



Annual Review 2023

and Chief Executive

Welcome from our Chair

We are delighted to present our Annual Review for 2023.

Lifelites is an innovative charity which enables children and young people with life-limiting conditions to play, create and communicate. We do this by providing assistive technology and high-quality training to every children's hospice in the British Isles, enabling thousands of children and families to experience unforgettable moments of connection and joy.

During the last year we have continued our award-winning services, supporting 56 partners across children's palliative care, who in turn provide the most remarkable care for over 12,000 children and young people with life-limiting conditions. 15 of these partners were invited to apply for new packages of the latest assistive technology and we are delighted to report that we were able to support all these requests, providing technology, training and services worth close to £600,000.

We want to pay tribute to all our partners, supporters, staff, volunteers, and other stakeholders who have made such an achievement possible. You belong to a truly inclusive, dynamic, and empowering cause, which breaks down barriers to give families opportunities to play together, laugh together and make long-lasting cherished memories. We are particularly grateful to our partners at the Masonic Charitable Foundation who provide us with office accommodation and back office services.

We also say thank you to Mike Woodcock, who stepped down as Chair of Trustees during 2023 after seven years in office.

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As we look to the future, we know that the sectors in which we operate are changing at pace. Due to ground-breaking advances in healthcare, there are more children and young people than ever living with complex, life-limiting conditions – an estimated 99,000 and growing.

To rise to the challenge of this increased demand and complexity, and in consultation with our stakeholders, during 2023 we have refreshed our Vision, Mission and Values, and we developed an ambitious strategy to take us to 2028. This will see us expand our services to help every child with a life-limiting condition to engage and interact with the people they love and enjoy the world they live in.

As we move into an exciting new chapter in our development, we need your support more than ever. As you read this Annual Review, please consider what you can do to help us achieve our Vision. Can you help us build awareness of our work within your network? Can you offer time to help us raise funds? Can you donate more today, or leave a legacy for the future?

Whatever you choose to do, we sincerely thank you for your past and future support for Lifelites and we look forward to developing our relationship over the coming year and beyond.



Rob Lightfoot, Chief Executive



Tony Harvey, Interim Chair of Trustees

Our year at a glance



Lifelites installations 2022–2023

Our vision, mission and 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.



Strategic priorities 2023–2028

Utilising our unique and credible track record to meet the challenges of increased demand and complexity, we have designed a five-year Strategy to achieve our Vision where every child with a life-limiting condition can engage and interact with the people they love and enjoy the world they live in. This strategy is formed of mission-focused priorities and enablers which will help us to deliver.

Mission focused

Improving impact: service development

We will improve existing and develop innovative new services

Increasing reach: service expansion

We will develop new services to extend our reach beyond children's hospice settings

Enablers

Income

We will generate more and sustainable income from new and existing funders

Brand

We will become well known and trusted by potential clients, partners and funders

Governance

We will align our governance with the Charity Governance Code

People

We will develop a skilled, motivated and well-resourced team within an empowering culture



Lifelites Learning

As part of our packages we provide training for palliative care staff to teach them new skills, improve their confidence and enable them to maximise the impact of the technology we provide.

In this past year, we've delivered over 3,000 hours worth of training, coaching over 250 people of staff in face-to-face and online sessions to use Lifelites technology. We travelled a total of 10,012 miles across the country to ensure the equipment was maintained and used effectively with our continued support.



"Dan was amazing and made us feel incredibly confident using the equipment. I found it so helpful to learn how to make the best of the tech." Ty Hafan

"Understanding how to use the equipment in my everyday role and make it age appropriate is vital for our service to meet the needs of the children and young adults in our care" Derian House Children's Hospice

The future

In the next five years, we will transform Lifelites Learning into a comprehensive and bespoke multi-channel training programme, including enhanced face-to-face support, a dynamic e-learning hub, digital user guides and specialist superuser workshops.





Over the last three years, against a scale of 1–5, the confidence level of 281 participants increased from an average of 2.4 to 4.5, indicating the strength and impact of this training.



98% of children's palliative care service staff reported improved skills and confidence in the use of technology.

Our impact

As part of our Strategy we are seeking to improve health and wellbeing outcomes for the children and families we support by increasing independence, reducing isolation and improving communication, emotional wellbeing and family relationships.

We capture monitoring data and case studies from our partners to understand the impact of our work and make improvements.



Reducing isolation Game Time



This year we launched our first Game Time event to unite children and young people using palliative care services and gamers across the UK. They had a friendly competition, shining a light on the power of gaming and technology to empower and connect.

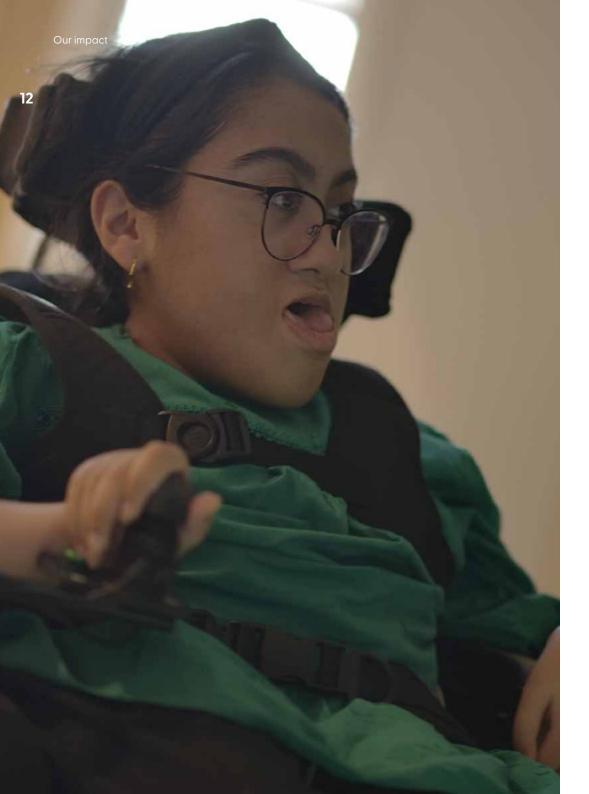
"Gaming gives our young people a feeling of accomplishment and togetherness, allowing them to build friendships and work together."

Naomi's House & Jacksplace

Many partners tell us about the importance of gaming and the unique solution provided by the Lifelites Interactive Entertainment HUB. The HUB is at the forefront of inclusive gaming, breaking down barriers for children and young people to compete on a level with their peers, make life-long friends and experience great adventures.

Our Game Time event provided the latest games, donated by our amazing gaming industry friends, and we organised afternoons of gaming and fun with our partners across children's palliative care.

From playing with friends to meeting new people, finding new ways to communicate and maintain independence, gaming offers a window to the outside world for many of the young people supported by our project partners.



Increasing independence Habibah baking with switches

Habibah is an amazing young adult who uses Alexander Devine Children's Hospice services. She has Merosin-deficient muscular dystrophy, which limits her mobility and dexterity. Nevertheless, thanks to the help of Switches she is an incredible baker.

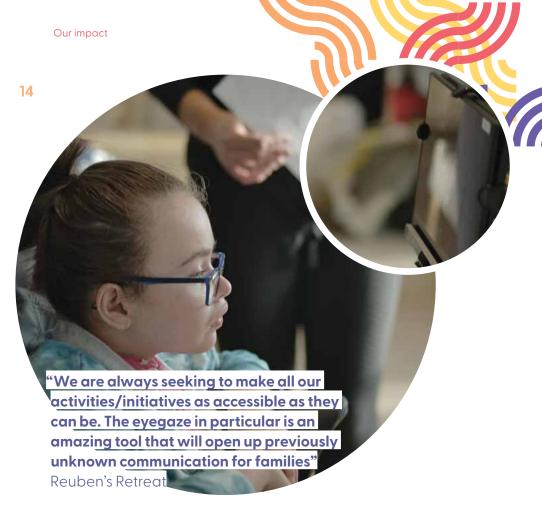
"I use the Switches for baking. You can plug it in and press it. It makes baking a lot easier for me. I enjoy it a lot more and I've been able to practice and it gives me independence.

The Switches enable her to control baking tools and make wonderful desserts, bringing joy and sweet treats to her family and friends!

"It allows me to do it myself, without saying to someone: 'Can you switch the machine on? Can you do this? Can you do that?' I can do everything myself and I'm in control. I like that.

I really like baking. So, I know when the Switch is out it's time to bake!"





Improving communication Eyegaze

Tye is 13 years old. He loves painting and racing and like most teenagers he gets annoyed when his personal space is invaded by his little brother Denholm! He suffered a level 5 brain injury that left him with restricted movement. Nevertheless, Tye's eyes are still very active and as his mum would say "very strong." Therefore it is no surprise that the Eyegaze was a life-changing piece of equipment for Tye and his family.

He started attending Keech Children's Hospice, and using an Eyegaze provided by Lifelites. The staff soon realised his talent for the equipment. At the time, his favourite thing to do on the Eyegaze was playing one of the games, popping balloons appearing on screen with his eyes. Tye became a champ at it, managing to pop as many as four rows at once!

Unfortunately, in 2017 Tye was very poorly, he was in a lot of pain but could not tell his family nor the doctor where the pain was. As a last resort, the family drove to Keech to let him try to communicate what he was feeling using the Eyegaze and, once again, it worked wonders.

As soon as he got his eyes on it, Tye started using the GRID app to look for body parts and to everyone's amazement, doctors included, he was able to express his pain and communicate with them. This enabled the doctors to provide him with the treatment he needed. Emotions ran high and everyone was left with tears of joy.

A lot has changed in the past five years, Tye is doing much better and he is no longer using the Eyegaze to communicate his pain.

He is teaching Denholm how to spell words on the Eyegaze and how to play his beloved popping balloons game. This amazing piece of technology allowed the brothers to get closer and discover together alternative and fun ways to communicate, interact and play.

Lastly and most importantly, Tye is now finally able to tell Denholm to get out of his room, and we all know how satisfying that is for teenagers!

Improving impact New tech pilots

Innovation is one of our core values. The technology we provide can be life-changing, and as the needs of our partners evolve, we are constantly seeking to combine our unparalleled knowledge of assistive technology with the complex and changing needs of children and young people with life-limiting conditions to improve our impact.

We regularly work with technology developers to gain insight to the latest trends. If we spot need in our sector, we challenge ourselves to identify a piece of equipment already used in medical or educational settings and apply it to children's palliative care. In addition, we are in constant dialogue with developers to influence them to create solutions for needs that we are seeing across children's palliative care.

Often, if we find an interesting piece of technology that we can adapt for use in palliative care, we ask one of our partners to test it out. We then support our partners to implement this new technology, providing consultancy and training, whilst evaluating both technical application and impact.

These pilots have proved invaluable over the years and enabled some of the most ground-breaking transformational technology to be used to empower children with highly complex needs.





CMPSR music system

We are currently implementing an exciting new pilot with Digit Music using their CMPSR music system.

CMPSR is an innovative MIDI instrument that enables music creativity through simple finger gestures, making it easier for children with limited dexterity to reach their creative goal and have fun. It can be plugged into any device and play musical notes by moving the central joystick. CMPSR is also highly portable and can go out in the community very easily allowing the whole family to be involved. The pilot is yielding positive results, CMPSR is used regularly by different children and young adults ranging from eight to 16 years old. Staff at our project partners, running the pilot with us, have found it particularly useful in music therapy sessions.

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Hospices and beyond... Reuben's Retreat pilot

As part of our new strategy, we want to improve access to our services for children and young people who are not using hospice services. Reuben's Retreat is a relatively new respite service starting out in 2012. The service currently provides support, guidance, therapeutic and social activities from their base in Derbyshire.

Lifelites adopted Reuben's Retreat as a new partner in 2022. Technology & training were provided in November 2022 and since installation 82 children have accessed support. **The team at Reuben's report that support from Lifelites has reduced social isolation; improved emotional wellbeing; and improved communication of the children and families accessing their services.**

Income

We are grateful to all of our supporters who make our innovative, life-changing work possible. As a Charity we do not receive any government funding. As such, we rely on support from a diverse and passionate range of donors, each of whom contributes to our extraordinary impact.

Income and expenditure

Income source	2,000	%
Community(inc. Freemasons)	227	35
Corporate	37	6
Donations	44	7
Legacy giving	1	0
Trusts & Foundations	208	32
Gifts in Kind	32	5
Investment Income	106	16
TOTAL	655	

20 Expenditure

Lifelites is committed to operating efficiently and ensuring that donors' generosity is used for the maximum benefit of the children and families we support. However, it is a universal truth that in order to raise money, investment in high-quality fundraising and stewardship programmes is necessary. We are fortunate to be able to apply income from our investments to cover some of the cost of generating income, which ensures that income from donations is directed to where it is most needed.

Expenditure source	£,000	%
Equipment, installation & maintenance	364	47
Support costs	214	27
Cost of generating funds	202	26
Total	780	



Our supporters

Lifelites has a wonderful, passionate base of supporters. We are grateful to all of them for supporting our Mission.

Middlesex Freemasons

In the last year, one supporter in particular went the extra mile to promote Lifelites. **John Briggs**, the outgoing Charity Steward of the **Provincial Grand Lodge of Middlesex** rallied Middlesex Lodges to raise funds for Lifelites.

John came into contact with our technology in 2022 at an event thanking the Province of Middlesex for supporting a Lifelites' work at Shooting Star House.

Motivated by what he saw, John embarked on a year-long appeal to help Lifelites raise money to provide Virtual Reality and iPads for children across the country, helping them to play, create and communicate, even from their hospice bed.

In total, John's appeal raised over £55,000 for Lifelites, adding to the £50,000 already pledged by the Middlesex Provincial Relief Fund. A truly remarkable achievement.

"As a parent and grandparent myself, children's charities have always been an area of interest for me. The work that Lifelites does is incredible and the idea that I and my brethren have made a positive impact on children using hospice services is thanks enough. I want to thank the members of Middlesex who have supported this campaign and urge any other brethren to look at what Lifelites is achieving across the country for children with disabilities and life-threatening conditions and do what they can to support them."

John Briggs, Provincial Grand Charity Steward

How you can support us

22 Adopt

Adopt a Lifelites project in your area and become a partner of Lifelites. Support can be restricted geographically and you could consider donating funding for all the technology we provide for one or more of our children's palliative care partners in your area. Your support would guarantee that we can provide the very latest assistive technology for children with life-limiting conditions, ensuring that they can play, create and communicate with the people they love.

We will work with you to recognise your support, which could include social media campaigns, news stories on our website and unforgettable opportunities to meet families and see the impact of your support first hand.

We have an exciting new honorifics programme for our Masonic supporters – Lifelites Heroes. Find out more on our website.

Partner

As we embark on our new strategy, we are seeking transformational partnerships to help us improve our impact and increase our reach. If you are moved by our work, we would love to speak to you about partnering to enable children and families to connect and create cherished memories.

For more information about adopting a Lifelites project, our free Will writing service, and donating to make a difference for the children we support please contact **admin@lifelites.org**

Pledge

Help to create lasting, cherished memories by pledging a gift in your Will. We can connect you to free Will writing services to help ensure your loved ones are taken care of and give you the opportunity to leave a gift to help Lifelites continue to support children with life-limiting conditions.

Donate

Donate via Bank Transfer

Please contact us at **admin@lifelites.org** for details on how to make a bank transfer.

Make a donation online

Visit our website **lifelites.org** to make a one-off or regular donation.

You can also make a payment directly from your CAF Account to Lifelites, charity number 1165791 via Direct Debit.



Donate by post

If you prefer to donate by cheque, please make your cheque payable to Lifelites and post it to us along with the form to the right:

Lifelites, 60 Great Queen Street, London WC2B 5AZ

Donation form Please return your complete	ed form with your donation to:
Lifelites, 60 Great Queen St	reet, London WC2B 5AZ
I enclose a cheque for £	Please do not send cash.
Title	
<u>First name</u>	
Surname	
Address	
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by post and/or email. Our contact of children you are helping to support	keep in touch and send you occasional updates with you will include the latest stories from the t, as well as activities and opportunities you may slow if you prefer not to receive these updates.
☐ Please do not send me u	updates from Lifelites.
-	ofor every £1 with Gift Aid pnations to Lifelites (Charity no. 1165791), ake in the future and have made in the
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