

# Strategic Impact Report

For the year ended 31 March 2024





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# Strategic Impact Report

## Welcome

At Lifelites we passionately believe that all children with life-limiting conditions and complex disabilities should enjoy a childhood filled with special moments of fun, learning, happiness, and meaningful connection.

Since 1999, we have provided cutting-edge technology, training, and ongoing technical support free of charge to children's hospices and palliative care services in Britain and Ireland. Over this time, thanks to our unique services, around 10,000 children each year have been able to access the joy that this life-changing technology brings. We know first-hand that these priceless moments not only brighten the lives of the children but also bring immense joy to their families.

The children's palliative care sector is changing at pace. With advances in clinical care, more children and young people in the UK are living with life-limiting and life-threatening conditions. The services they are accessing and the settings in which they are receiving support are also evolving. Today, an estimated 99,000 children are navigating these challenges, often with increasingly complex needs. Most are supported beyond hospice services in hospitals, community settings or at home.

In April, we launched our ambitious new strategy, at the heart of which is our Vision that **every** child with a life-limiting condition will be able to engage and interact with the people they love and enjoy the world they live in.

To turn this vision into reality, we have reimagined our service model, forming exciting new partnerships across the wider children's palliative care sector. This has included an exciting new collaboration with Sebastian's Action Trust, a short breaks, outreach and family support service, extending our reach to another 1,000 seriously ill children and young people. Based on this experience, we are now developing further partnerships.

Over the last 12 months, this expansion has given access to the latest assistive and sensory technology for 13,710 children but this is just the start.

In order to increase our reach and performance over the longer-term, we have been laying the fundamental foundations to ensure that we can deliver our strategy safely, sustainably and to the highest quality.

As we drive forward, we are determined to bring life-changing technology to more children through innovative, impactful partnerships with respite centres, specialist care facilities, and special educational needs services across Britain and Ireland.

Central to this will be our transformational Lifelites 25 programme, which will be the epicentre of our 25th anniversary celebrations. You

can read more about Lifelites 25 later in this report but we are planning a once in a generation investment into children's palliative care, to extend our reach far beyond our current achievement and closer to the 99,000.



The last year has been a journey of discovery and we would like to thank all of our key partners and stakeholders for their advice, encouragement and support, which has enabled us to think bigger and initiate such ambitious plans for the future. We are particularly grateful to our partners in Freemasonry whose ongoing support is integral to our aspirations. We are proud of the progress we have made in the last year but we are under no illusions there is still much work to be done.

And we know that partnerships both large and small, formal and informal will be integral to achieving outcomes for children and their families. As we seek to accelerate through our strategy, your support is more crucial than ever.

While reading this report, please think about how you can help us achieve our Vision. Can you spread awareness of our work within your network? Can you volunteer your time to help us raise funds? Can you contribute more today or consider leaving a legacy for the future?

Whatever you choose to do, we greatly appreciate your past and future support for Lifelites, and we look forward to strengthening our relationship in the coming year and beyond.



**Tony Harvey**  
Chair of Trustees



**Rob Lightfoot**  
Chief Executive

# Vision, Mission & Values

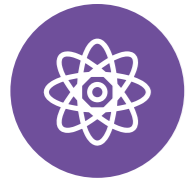
## VISION

We believe every child with a life-limiting condition, should be able to engage and interact with the people they love and enjoy the world they live in.

## MISSION

We harness innovative technology to empower all children and young people with life-limiting conditions, along with their families, to experience unforgettable moments of connection and joy.

## VALUES



### Dynamic

We constantly evolve to respond to the changing needs of children, families and partners, adapting our approach and using our expertise to maximise our impact.



### Inclusive

We look beyond the traditional, obvious and familiar to remove barriers that prevent children and families from connecting, playing and expressing themselves. We partner with and recruit people based on their merits and alignment to our goals.



### Collaborative

We bring together and collaborate with diverse people and organisations that share a common passion for our Vision, believing that combining resources improves outcomes for all.



### Empowering

We believe everyone has an innate desire to play, create and communicate. We empower children, their families, our partners and our team to discover and reach their full potential.



### Innovative

We seek new ways to achieve our Vision, serve children in need and their families, develop our team and build our relationships with our partners.

## 2023/24 at glance



**14**  
packages of new technology.



**57** children's palliative care partners across Britain and Ireland.



**195**  
children's palliative care staff trained.

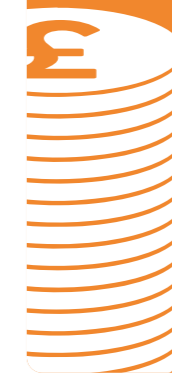


**2,084**  
hours worth of training delivered.

**13,710**  
children and young people accessing support.

**10,638**

miles travelled to deliver installations and training.



**£608,000**  
worth of new equipment, training and technical support.

# Quality

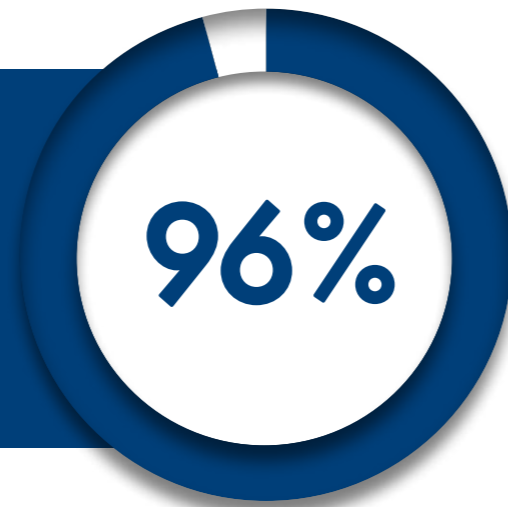
Central to our strategy is the ambition to deliver the highest quality services providing maximum impact for our service partners, children and their families.

Our unique services enable children to play, create and communicate, contributing to measurable improvements in their wellbeing. 2023/24 partner monitoring data highlights:



## Improvement in emotional wellbeing

100% noted enhanced emotional wellbeing, with our technology alleviating stress and boosting happiness.



## Reduction in social isolation

96% of partners reported that our services significantly reduce social isolation, helping families stay connected.



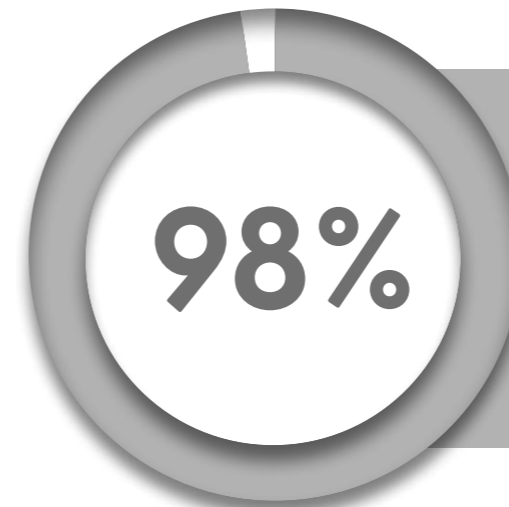
## Enhancement of communication

94% reported improved communication, particularly enabling non-verbal children to express themselves.



## Increased independence

98% observed increased independence in children, enabling them to engage more actively and take control.



## More resilient families

98% saw strengthened family relationships and resilience.

## Shay and Alan family story

Like many teenagers, Shay is an enthusiastic gamer. He loves to use the Lifelites technology when he visits his local hospice, where he can enjoy world's of excitement using special adaptive controls or get lost in the adventures of VR gaming.

Shay has Pearson syndrome, an incredibly rare mitochondrial disease that affects multiple body organs.

Shay's dad, Alan, explains the impact Lifelites has had on Shay:

**“Gaming gives Shay an opportunity to connect with his peers and control something for himself. Video games have been fantastic. They keep him believing he is a normal kid; he would not be able to play football with friends, but he can play FIFA!**

**Gaming provides a shared interest and it lets him compete on the same level, even though he has a disability.”**

**“Shay's condition has affected his memory, but when he's playing online with his friends, they're flowing, they're chatting away.**

**Shay doesn't know a lot about his condition, but he knows he's different from other children. This technology gets him away from it. He doesn't think about his feeding tube or his medicines as he plays.”**



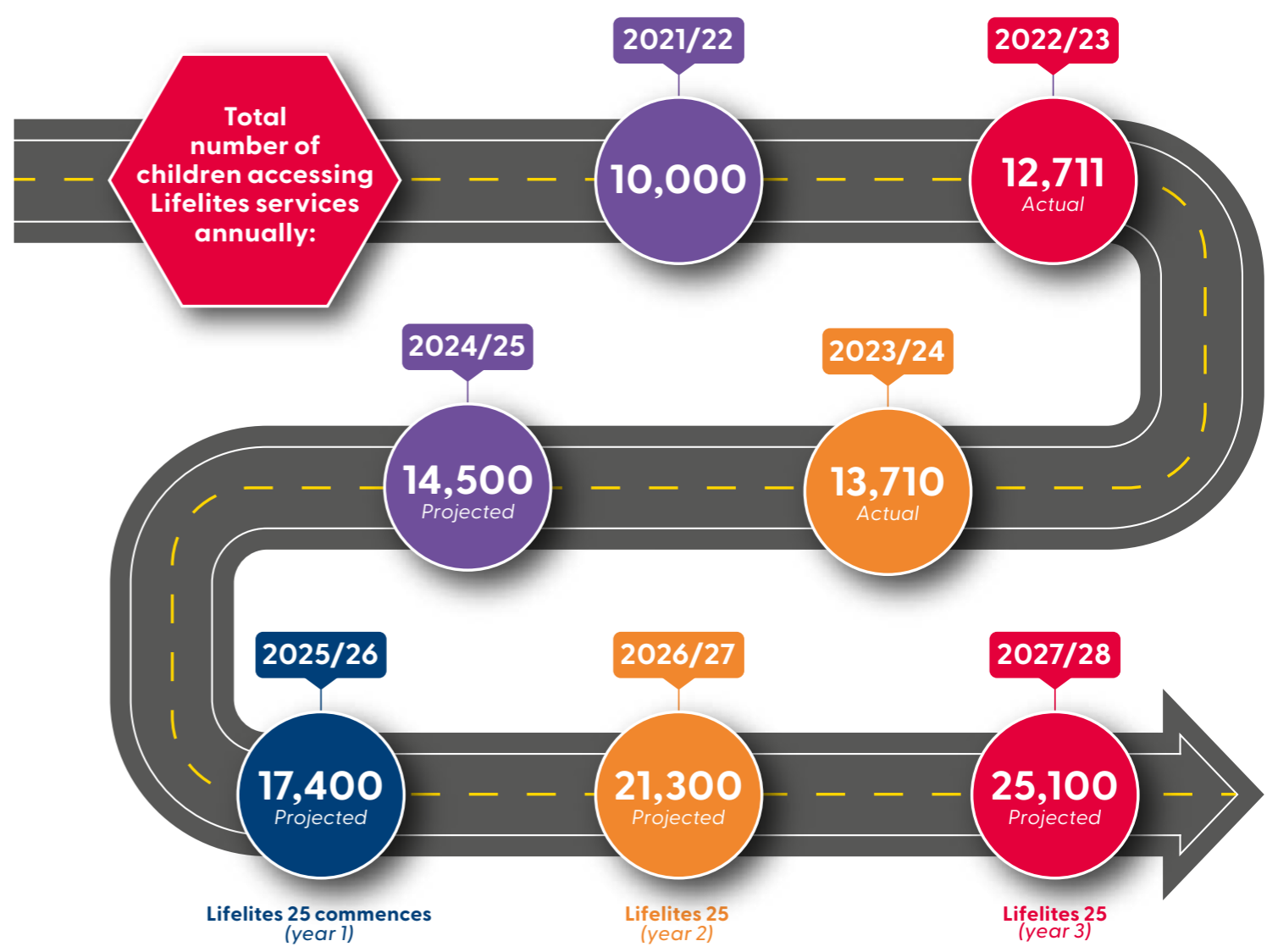
# Access

National charity,  
local impact



Lifelites has long had the aspiration to expand its reach, most recently developing the Tech Trunk to provide support for hospice at home and community services. We want to go much further by developing new partnerships with respite centres, specialist care services and special educational needs organisations across Britain and Ireland.

Over the last two years we have added new core service partners and identified many more with whom we would like to work in future. By evolving our service model, we aim to double the number of children accessing our services by 2028.



# Beyond hospices

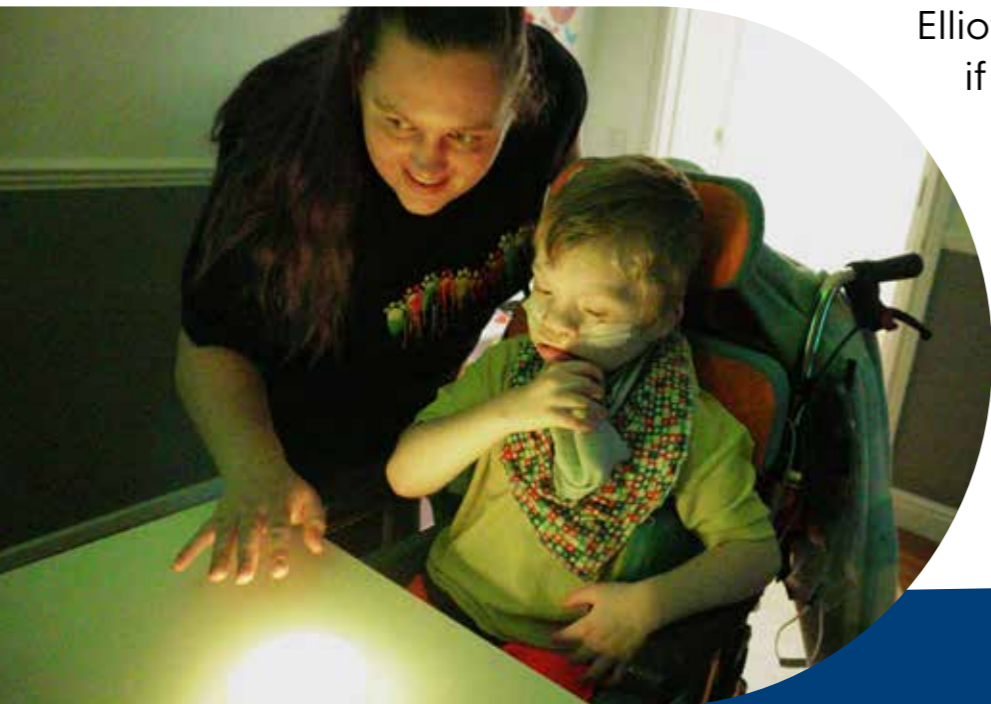
## Creating memories in partnership with Sebastian's Action Trust

In December 2023, we proudly launched our newest partnership with the incredible Sebastian's Action Trust, which provides family breaks and holistic support services for families living in Hampshire, Berkshire and surrounding areas.

As we installed this brand new package of technology, we were honoured to meet Elliot and his mum, Marnie, as they tried out our assistive technology for the very first time.

Elliot is a happy, vibrant 7-year old boy who loves to dance and play. He was born with a rare and complex genetic condition called 8;18 unbalanced translocation, which causes a variety of health issues.

Marnie says **“Elliot is a massive fighter. We've nearly lost him twice. He's on full-time oxygen, he's got a single kidney, his stomach doesn't work, he's had 12 surgeries, he's been intubated twice but he's still here and he's the healthiest he's ever been. He's the light of my life and I'm so lucky to wake up to him every day!”**



Elliot is full of life, Marnie says if things were different she thinks he'd be a ballet dancer because he loves music.

We let Elliot loose on our equipment while we chatted to Marnie.

**“We've had support from Sebastian's Action Trust since Elliot was four months old. They've been there for us through the good, the bad and the ugly.”**

**“We come here for so many different activities, therapies and support. We don't know how long we've got with Elliot but it's so important for us to know that when the time comes that we lose him, he's got some amazing memories of doing all the things that he loves.”**

We moved back through to see how Elliot was getting on. We found him playing with the Cosmo, a unique sensory switch system, which re-imagines physical therapy and play and helps to improve both cognition and physical mobility.

**“He is loving being in control” says Marnie, “a lot of our children can't communicate, but with technology like this, it's led by him. They can show us what they want and what they like. For example, different colour switches. We can see which switch he navigates to and we can see what his favourite colour is and stuff like that.”**

For Marnie enabling Elliot to express himself and let his bubbly personality come to the fore is vital for his development.

**“He loves people, he's very social. He is just your typical seven year old, but he just can't express it the way most seven year olds do.**

**He's been out here for half an hour now, quite happily, independently playing, which is so, so important for our children because so much of the time they're vulnerable and need protecting.**

**So when they can do an activity independently, it's so important for their mental health and their development that they can express who they are.”**



# The power of partnerships

## The power of partnerships in children's palliative care

At Lifelites, we believe in the transformative power of technology and collaboration. Our partnerships with children's palliative care services like Naomi House and Jacksplace are at the heart of our mission. This case study highlights the impact of our work through the experiences of two dedicated Lifelites Champions, Claire Potterton and Claire Floyd, whose passion and commitment have significantly enhanced the lives of children and young adults in their care.

## Meet the Champions

Claire Potterton has been a part of the Naomi House and Jacksplace team for two years, serving as the Play and Activities Team Lead. Her role involves creating meaningful and memorable experiences for children, young adults, and their families, often in challenging circumstances. Claire emphasises the privilege she feels in making a difference, providing spaces where families can connect, laugh, cry, and create lasting memories together.

Claire Floyd brings nearly 20 years of experience to her role as an Activities Team Youth Worker. With a deep commitment to helping young adults achieve greater independence, Claire has been a Lifelites Champion since 2005. Her long-standing involvement with Lifelites reflects her dedication to empowering young people through technology, even as they face the most difficult times in their lives.



## The impact of Lifelites technology

Both Champions have seen first-hand how Lifelites technology can transform the experiences of the children and young adults they support.

For Claire Potterton, the PODS Sensory Tent is a stand out piece of technology. This versatile, inflatable tent allows her team to create immersive, sensory-rich environments tailored to the needs of the children. It's used daily for calming sessions, one-on-one activities, and sensory stories, making it an indispensable in their care toolkit. The Eyegaze technology is another critical asset, offering children a new way to communicate and interact with their surroundings. Claire has witnessed how these tools open up opportunities not only within Naomi House but also in the children's broader lives.

Claire Floyd, on the other hand, highlights the Click-on Switch technology. This device allows children with limited mobility to operate everyday items like fans and food mixers, fostering a sense of independence that might otherwise be out of reach. Claire recounts the joy of seeing children engage with these tools, gaining confidence and control over their environment.

The impact of Lifelites technology extends beyond the immediate sensory and communication benefits. For many families, it provides hope and reassurance. Claire Floyd shares a touching story of how Lifelites technology helped a non-verbal child communicate with his family for the first time. The simple yet profound moment of a child saying "Hi Nanny" through an app provided by Lifelites brought tears of joy to the family, demonstrating the profound difference that access to the right technology can make.



## Stronger together

These stories underscore the broader outcomes of the partnership between Lifelites and Naomi House and Jackspace. By providing cutting-edge technology and training, Lifelites empowers care teams to deliver more personalised and impactful support to the children and young adults they serve. The result is a more enriched, engaged, and empowered community, where children can explore their potential and families can find moments of connection and joy amidst challenging circumstances.

The partnership between Lifelites and Naomi House and Jackspace exemplifies the power of collaboration in children's palliative care. Through the dedication of Lifelites Champions like Claire Potterton and Claire Floyd, technology becomes more than just a tool—it becomes a lifeline, a source of joy, and a gateway to independence. Together, we are making a tangible difference in the lives of children and their families, showing that with passion, innovation, and teamwork, we can achieve extraordinary outcomes.



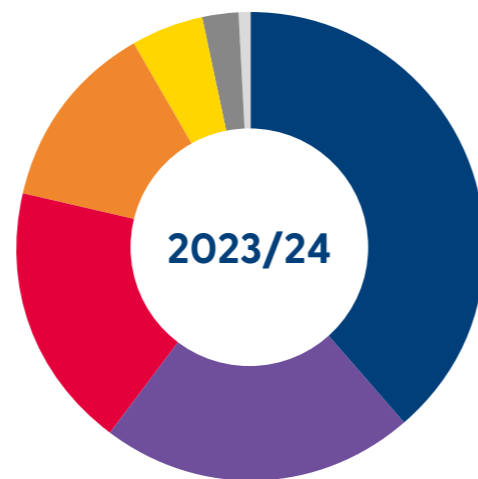
# Strategy enablers

## Income

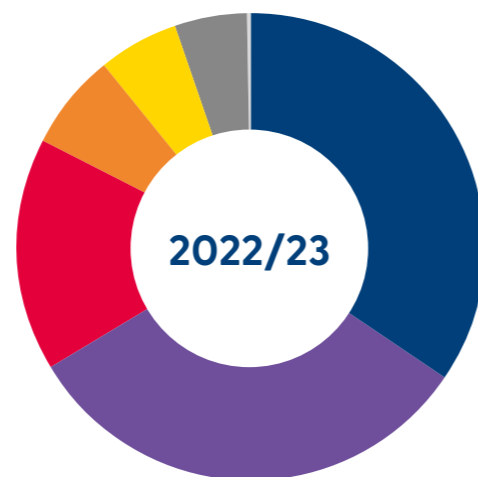
Fundraising in the year was challenging and we are extremely grateful for all those funders and individuals who chose to support Lifelites during such difficult economic circumstances. Overall, our income for the year was both down on our target and prior year performance. However, the figures in isolation do not tell the story of enormous progress as we have established a new fundraising strategy to diversify income and seek to improve recognition and retention with existing supporters.

In the year we were delighted to work with a number of new major funders, including Wooden Spoon, the Smurfit Kappa Foundation and VINCI Foundation, as well as receiving support from long-standing partners from Freemasonry, Childwick Trust, the Worshipful Company of Information Technologists and GamesAid.

Income source	2023/24
Charitable Trusts	190,000
Investment income	107,000
Community - Freemasonry	91,000
Corporate	64,000
Individual Giving	24,000
Gift-in-Kind	12,000
Events	4,000
<b>Total</b>	<b>492,000</b>



Income source	2022/23
Community - Freemasonry	226,000
Charitable Trusts	209,000
Investment income	106,000
Individual Giving	44,000
Corporate	37,000
Gift-in-Kind	32,000
Legacies	1,000
<b>Total</b>	<b>655,000</b>



## Expenditure

During the year, despite the challenging fundraising climate the Charity honoured all its funding commitments to our children's palliative care partners. To ensure this level of continued investment, costs were held back elsewhere whilst attention focussed on ensuring internal building blocks for good governance, fundraising development and service expansion aspirations were developed thoroughly.

Expenditure Source	2023/24	2022/23
Equipment, installation and technical support	349,000	364,000
Partner support and service management	259,000	211,000
Generating income	185,000	183,000
Investment management	20,000	21,000
<b>Total</b>	<b>813,00</b>	<b>779,000</b>

## Targeting our resources where it matters most

At Lifelites, 75p of every £1 we spend goes directly towards delivering our charitable activities. This includes the cost of technology, specialist technical support, training, advice for partners, and project coordination. This high level of efficiency ensures that donations are used effectively to make the greatest impact on the lives of children with complex disabilities and their families.

## Brand

Brand performance within the year held steady, with some positive increases in engagement on social media platforms. The new Lifelites branding and case for support gained traction with new audiences evidenced by new partnerships with trust and corporate partners. During the year we commissioned a comprehensive review of our website performance and identified a clear need to develop a new website, which will be launched in September 2024. We also laid a solid communications plan for our 25th anniversary celebrations, which we intend to use as a platform to transform awareness of our unique work.



## Governance

Significant progress was made during the year in our ambition to align to the Charity Governance Code. A comprehensive self-assessment was undertaken in May 2023, which resulted in a thematic action plan addressing a wide range of improvements against each of the seven principles of the Code. At the end of the period, this action plan was almost complete and the Charity is due to complete a further self-assessment in July 2024 to review and identify further recommendations for implementation.



## People

As part of the resourcing requirements for our new strategy, Lifelites recruited successfully to a new role within the Services department within the year. This role will drive quality and engagement with our partners across children's palliative care and provide an essential link between service delivery and communications. Elsewhere, we successfully recruited an experienced Head of Fundraising and Communications, who rapidly set about auditing all departmental operations and established robust long-term plans for improved brand awareness and income diversification.

## Future plans

### Celebrating Lifelites at 25

Our Strategic Plan 2023–28 is designed to centre on Lifelites 25th anniversary and it is intended to use this milestone as a catalyst to transform the organisation into a dynamic, influential provider of services across children’s palliative care.

At the heart of these plans is Lifelites 25, our unique partnership programme, designed to significantly increase access to assistive technology for children with life-limiting conditions and to deliver transformational partnerships which will break new ground in the use of digital and technology services for children and families. Lifelites will identify 25 new projects over three years, both large and small as we seek to ensure that more children and young people with life-limiting conditions have the opportunity to experience unforgettable moments of connection and joy with their families.

The programmes will launch in Autumn 2024.

### Sustainability

Increasing brand awareness and diversifying our income are key priorities within our strategy. In order to achieve our ambitions long-term, it will be fundamental for Lifelites to increase the scale and diversity of our funding. To this end, we will be seeking to develop corporate, philanthropy, legacy and individual giving programmes, which will be a significant focus in the coming year. In addition, we have already put improved donor recognition and retention plans in motion and intend to ensure that both new and existing supporters are engaged, motivated and bought into our journey. Much of this activity will pivot around Lifelites’ 25th anniversary as a unique opportunity to celebrate our achievements, inspire and engage new and existing supporters.

This kind of long-term income growth and diversification will take both resources and time. Therefore, the Trustees have established a designated fund to invest in brand awareness growth and long-term income diversification, relationship management and sustainability over the duration of the strategy.





## Lifelites

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Charity No: 1165791