60% of families make the donation. There is no contribution request for mid-week crisis breaks. The real costs to SAT are £1,875 per apartment and break.

A break from the medical

The families supported by SAT spend a lot of time in medical environments, whether that is in hospital, in a hospice, or through visits from community nurses or community hospice staff. All the families value the medical support they get. Equally, they enjoy the possibility of getting away from everyday life and having fun as a family.

"And to demonstrate to [daughter] that we stay other places than hospitals and it's actually quite enjoyable to go away." (Parent)

Children with life-limiting or life-threatening conditions are still children. They want to play, learn, develop, and have some freedom and independence. The parents of these children are also more than just carers. They have jobs, interests and needs of their own. These families, like others, want to spend time together, have fun, make memories and feel normal. They want to go on holiday and relax. SAT complements existing medical services by offering social palliative care that isn't available elsewhere.

"They are different from the medical side they are more the social, mental side. I'd say they are just as valuable as any doctor or diagnosis that somebody can give because everybody needs that. (Parent)

"They say a problem shared is a problem halved but it is not just a problem halved, it is friends gained, solutions found, it is everything really." (Parent)



Families' experiences of the staff and atmosphere

As a holiday for the whole family, the staff offer activities, like baking and arts and crafts, not only to the referred child but also to siblings. Families really value this as, apart from The Bluebells, it is difficult to find places that cater for all members of the family.

"There is something about Bluebells isn't there? It is just so relaxing and you just walk in and you can breathe, and it is a place where you get to be you and you are quite normal." (Parent)

"Staff really make you feel welcome, very engaging with the children, the facilities are amazing, and a relaxed atmosphere all makes for a much-needed break." (Parent)

Families' experiences of the wellbeing treatments

As part of their weekend stay at The Bluebells, on Mondays families are offered wellbeing therapies including a massage, facial, or a manicure. Everyone who took advantage of the wellbeing therapies greatly appreciated and enjoyed them.

"The wellbeing therapist was warm and kind making me instantly relaxed in her presence. The treatments I received are a welcome rare treat as I struggle to prioritise my needs as a carer." (Parent)

Families' experiences of the communal facilities and day visits

The Bluebells offers a wide range of facilities to both residential families and day visitors. These include: a hydro pool, a cinema room, an art space, a lounge, a sensory room, a music room and a large garden with a playground. In addition, there is a communal kitchen, a changing facility with hoist, as well as a hoist in the pool area. The entire house and gardens are accessible. As one mother states:

"It is effectively Center Parcs for special needs families and there is nothing like it anywhere else." (Parent)

Using public spaces with a child with a life-limiting or life-threatening condition is difficult for the families for a whole range of reasons, including:

- The logistics of getting the child with all their equipment ready to go out
- The lack of suitable facilities such as changing rooms
- The risk of infection

Being exposed to other people's reactions to the life-limited child

"It was just nice to get away from home and it is just like a mini holiday, it is nice to know that we can go there and we have all the support that we need and all the equipment for [referred child] and we don't have to worry about anything and we have the pool and the garden to use. It is just really nice to be able to go somewhere where we don't have to worry about you know if [referred child] kicks off or if he makes a scene or if there is going to be somewhere where we can change him." (Parent)

The swimming pool is particularly popular with families. Many life-limited children love to swim but cannot go to a public pool. SAT not only offers a warm hydro pool that the families can book for exclusive use, but also has dry suits for children with central lines. They also have the hoist and changing facilities that are not available at most public pools.



Outcome 1 – Improved mental health, Happier after break

46 individuals responded to the statement 'Do you feel happier after accessing a break at The Bluebells? 97% either agreed or strongly agreed that they feel happier after the break.

"Mental Health 100x better and feel relaxed and well." (Parent)

Outcome 2: I feel rested and better able to care for my child

Over 90% of all respondents agree or strongly agree that they feel rested and better able to care for their child.

"We feel fully rested and recharged after our break at The Bluebells, with an extra burst of energy to carry on with our daily routine of appointments, therapies and medical issues." (Parent)

It is interesting to see how the families can recharge while the referred child is with them and they are still caring for him/her. Respite care available to families of life-limited children at other non-SAT facilities around the country usually offers a short term placement for the life-limited child only. This is certainly an important service. However, for families who don't know how much time they have with their children, The Bluebells offers a fun holiday for the whole family and the opportunity to create memories that are cherished as well as respite for the parents.

Outcome 3: Feel less isolated

67% of all respondents agree or strongly agree with feeling less isolated after a Bluebells break. It is important to understand the survey results and comments from a geographical perspective. Whether a family feels isolated seems to be dependent on their everyday situation. For example, the three families below who live out of county feel isolated on a day-to-day basis, which cannot be changed by four days at The Bluebells:

"We are isolated as it's lonely looking after a child with a terminal illness. No-one can understand unless they have walked that path." (Parent, Cumbria)

In contrast, some local families commented that they did not feel isolated to start off with, as they already make good use of The Bluebells. Other local families who stayed at The Bluebells but also use it throughout the year, felt that The Bluebells reduces isolation:

"Having other families around and support workers have made me realise we have somewhere to go and people to talk to." (Parent, Hampshire)

The community of families with life-limited children is relatively small, so it is not uncommon for families to meet during hospital stays or visits. Meeting others at SAT events makes it easier to have a chat:

"We have met a few people through Sebastian's and then we will see them here and then when we see them at the hospital you are like Oh I know you and then you can sit there and talk which is a lot easier." (Parent)

Families also arrange to meet at The Bluebells to socialise. This gives children the chance to play with friends as well as meet new people.



The Bluebells – providing public spaces without public funding

The Bluebells provides many spaces for families with life-limited children that other families can access in the public sphere either free of charge or heavily subsidised. This report has shown that families with life-limited children cannot use general public facilities. The Bluebells plugs the gap by offering:

- A children's centre
- Leisure facilities that are accessible

Whilst there will also be savings to other services the bottom line is that additional spaces and funding are required for families of life-limited children to be able to enjoy the same experiences as other families. Thanks to generous donations and grants SAT has been able to address the unmet needs of families with life-limited children at The Bluebells. Given that local authorities provide and maintain parks, playgrounds, children's centres and subsidise swimming pools for the general population, it is not unreasonable to expect them to provide these facilities for all members of society and therefore offer funding to organisations like SAT to provide public spaces for families who cannot access mainstream facilities.

Family respite breaks at The Bluebells should be included in the respite care funded by local authorities to give parents choice. The time families have with life-limited children is finite, so spending time together and making memories is especially important and valued.

Research commissioned by Scope reveals that on average families with a disabled child need an extra £581 a month to enjoy the same quality of life as families without a disabled child and 24% of all families need a minimum of £1,000 a month.

Conclusion

As a community venue The Bluebells is very successful and could be a blueprint for similar venues across the country.

It is interesting to see how the families can recharge while the supported child is with them and they are still caring for him/her. The Bluebells is self-catering so some household tasks are still required. However, taking all the everyday chores and appointments away, and offering the families an adapted environment and a helping hand from the house manager, means that all members of the families can enjoy the holiday.

Given the many benefits of The Bluebells, and the fact that many of the supported families cannot access general public spaces, it is necessary to start a conversation about publicly funding social palliative care for children. Families with life-limited children will only be able to enjoy the same experiences as other families if additional spaces, tailored to their needs, are adequately funded.



Evaluation two: Outreach care

Executive summary

The Outreach Service has grown significantly during the time it has been in operation. The original target for the first 3 years had been to support 300 families; by the end of the 3 years a total of 395 families had been supported. In 2018/19 SAT outreach workers supported 522 families (2,038 individuals) across the five counties of Berkshire, Buckinghamshire, Hampshire, Oxfordshire and Surrey.

The support offered to families is bespoke; Outreach Service families can also access other services offered by SAT, including a tailored calendar of events, holidays at The Bluebells, financial advice and day visits to The Bluebells or The Woodlands. This combination of services, together with the fact that the Outreach Service supports all family members, makes this a unique provision that cannot be found elsewhere.

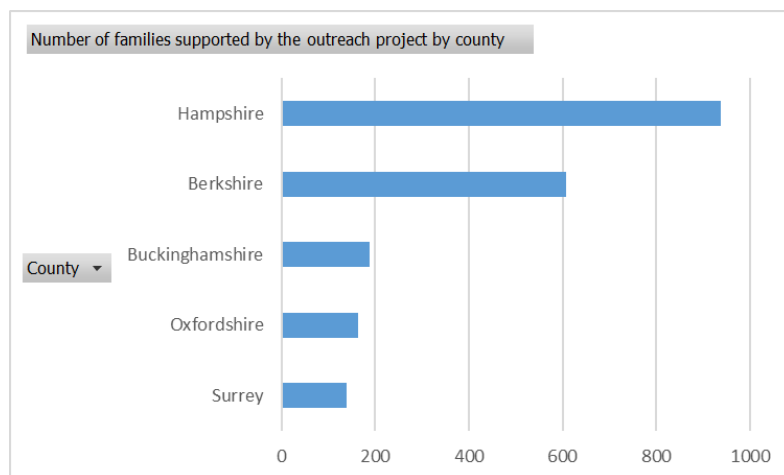
Funding for the Outreach Service is currently secured until March 2020. Given that there is no alternative support for the families, and in light of the positive impact of the service on families and the savings it provides to health and social care, it is imperative that work continues to ensure the existence of the Outreach Service.

Referral and assessment

A referral rate of over 70% from health professionals demonstrates that SAT has good links to, and a strong reputation amongst, relevant professionals ensuring that families receive information about the Outreach Service. The dropout rate is low at just under 18%.

During the initial home visit to a new family, the outreach worker assesses the family to establish the level of need. SAT uses three categories: Critical, Moderate and Maintenance. In addition to the three categories cited above, a family will be sub-classed as Critical Palliative if their child has an advanced care plan, is engaged with hospice services or is actively dying. Those who have this status are deemed a priority for SAT's services, due to the immediacy of their life being shortened. It does not reflect their unmet need.

It is interesting to note that families in all four categories (including Palliative) have been interviewed, and all felt that the outreach worker was available whenever needed. None mentioned limitations to their access to the outreach worker.



Location

The outreach workers support families within the five counties of Berkshire, Buckinghamshire, Hampshire, Oxfordshire and Surrey. Unsurprisingly, most families supported by the Outreach Service live in Hampshire and Berkshire, reflecting the location of the two SAT facilities.



A whole family approach

SAT understands that a life-limiting condition does not **only** impact the child who lives with it, but also parents, siblings and extended family members.

“Having [outreach worker] to talk to makes me feel less invisible. With every other service that we engage with, they are focused on the outcome for the child and the parents are almost an afterthought. SAT focuses on the family as a whole and [outreach worker] is the only person who asks how I am coping, both emotionally, physically and practically.” (Parent)

Emotional support

Life with a life-limited child can be a roller coaster and a large part of the Outreach Service is to provide emotional support:

“The main thing is that when things are going a bit rubbish I can phone up and speak to [youth worker] for the kids or [outreach worker] speaks to me and she comes out to the hospital to see me and sits and has a coffee with me and listens and gives a shoulder to cry on.” (Parent)

92% said that they are better able to cope with their day-to-day struggles due to support from SAT.

Practical support

The underlying premise of the Outreach Service is to respond to the needs of families, and as part of this, outreach workers help with many practical tasks.

“There has never been anything that they haven't helped with. They have come round and helped us pack up the house. Packing up for building work and things, they really do walk alongside you and do life with you and sometimes I go out with [counsellor] and we go out and walk the dog or she'll help me do some washing up, just normal life. Because they understand that life is hard”. (Parent)

Mobility

Mobility with a life-limited child can be difficult for several reasons. Often the parent(s) do not have a driving licence or a car, and public transport can be unsuitable for children with suppressed immune systems, complex medical needs, or those in wheelchairs. Some conditions, for example when the child has a tracheostomy, require a second person in the car sitting next to the child. The SAT Outreach Service provides mobility to families in two ways. Firstly, by providing transport, SAT can help families to get to appointments and events more easily. This leads to fewer missed appointments, less social isolation and takes pressure off the parents:

“Having someone transporting us to our son's appointments takes a lot of pressure off my husband as he mainly uses his annual leave to attend the appointments and also someone needs to be with our son all the time as he cannot be left alone because of the medical issues he has”. (Parent)

Secondly, the outreach workers help the families to fill in forms to obtain a car through the Mobility Scheme, and get a disabled parking badge. Most families were unaware that they were eligible for these or how to obtain them.



A safe environment with people having similar experiences

SAT ran 89 events in 2018/19 which were attended by 1,869 people. The frequency of attendance varies widely with just under 50% attending one event a year, whereas others attend up to 21 events per year.

For those attending the events, the benefits extend well beyond the activity itself. In a survey of 118 beneficiaries, 99 stated that they feel less alone as a result of having access to activities and events.

"It is nice to have the opportunity to connect with people whose normal is like mine." (Parent)

"I have made friends with so many people here who I see regularly. In the two years prior to using this I didn't have any friends who understood or related to our situation." (Parent)

Support and advocacy during professional and medical meetings

Outreach workers not only offer transport to appointments, but also attend medical and professional meetings with the family on request:

"[Son] had to go to hospital and I felt I wasn't getting the right answers from the doctors so I said to [outreach worker] like would she mind coming with us and she was absolutely brilliant because not only did she come with us but also when I go in to talk to the doctor I sit there and he says what he says and I say what I say and then I walk out and am like "What did he say?" because usually it is too much but [outreach worker] wrote everything down so half of what I forgot she has written down—that was so much better and really helpful. She manages to get everything sorted somehow". (Parent)

Continuity of care

"I think it is amazing that as the main person for the bereaved families she comes and walks alongside you before the bereavement happens, so that you know her, which is just outstanding, and it is not something that is done anywhere else. Because of the type of condition [son] has we have a network of friends and families across the UK and in fact in America and all over the place and Sebastian's Action Trust is utterly unique, there is nowhere else like it across the UK and friends have said they wished they had something like it placed near them because there is just nowhere else". (Parent)

A safety net

Life with a life-limited child is anything but predictable. Therefore, families require a flexible service that can be upscaled or downscaled depending on the current situation, for example the health of the child, or the need to attend appointments.

All the outreach workers and the counsellors work part-time. This means that they cannot always be available to the families. In addition, the assessment criteria allocate a certain amount of time to families depending of their level of need. Nevertheless, all the beneficiaries spoken to, and who completed the questionnaires, felt that they could contact their outreach worker at any time:

"I can call Sebastian's anytime and there is someone there to help me". (Parent)



The “red” button

The life-limiting conditions that qualify for support from SAT are by their nature unpredictable and uncontrollable. The families live with a high level of uncertainty, often caring for the child 24/7, and needing to respond to another (medical) emergency or bureaucratic process without much notice. And yet this is only one part of family life – there are plenty of other factors in play such as work, siblings, relationships, family time, school and household chores which all require time and attention and can very often be demanding.

In the 1970s Glass and Stringer (1972) performed experiments to find out how participants adapt to stressors. Analogously with the experiments of Glass and Stringer, the SAT Outreach Service gives families with life-limited children a “red button”. Knowing that they can contact the outreach worker at any time and receive support enables the individuals “to label their situation as one in which they are not helpless” . Or to put it in the words of the beneficiaries:

“I am really struggling and the support I have received has really shifted my ability to accept help and cope with so many unknowns.” (Parent)

Where would the families be without the SAT outreach service?

“If they weren’t there I wouldn’t know people with brain tumours, I wouldn’t know what questions to ask, I wouldn’t know where to go for help. I would have probably just gone mad, because everything I am unsure of I can just phone up and ask them and then there is someone there that can give me the advice that I need. And it doesn’t have to be just about [son] either -you know what I mean? If I have a problem I can talk to her about anything- debts and bills and all that kind of stuff. Even if she can’t help me there and then that day she will go and find that answer and then she will get back to me the next day and say I think you should do this or you can do this or try this and without them I just don’t know where I would go or how I would cope.” (Parent)

“I would feel very unsupported without the help I receive from SAT” (Parent)

Benefits for health and social care

SAT Outreach Service leads to direct and indirect savings to health and social care by providing transport, counselling and reducing the need for respite care. In addition, the Outreach Service helps to prevent families from hitting rock bottom and needing crisis intervention either from mental health services and/or children’s social services.

From a human and social standpoint, the benefits for the families go far beyond the cost savings to health and social care listed above.



Meet the Kemp family

"They help keep our spirits up "

Ed Kemp, 42, became concerned about the health of his elder child, Matthew, now seven, the moment he was born. "Matthew stopped breathing after birth and needed resuscitation, which was terrifying," remembers Ed. "He was also very weak and floppy and had physical features – such as a high-arched palate in his mouth – that seemed to point to a medical condition. It was obvious there was something wrong, although my wife, Sarah, and I didn't know what."

Matthew remained on a ventilator in Southampton Hospital for three months. "We were told multiple times he didn't have very long left and, at one point, that they would be turning the ventilator off that night – which thankfully didn't happen. The doctors also went through a whole raft of tests. They ended with muscle biopsies, which were sent to a specialist doctor in Hammersmith, along with some photographs of Matthew."

Matthew was diagnosed with myotubular myopathy – "Although it was a relief to get the diagnosis because at least we now knew what we were dealing with, it was also extremely difficult," says Ed. "We didn't know anything about the condition and were told not to google it because of the awful stories you can find online. Of course we did, but we also came across some great charities that gave us information and support."

After four months in hospital, Ed and Sarah were allowed to bring Matthew home, where he was regularly ventilated overnight using a mask ventilator. However, at nine months old, he was back on the intensive care unit with breathing difficulties. "We made the decision then for Matthew to have a tracheostomy – where a tube was inserted into the windpipe and connected to a ventilator. Since then, he has been ventilated this way 24/7, as if the ventilator comes off he will stop breathing."

Getting out and about together as a family has also been difficult. "It takes about an hour for us to get ready and make sure we've got all the emergency bags, ventilators, oxygen etc, and get out of the house. We also need to check places are accessible, so often just stick to places we know."

Several years ago, the family were approached by the founder of the charity Sebastian's Action Trust, "The charity is all about **enabling families to spend time together in a safe and accessible environment**, which has been invaluable to us. We have **stayed** at its purpose-built facility, The Bluebells, **for holidays**, but also, as it is just five minutes away from us, we will often just **pop in at the weekend or after school**."



"Matthew and my five-year-old daughter, Charlotte, love using the facilities – including the swimming pool and art room – and Matthew loves the freedom as there's space for him to zip around in his wheelchair and explore, with a carer following behind. I can have a cup of tea and relax, knowing they are happy and safe. Meeting other people who understand what we're going through has also helped. I also attend a dads' group and Charlotte now attends a weekly club for siblings, which provides her with a network of people she can talk to who understand her situation."

The charity has helped to **relieve some of the worries** that come with caring for a child with a serious health condition. "Being in this environment – dealing on a daily basis with complex medical needs, an uncertain life expectancy, the appointments, the emergencies, the stresses, all that sort of stuff – is like being on a roller coaster, and you don't know what to expect from one day to the next. The fact there is somewhere we can go, irrespective of what's going on, and be supported is critical to keeping our spirits up".

Evaluation three: Child support

Executive summary

Sebastian's Action Trust (SAT) runs a child and youth support programme for children with a life-limiting or life-threatening condition and their siblings. Through regular group and one-to-one sessions, youth support workers offer children and young people creative activities, a chance to meet children in similar situations and emotional support.

Research reveals that in comparison with children in the general population, siblings of children with a life-limiting illness have a reduced quality of life, a higher level of emotional symptoms and more behavioural problems (Fullerton et al 2017).

The Youth Support Service is highly valued by families both for the one-to-one support it offers, as well as for the regular group sessions. In addition to scheduled one-to-one support the youth support workers also offer additional sessions to families during times of increased pressure, such as during protracted hospital stays. The youth support worker does not only support the child or young person. Their presence also reduces the loneliness of parents and strengthens family relationships. It also has a positive impact on the mental health of all family members.

The Project

Current funding levels do not enable youth support workers to give the families the level of support they feel they need. We need to realise funding levels that are high enough for families to receive weekly, or at least fortnightly, sessions and to have a say in how long sessions should continue.

During an initial visit or phone call, the youth support worker completes an assessment to determine the young person's level of need. SAT uses the Youth Star (Outcome Stars) developed by Triangle Consulting Social Enterprise to assess need. The Youth Star covers the following six areas:

- Making a difference
- Hopes and dreams
- Wellbeing
- Education and work
- Communicating
- Choices and behaviour

Of the 59 children and young people who were assessed, 27 were male and 32 were female. Across the five countries the distribution is very uneven with most families living in Hampshire and Berkshire, where SAT's two facilities are located.



Sibling Support

Sibling support is a very important and often overlooked part of supporting families with life-limited children. Within families with a special needs child, siblings and their needs are often overlooked:

“The disabled and their parents have much-needed advocates; until now their siblings have had practically none. On their behalf, I take issue with the current politically correct euphemism “special needs” children because I believe that all children have special needs. Compassion for the extraordinary trials their families endure and admiration for their achievements should not blind us to the damage done by ignoring the toll on their normal siblings. I use the terms normal, abnormal, intact, and damaged not to make value judgments but to reflect more accurately the point of view of higher-functioning siblings, who typically live in an environment that requires them to suppress taboo emotions, judgements and the evidence of their senses.” (Safer 2003)

Stepping Stones is a six session course with fortnightly after-school sessions for children between the ages of 5 and 8 years. Each course comprises approximately five participants who get to know each other well during the course. The sessions are two hours long and the youth support worker uses creative activities to help the children to explore emotions including: worry, anger and jealousy.

PYG (Pathways Youth Group) is a monthly group for older children and teenagers. Through creative activities the participants can explore emotions such as worry, anger, and jealousy as well as their role as young carers.

Families' experiences of the youth support project

“He is frustrated that it is just me. He is frustrated that he is bored. He is frustrated that he can't do things that his friends do and [youth support worker] would come in once a week. It makes such a difference. She gets him completely which amazes me because so many people don't. [...] She doesn't do active games with him she just sits down on the floor and spends hours playing Lego with him [...] and just chats to him [...] When [youth support worker] goes home he is on an absolute high because he has not caused any more pain to himself, he has had a great time with her, and it reaches so many more benefits for us than anything else.” (Parent)

The youth support worker does not only support the child or young person. Her presence also supports the parents.

Having the support from the youth support worker for day trips and hospital appointments for this family means that the father, who drives trucks at night, can sleep during the day:

“I don't think our marriage would be as strong as it has been since we discovered the Trust, because I don't have to rely on him that much. So [youth worker] taking us to Legoland means that [husband] can go to bed. [...] Happy husband makes for a calmer life.” (Parent)

“The support workers just came and took [sister] and just do activities with her and keep her occupied 'cause it was quite a stressful time. But yeah they really helped us and like I said they were really good with [sister] just taking her away and doing activities with her.” (Parent)



The families also spoke highly of the group sessions that are offered to the supported children and their siblings. One mother spoke about how helpful the Stepping Stones sessions were for her daughter:

“They got to know each other really well and it was nice knowing that [sister] was with a group of people who just understood what life can be like at home sometimes. And she was able to talk to the support workers that were there if anything was worrying her, if she felt anxious about anything, just talk about it.” (Parent)

The Youth Support Service is about more than offering fun activities to children and young people. It mitigates to some extent the impact of family life with a life-limited child and stabilises the family as a whole.

Not enough support

“Our sessions were about to end with [youth support worker] and it literally brought a lump to my throat and tears to my eyes at the thought of her not coming and [daughter] not having that to look forward to. It has made such a difference and it seems really simple.” (Parent)

Having some access to the youth support worker but not at the level the family would consider adequate causes a dilemma. On the one hand families would like regular support as they can see the positive impact this has on their child:

“She [youth worker] is fantastic. She really is fantastic. She is like a member of the family really and she does bring joy in this short period of time. So on a purely selfish level I’d like her on a weekly basis.” (Parent)

On the other hand, the little support they are getting from SAT is all they get. There is no other organisation or local authority support the families can access. As a result, the families feel they need to be thankful for, and content with, the level of service offered, rather than asking for more.

Conclusion

This evaluation has shown that SAT offers a unique Youth Support Service that families cannot access anywhere else. The service is highly valued by families, but the current level of funding is not high enough to satisfy demand.

The Youth Support Service saves public money by:

- Preventing family breakdown
- Giving siblings a space to address their feelings before they turn into serious mental health problems or behavioural problems that will impact their school attendance and performance
- Providing specialist youth services for life-limited children that would otherwise need to be publicly funded
- Providing transport and emotional support during hospital visits

Given the uneven distribution of assessments by geographic location it is very likely that more families across the five counties could profit from the Youth Support Service than currently do. All of the above points make a strong case for the need for additional, long-term funding for the Youth Support Service.



Evaluation four: Finance and welfare

Executive summary

The project covers the areas of welfare benefits, education, housing, social care, health, grants as well as individual support needs that come up during the sessions, for example planning a funeral.

Before evaluating the SAT Finance and Welfare Service it is important to understand the financial pressures families with life-limited children are under as they are distinctly different from other families.

Families with disabled children face increased additional costs not faced by other families:

- Specialised equipment including wheelchairs
- Home adaptations
- Therapies
- Sensory toys and specialised buggies
- Higher energy costs
- Higher transport costs
- Higher (travel) insurance costs

Research commissioned by the Disabled Children's Partnership estimates that an extra £1.5 billion is needed in NHS and social care services to meet the needs of disabled children (Disabled Children's Partnership 2018).

In 2019 Scope calculated the "average additional monthly income a disabled person would need in order to enjoy the same standard of living as a non-disabled person" (Scope 2019, 1). They concluded that the monthly additional costs for a family with one disabled child amount to £528, and for a family with two or more disabled children amount to £823 (Scope 2019, 8). For 24% of families the extra monthly cost is £1,000 or more (Scope 2019, 4).

Not only do families with disabled children incur higher costs but their earning potential is also limited due to the many hospital and doctors' appointments and the care needs of the child/ren. Often one parent stops work after diagnosis. As a result, families with a disabled child have on average fewer savings, fewer assets and are more likely to have a high level of unsecured debt. This puts families with a disabled child at increased risk of poverty. Forty-eight per cent of people in poverty live in a family where someone is disabled (Social Metrics Commission 2019, 32).

The Project

In the financial year 2018/19 SAT assessed 39 families, (190 individuals). The aim of the finance and welfare service is to improve the economic wellbeing of the family. The location of the 39 assessed families is as follows: 51% of the families live in Berkshire, 41% in Hampshire, 5% in Buckinghamshire, 3% in Surrey and 0% in Oxfordshire. These results are roughly in line with the distribution of families supported by the outreach service. These percentages reveal a need to ensure that families from all five counties have equal access to the service as well as establishing whether there are pockets of increased need in certain areas.



Below are examples for each of the six areas included in the assessment and other support offered, taken from the anonymised communication logs recorded in 2018/19:

- Education
- Attend Education, Health and Care Plan (EHCP) meetings
- Support in cases of difficulties with schooling
- Welfare
- How to manage direct payments including signposting to agencies who can do payroll
- Application for DLA (Disability Living Allowance)
- How to apply for Motability rate and car
- Housing
- Contact occupational therapist for house adaptation assessment
- Help to write an application for adaptations
- Grants
- Equipment
- Home furnishing and flooring
- Social Care support
- Child and Family Assessment for Social Services
- Transition to Adult Social Care
- Develop debt repayment plan with family
- Create household budgets with families

Families' experiences of the finance and welfare programme

When faced with the extra cost and care of having a life-limited child most parents do not know what support they are entitled to or how to apply for help:

"We had someone come to our home as well to do a financial breakdown list of what we may or may not be entitled to. Cause when you have a child with a disability you don't know where to turn and it was really nice that they came out and talked us through everything. There was no such thing as a silly question as far as they were concerned. Being brand new to it you don't know anything, and they have all the information that you would possibly want and they are very supportive about the way they give it to you as well. And they don't just bombard you with so much information that you can't take anything in. It is very much in bite size chunks but the chunks are relevant to you so you can tell it is very much they have looked at [daughter] and what her needs are and they go about how can we assist the family not just [daughter] but assisting the whole family to help with the condition that she has got rather than just label her as disabled and bombard you with all that information, 90% of which isn't necessarily relevant. So that was really nice." (Parent)



For this family the benefit check meant the father qualified for Carer's Allowance and could stop working in the afternoons to care for his daughter. This has made a big difference to the family. This family was also able to get new equipment for their daughter and with the father at home in the afternoon he could use it with her to support her development.

Many families feel daunted by the prospect of filling out forms and appreciate the assistance of a Finance and Welfare worker.

"I am not very good at forms and paperwork. It is a nightmare. So, I know I can come here, and somebody will sit down and go through it with me." (Parent)

Interview participants have also mentioned that outcomes improved as a result of the involvement of SAT.

Interview participants also indicated that better information, advice and help have empowered them and given them the skills to achieve more independently.

"Because I didn't know nothing about any of that – so you know – the fact that they have given me the information, now I can do something with that, like I didn't know that I can get a mobility care for [son]" (Parent)

A big part of the Finance and Welfare service is to maximise the families' income by applying for benefits and grants. The Finance and Welfare workers also support the parents in reducing their outgoings by offering budgeting and debt advice.

"They are helping me to get my finances in order, sorting all my debts out, just everything really" . (Parent)

Parents of disabled children who care for their children 24/7 are often tired and already stretched. There is also the emotional impact. This leaves them with little time, resources and headspace to research and apply for benefits. The SAT Finance and Welfare service makes the very complex system of benefits, health and social care services and grants accessible to parents.

Interview participants indicated that their extended family is supportive but at the same time too close to the life-limited child and too emotionally involved.

"Without support I don't think I would be able to cope; I wouldn't know where to go, I think I would have just crumbled and sat in the corner and hoped that somebody would help me. I don't think I would know what to do, where to go, anyway you would rely on your mum but I don't think my mum would have even you know she was an emotional wreck as much as everyone else in my family so just to have someone that wasn't connected." (Parent)

Finance and Welfare workers offer emotional and practical support to families during times of change and transition. They help children move to a new school, move to adult services once they reach 18/19 years of age and support parents with school and college applications.

In 2018 the Finance and Welfare and outreach workers helped a family to plan, organise and apply for funding for their daughter's funeral. The outreach worker connected the mother to everyone. The prospect of losing a child is daunting. In addition to coping with this emotionally, the mother cared for her daughter and the younger siblings. The thought of organising and financing a funeral was overwhelming to her:



"I didn't know where to start, who to ask, what I could get, what help I could get, what I would need to pay for myself. She did amazingly. And it wasn't full on, it was calm and at my own pace it wasn't stressful, you wouldn't even know that you have done stuff. It was all sorted, her funeral, before [daughter] passed away. Which really took the stress off. So, when she did pass away, I literally had [brother and sister] and [referred daughter] to watch and that is it. She is an amazing lady." (Parent)

This report has revealed that the Finance and Welfare service offers families a very tailored and individualised service that increases their economic wellbeing.

Transport

SAT offers transport to families, mainly but not exclusively, to hospital appointments. The supported children are often in the care of several hospitals that can be located at some distance from the family home, for example in Southampton, London or Oxford. The logistics of getting to these appointments are not easy and using public transport could entail a lengthy journey, which is not always accessible or suitable due to compromised immune systems. Moreover, taxis are expensive.

In addition, some children require someone to sit next to them during the journey for safety. Once at the hospital the parking charges are high, especially if the child is in hospital for weeks at a time.

"I mainly use service for transport because neither me nor my partner drives and [son] is very complex and spends a lot of time in hospitals further away either for appointments or surgery. So instead of me getting a train to Southampton and then getting two buses to the hospital, do the appointment and come back I get picked up at home in a car that is suitable for [son] and all of his equipment, taken there, they either spend the time with you in the appointments for company or if you are more comfortable on your own they'll go off and then bring you all the way back. So, it makes life a million times easier." (Parent)

The provision of transport plays an essential part in stabilising families both emotionally and financially.

SAT also offers transport to take families to The Bluebells or The Woodlands for events and even drove one family to their holiday.

At times demand for transport provision outstrips supply. It would be highly beneficial if SAT could secure additional funding to provide transport, as it alleviates stress on the families who use it and makes their lives easier. The potential availability of transport even reduces stress and offers peace of mind to families who do not use it:

"If I had a really important appointment to go to and my husband could not make it I know I can phone up and ask [outreach worker] to come with me and I know that she would. So that kind of support – I have never needed it – but I know it is there. That is really good to know, that takes the pressure off just in that kind of situation". (Parent)



Evaluation five: Bereavement care

Executive summary

Sebastian's Action Trust (SAT) supports a growing number of bereaved families through the Bereavement Care Support Programme (BCSP). The BCSP is very specialised bereavement support, as it is solely for families who have a critical palliative child with a life-limiting condition, or who have lost a child due to a life-limiting or life-threatening condition. SAT offers a whole family approach and supports bereaved parents, siblings and grandparents. Families in this cohort are called 'Butterfly' families.

SAT runs an annual programme of events specifically for bereaved families to reduce social isolation. During the 2018/19 financial year SAT organised 10 events which were attended by 145 people. In addition, 43 individuals were offered one of the 12 Bluebells 'Butterfly' breaks.

Some families receive pre-death bereavement support, which includes memory and keepsake making opportunities as well as support with the practical and emotional preparations for their child's death, such as advance care plan and funeral planning, which are topics parents cannot often discuss with anyone else.

Another unique feature of the BCSP is that the bereaved families decide for how long they wish to be supported. Unlike other counselling services which either offer a set number of sessions, or offer support for a specified time (for example one year post-death), SAT leaves it to the parents to end their involvement. This gives families the assurance that they are not alone. It also acknowledges that periods of grief can be triggered years after the child is deceased.

Families' experience of alternative bereavement support has shown that there are only limited alternatives available and the families found them less suitable because they:

- Required set appointments with no flexible or short notice support
- Took place in a medicalised environment that bereaved families do not wish to enter, especially in the hospice or hospital where their child died
- Were delivered by non-specialised counsellors
- Had too limited availability in the NHS

The experiences and needs of bereaved families should be considered when planning and commissioning bereavement support services. For many families, both the hospice and other medical environments retain negative memories as those are the places where their children were at their worst and in many cases died. This makes it difficult for parents to go back. For families to learn to live with the loss of a child, but also to move forward in their life, a non-medicalised environment such as the one offered by SAT is more conducive. It offers specialist bereavement support but also a relaxed space to come, meet other families and enjoy time as a family. Unlike bereavement support in a formal, appointment-based practice, BCSP acknowledges that there is more to a bereaved family's life than grief, even when it feels all-consuming. Sadness and happiness, memories and new experiences are present at the same time, and SAT caters for that.



The Bereavement Care Support Programme (BCSP) in 2018/19

Families are referred to the programme for pre-death bereavement support if the child is critical palliative. Alternatively, families who have not received pre-death support can be referred for post-death bereavement support once the child has passed away. SAT has no formal way of assessing family need other than offering families the support they wish to engage with. Support is ongoing for as long as the family wants it. The bereavement service is user-led, and the Bereavement Support Worker (BSW) responds flexibly to the needs of the families. As with their other services, SAT offers a whole family approach and supports bereaved parents, siblings and grandparents – individually and collectively.

During 2018/19, the BCSP supported 102 individuals from 97 families with face-to-face emotional support, activities and events, short breaks at The Bluebells, bereavement support for siblings and a dedicated Facebook group for bereaved families.

Critical and moderate families have more direct contact with the BCSP and also receive thoughtful cards and gifts (for example a memory candle) to commemorate:

- The child's death
- Anniversaries of the child's death
- The child's birthday
- Father's Day
- Mother's Day
- Christmas

Over two thirds (76%) of all individuals who are supported through the BCSP live within the five counties covered by SAT. The other 24% live in other parts of the country. This is partly due to the availability of 'Butterfly' breaks at The Bluebells to families from all around the UK, and partly due to families moving from the five counties to other areas.

Families' experiences of the BCSP pre-death support

Table 1: Level of need for individuals supported	
Score	Number of individuals
Critical	11
Moderate	28
Maintenance	63
Total	102

Table 2: Location of supported individuals in five counties	
County	Number of individuals
Berkshire	29
Buckinghamshire	6
Hampshire	22
Surrey	3
Oxfordshire	18
Total	78

"I think it is amazing that as the main person for the bereaved families she comes and walks alongside you before the bereavement happens, so that you know her, which is just outstanding and it is not something that is done anywhere else." (Parent)



Families who receive pre-death bereavement support are offered memory and keepsake making opportunities. SAT can also support families with practical and emotional preparations for their child's death, such as the advance care plan and funeral planning, which are topics parents can often struggle to discuss with anyone else:

"I could speak to [BSW] about concerns I had around funerals and things and it wasn't scary to her because it is [her] every day and I have not been able to speak to anybody else [about] my son's funeral and the fact that I am even having to think about that. Everybody else just backs away from it and it is too scary whereas to her that is part of normal life and she is perfectly happy to walk me through this process and the concerns that I have." (Parent)

For families whose children are not at the critical palliative stage, just knowing that the BCSP is available, is comforting.

"Our son has an unknown life expectancy with his condition and as scary as the thought is, I know that when that time comes, I guarantee [outreach worker] or somebody will be next to me, supporting me, there is this place for respite. When you think of the scary things at least there is this little ray of hope because everything they have to offer here you know with [BSW] and everything she does." (Parent)

Families' experiences of the BCSP post-death support

The Bereavement Support Worker is pro-active in engaging families and sends letters and messages to families who are new to the service, or who have not been in touch for a while, to remind them that SAT is there to support them. With the death of their child, families instantly lose all connection to, and support from, (medical) professionals who have until then been a big part of their life:

"I know when [son] passed away it was very odd as we have been surrounded by medical professionals and hospitals and nurses and when that all fell away it's actually dreadful- even though it's not nice to be in that environment it's very disconcerting to suddenly just be left you know all that falls away and you are just kind of there. And having this, access to this kind of service has really picked up where that kind of comfort blanket left off." (Parent)

Not only does the lack of medical involvement after the child has passed away leave an absence of people to talk to, it also leaves families with a lot of free time that had up until that point been spent in hospitals or hospices. This can enhance the feeling within bereaved families of being lost.

Flexible service at short notice

Grief is unpredictable and not linear. A service that has a long lead time for appointments would therefore not be suitable to meet the families' need for support.

The 'Butterfly' families can contact the SAT Bereavement Support Worker at any time; they will get back to them quickly, and can offer appointments at short notice if needed. Equally the frequency of contact is flexible according to the situation of the families.

The BCSP service is not only flexible with regard to time but also with regard to location.



"The first couple of times she came by and hung out for 20 minutes and it was always like, yes, we will get to this and we will get to that and we can talk about this that and the other. And she leaves and I would feel better, but I also assumed that she was just between two places and stopping by to have a quick chat on her way. And we were all making plans about things. It wasn't until the third time that it finally dawns on me that no this is, she is doing her job. And that is why I feel better every time she comes." (Parent)

It also allows (younger) siblings to either be in their familiar environment at home, or at one of the SAT venues where there is lots to do and play with. Parents prefer this to taking a child to an appointment which is a bit more structured, or more like a doctor's surgery or hospital.

Continuity of the bereavement support coordinator

In a climate where the service delivery is dependent on short term grants and donations to sustain it, this can be challenging to achieve. It would be preferable for funders to offer longer term grants for this service so that families can be adequately supported.

"Building up that rapport with somebody when you are talking about very deeply personal things and you feel very vulnerable talking about it is really important isn't it? You don't want to see another person every time." (Parent)

Lasting support

Another unique aspect of the BCSP is that the 'Butterfly' families decide for how long they want to be supported.

This gives families the assurance that they are not alone. It also acknowledges that periods of grief can be triggered years after the child is deceased. For example, some parents struggle when they get to the point where the child has been longer dead than alive, or when a younger sibling is older than the deceased child was. And then there are days throughout the year like the child's birthday and anniversary of death that are difficult.

Peer to peer support – in the same boat

In addition to direct support from the Bereavement Support Worker, parents have the chance to support each other. 'Butterfly' events offer parents the opportunity to meet other families in the same boat:

"I didn't realise how much it is helpful to talk to other families who have been through the same thing." (Parent)

The Bluebells and The Woodlands are also safe spaces for families who are not ready to go out in public and face other people and their reaction to the child's death.

Friendships made at SAT can also help to keep the memories of the deceased children alive.

"I have made friends through the bereavement side of things so I have met another mum who lost her daughter a month or two month before [daughter] so we were really in a similar stage and we don't live far away from each other and she had a younger daughter so her little girl and my [daughter] were the same age and her daughter and [son] are the same age and they were both younger so they both lost their older sister. There were lots of things that were the same which was really, really helpful. So, I have met her, and she has been amazing. And we can talk about our girls forever and a day". (Parent)



Improved/sustained mental health/wellbeing

Interviewed families have reported that without the BCSP their mental health would be worse:

“We have [hospice] and we have here and that is the only support that we get and having to have gone through advanced care plans and things with no one to talk to would have definitely had a different impact on mine and [father's] mental health. Yeah I think we would be in a much darker place.” (Parent)

An Advanced Care Plan (ACP) is a formal care plan that ensures that children and families have a say in the care that they wish to receive. It forms a core part of palliative care. The ACP is first and foremost a medical document and usually completed by medical professionals together with the family. The ACP requires difficult decisions of the parents, for example, whether they want their child to be resuscitated or not. Guiding families through this process requires professionals to be sensitive. The emotional implications for the parents can go way beyond medical decisions. For some parents it might be the first time that they admit to themselves that there is a chance their child may not live. It is important to give parents space to talk about the emotional impact the decisions have on them.

Which organisation is best placed to offer bereavement support?

Listening to the families, it seems that they do not consider hospices the right place for this support. Hospices provide a fantastic service in terms of supporting the families through the final days or months of their child's life, and the first few days after the child has passed away. All families spoke highly of the support they received from the hospice. At the same time, they were also clear that they find it incredibly difficult to go back.

SAT and The Bluebells, on the other hand, hold only positive memories for families. Hospitals and hospices only see the children when they are at their worst, whereas at SAT the families have spent good days, made memories and there are people who have known the child beyond the condition and medical needs.

Conclusion

Families who have lost a child need a specialist bereavement service. As the loss of a child disrupts the natural order and the expectation that children outlive their parents, it would be inappropriate for parents to attend a general bereavement support service with people who might have lost their elderly parents or a relative. Currently there are few, if any, options available to bereaved families, and what is available is offered either through the NHS or hospices. The families interviewed for this report consider these medicalised settings not suitable for bereavement support. They particularly attach negative memories to the hospice where they spent the final days with their child. This makes them reluctant to return to the hospice.

This report has shown how well received the BCSP is, and how SAT is ideally placed to provide that kind of service. It would be beneficial to secure long-term funding for the service as it is meeting an otherwise unmet need of bereaved families. Families need reliable, long-term support ideally provided by the same Bereavement Support Worker .



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