

Lifelites



Highlites

The latest news from the charity donating technology for children using hospice services.



What's inside ★

Read Jess's story ★

Bringing accessible gaming
to children in hospices



Welcome to our 2019 Highlites newsletter

There are currently 60 children's hospice services across the British Isles, providing crucial, round the clock care for thousands of children with life-limiting and disabling conditions. Thanks to your support, we've been able to help them live their lives to the full by donating our technology for children using every one of these services.

In this edition you'll read about how Lifelites' donation of an Eyegaze has helped give children like Jess a voice, and how your support has also helped others in lots of ways. You'll also see more of the incredible technology you help us to provide; technology which helps children with limited lives escape the

confines of their conditions and do things they never thought possible.

We've been able to do so much thanks to you, but we can always do more, so if you have ideas about how you could help us, please get in touch.

Thank you.



Simone Enefer-Doy
Chief executive



What is Lifelites?

Lifelites donates and maintains specialist technology packages for the 10,000 life-limited and disabled children and young people using every children's hospice service across the British Isles. They can use our life-changing technology to play, be creative, control something for themselves and communicate, for as long as it is possible. Most importantly, it doesn't cost the hospices a penny for all our equipment and services.

www.lifelites.org 0207 440 4200 info@lifelites.org

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Registered charity number: 1165791

News and updates



It's awards season for Lifelites

At Lifelites we strive to do the best job we can for children in hospices, so it's wonderful to have our work recognised by being nominated for a number of prestigious awards.

We were finalists in the Digital Charity of the Year category as part of the **Digital Leaders 100 Awards**, which recognises individuals and organisations championing digital transformation in the UK.

We were also selected as the finalists in the **Children and Young People Now Awards** to win Charity of the Year. These awards recognise the hard work and dedication of people working to improve the lives of children and young people across the country.

Finally, our chief executive Simone Enefer-Doy was shortlisted for Inspirational Woman of the Year and Outstanding CEO in the **Venus Awards**, also known as the 'working women's Oscars'.

Thank you so much for everyone who voted for and supported us, and helped us gain recognition from these important industry leaders.



New technology alert

At Lifelites we know how important gaming can be for the children and young people we support, which is why we're really excited about the latest addition to our technology package – the brand new mobile entertainment unit.

This portable trolley is jam packed with the latest tech to impress even the most advanced gamers. And most importantly, it is suitable for use by people with a wide range of abilities. The bundle includes a PlayStation 4 with a Virtual Reality headset, an Xbox with plenty of great games and the brand new Adaptive Controller specifically designed for gamers with disabilities as well as a pop up projector which can beam images onto any surface.



With this technology we can remove barriers and help young people like Shay (pictured above) do what they love – playing games and having fun – for as long as it is possible.

Read more about the mobile entertainment unit on our website: www.lifelites.org



Jess's story



Nine year old Jess has Rett Syndrome and is unable to talk, but her life completely changed when she was introduced to Eyegaze about three years ago. We spoke to her mum to find out more about the impact this incredible technology has had:

"Jess is very medically complex and has lots of hospital admissions. She is non-verbal, and the only part of her body she can control accurately is her eyes. However, she understands everything. Imagine just how frustrating that must be - to understand everything that's going on around you but having no way to communicate anything back.

"About three years ago, Jess began to use Eyegaze. She can control the cursor with her eyes and uses this to communicate. This has made a huge difference to her quality of life. She can tell us what she wants, what she likes, when she's in pain and what she wants to do. She has told us that one of her medications was causing her horrible side effects, so it was



changed. She plays with her friends and her sister, and they can argue about what DVD to watch! She can even control a portable speaker to put her favourite music on.

"Eyegaze is the one thing that we can do for Jess which will make the biggest difference to her life both now and in the future. The funding of such devices is essential for children like Jess, and makes such a positive impact on their quality of life."

If you'd like to help Lifelites fund more technology like Eyegaze, please visit our website to find out how you could support us: www.lifelites.org



Imagine just how frustrating that must be - to understand everything going on around you but having no way to communicate anything back

We met Jess in November 2018 when we were celebrating the donation Lifelites made to her local hospice at home service, Noah's Ark. It was a particularly memorable meeting as another one of our guests was our patron and Eyegaze artist Sarah Ezekiel, who uses Eyegaze to paint and communicate. Sarah has Motor Neurone Disease and just like Jess is completely reliant on Eyegaze. Jess was very excited to meet Sarah and they were actually able to communicate using this incredible technology. It was a very special moment for everyone.



The impact you make



"For many of our children, simple interactions with the world around them are not possible, but the technology that Lifelites provides equips them to do this. They can control aspects of their environment, make choices, and make their feelings and wishes known. It makes such a difference to their lives."

Andy's children's hospice

"Creating memories is an invaluable part of the care and support we provide to families facing the most difficult journey. The cameras are a big part of helping us to do this. We use them to take photos of everyday moments to share with families. Parents don't want to miss out on any part of a child's life, especially if this life is going to be cut short. Thank you, Lifelites."

Hope House



"Lifelites technology is crucial to the hospice. Many of our families are experiencing very hard and stressful times, with several hospital appointments and difficult decisions. The Lifelites technology provides a welcome distraction for families to have fun and forget about everything, even if just for a moment."

Derian House

"Using the Lifelites technology we can improve communication, choice, independence, sense of self, creativity, opportunities for fun, inclusiveness, improve connections and build relationships. The possibilities are endless!"

Rachel House



★ Spotlight on our magical technology – Switches

Our magical technology comes in all shapes and sizes. Little things you may never have seen or heard of make such a difference to life-limited and disabled children. An example of this is our collection of switches...

What are they?

A switch is a special type of mouse which can be connected to a computer or specially adapted toy and is operated with a single touch.

How are they used?

Just pressing one of these switches can help children with limited motor skills control something for themselves. We install specially designed games and apps on large touchscreen computers which they can operate with the switch. When attached to a special converter, a switch can turn a fan, hair dryer or any plugged in electrical item on and off and even severely disabled children can take control of everyday activities for themselves.

They are much easier to use than a mouse for children with limited dexterity, and come in a variety of sizes and colours - some even light up and vibrate when pressed which stimulates the children to use



them. They can help those who are not used to having a choice make something happen for themselves.

In a life where everything is done for them, it puts them in control.

How much do they cost?

Our switch bundle comes complete with a touchscreen computer and a range of switches and toys and costs £1,808. The individual switches range from around £50 to £200.

What do the families say?

Lily Mae is five years old and has Rett Syndrome, a rare genetic disorder which affects brain development. She loves playing with the switch toys at

her local children's hospice, especially BeatBo (pictured), a toy that dances and plays music when the switch is pressed. Her mum said:



*The toy is amazing!
It's great that
it lights up and
vibrates. She had
so much fun playing
with it. I'm so
glad she had the
opportunity to use it.*

To help Lifelites donate more magical equipment like this, please visit our website and see how you can support us:
www.lifelites.org/get-involved

★ ★ Our hospice heroes

The success of our work relies on the hospice staff themselves. Without their ability to recognise how our special technology can be used to make the most impact, all our efforts could go to waste. Luckily, we meet so many hospice workers who are passionate about the Lifelites technology. Here, one of our hospice heroes talks about why Lifelites' contribution is such a vital aspect of the care they provide at the hospice.

Vicky works as a nurse at Butterwick House children's hospice. She's so enthusiastic about the Lifelites technology that she came in on her day off to take part in our training!

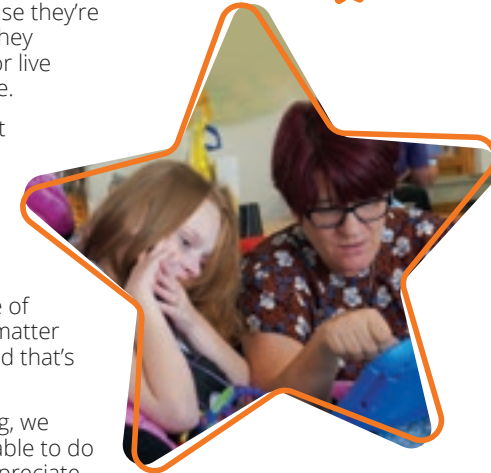
Vicky explained: "The children we look after are so wrapped up in hospital appointments, medication and procedures. When I'm on shift, I like to try and think how I can make things as normal as possible

for them. Just because they're sick, doesn't mean they shouldn't have fun or live a life that's enjoyable.

"The technology that Lifelites donates to us is magical; it's amazing how much it can enhance their lives. All our children will be able to make use of the equipment, no matter what their ability, and that's so important.

"It's so overwhelming, we simply wouldn't be able to do what you do. We appreciate the support so so much, I just think it's amazing. Thank you, Lifelites."

To find out more about our work for children using hospice services, please visit our website:
www.lifelites.org



There is a Lifelites project for children near you



In addition to our continuous services for life-limited and disabled children using children's hospice services, this map indicates where we would like to deliver a whole new technology package in 2019.

Can you help us raise funds to support our work for children from your area? Please give us a call **0207 440 4200** or email info@lifelites.org

2019 projects

1. Acorns for the Three Counties, Worcestershire
2. Brian House, Lancashire
3. Christopher's (CHASE), Surrey
4. The Donna Louise, Staffordshire
5. EACH Ipswich, Suffolk
6. Ellenor, Kent
7. Forget Me Not, West Yorkshire
8. Grace's Place, Lancashire
9. Haven House, Essex
10. Julia's House, Dorset
11. Little Harbour, Cornwall
12. Little Havens, Essex
13. Noah's Ark, London
14. Oakwell, Jersey
15. Richard House, London
16. Tŷ Gobaith, Conwy



As well as the hospices on the map above, we provide constant training and technical support to every hospice across the country, and these projects are always in need of funding. If you think you can help us, please call us on **0207 440 4200** or email info@lifelites.org.



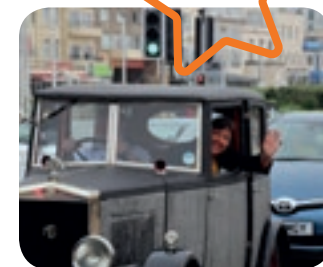
Help drive up the funds for Lifelites



Last year, our chief executive embarked on an epic road trip, Lift for Lifelites, to raise funds for our vital work. She asked volunteers to give her a lift through every county in England and Wales in the weirdest and wackiest modes of transport they could think of.

It was an incredible success raising over **£100,000** so we are now calling on all motoring enthusiasts to hold their own car themed events for Lifelites.

If you're a member of a car club, or just love anything to do with cars, could you make Lifelites your chosen charity for your shows, rallies or treasure hunt? If you'd



like advice on how to raise funds from your event just let us know and we'll be happy to help.

If you prefer to travel on two wheels, we'd love to hear from you as well! If you are part of a motorcycling club and would like to organise a fundraising event for Lifelites, do give us a call.

If you have any other ideas of ways to raise funds for Lifelites, please get in touch with our head of fundraising and PR Samuel Davies by emailing sdavies@lifelites.org or calling **0207 440 4200**.



Our fundraising stars

Our fundraisers are our stars; we simply wouldn't be able to do what we do without them. Here's what some of them got up to in 2018:

£315



Graham Button
Graham raised £315 when he took on his first ever half marathon in Southend.

£1,055



Karan Rochford
Like Graham, Karan ran her first ever half marathon in Manchester, and raised £1,055.

£850



Chequered Flag Lodge
This car Lodge in Hampshire raised £850 from their annual rally, which saw a very eclectic selection of vehicles, including a fire engine, a Cadillac, a 1938 Hudson motorcycle and many more!

£10,000



Square Enix
Staff from the gaming company Square Enix raised nearly £10,000 by taking part in Cyclothon UK at Brands Hatch.

Sustainable funding

We'd like to say a **huge thank you** to donors who choose to support Lifelites on an ongoing basis. We depend on support like this to move our work forward and make a bigger impact for life-limited and disabled children. We're very grateful for the on-going support of these trusts, companies and their staff: The ACT Foundation, The British Medical Journal, Capco, The Crerar Trust, Children with Cancer UK, GamesAid and the Worshipful Company of Information Technologists.

Fundraising focus on...

Mike and Kay Wilks

Mike Wilks leads hundreds of Freemasons in the Province of Hampshire and the Isle of Wight, and as part of his role he is able to choose charitable projects to benefit from their support. Mike is incredibly active in the community, commonly referred to as the 'Ninja Provincial Grand Master'.

Mike and his wife Kay have championed support for Lifelites for several years now. Thanks to their help, in addition to funding technology for children and young people at Naomi House and Jacksplace in Hampshire, they have also enabled Lifelites to support two brand new projects for life-limited and disabled children in their region: the hospice at home project on the Isle of Wight and the package for the new Long Term Ventilation unit based at Naomi House.

Donations from the Province now total over **£100,000**, which has changed the lives of hundreds of children. We asked Mike and Kay what inspired them to adopt Lifelites' work for the children of Hampshire and the Isle of Wight as a focus for their charitable giving.

"We already support the local children's hospice services, so I've seen the impact of the Lifelites technology first hand. The excitement with which the children embrace and utilise the technology is so heart-warming. We wanted an initiative that would be popular with Freemasons in the area and I had absolutely no doubt that this would be it. It felt like a really tangible project that we could raise all the funds for, including the cost of the ongoing support. Lifelites restricted donations scheme also means that projects benefit from national expertise at the same time as ensuring local donations help local children, which is important to my members. We had absolutely no trouble encouraging them to donate. The dedication and commitment of Lifelites is an inspiration and it's a privilege to be involved."

Do you know an organisation or company which could adopt a Lifelites project for children from their area? Please give us a call on **0207 440 4200** to discuss how we could help you make a pitch to them to support Lifelites.



We were very sad to hear of the untimely death of one of our much loved former trustees, *John Martin*. A trustee for 10 years, we knew him as quiet and thoughtful, always thinking about how we could maximise our support.

He remained doggedly determined to pitch the idea of support for the new children's hospice at home project on his doorstep on the Isle of Wight, which we have now successfully provided a package for.

Our best wishes and thoughts go to Pam and John's family.

Why does Lifelites need your support?



We asked a parent why your donation matters:

“Eyegaze has given Aimee a chance to be proactive and make her own decisions in life. It’s given her a voice”

Yes, I would like to help children like Aimee with a gift of: £ _____

I enclose a cheque postal order CAF voucher **Please do not send cash**

Please complete all relevant sections and return your completed form with your donation to:
Lifelites, 26 Great Queen Street, London WC2B 5BL

My personal details

First name _____ Surname _____

Address _____

Postcode _____

Phone number _____ Email _____

As a supporter of our work to give kids with limited life unlimited possibilities, we will keep in touch with you, sending you occasional updates by post. Our contact with you will include the latest stories from the children you are helping, as well as activities and opportunities to support these children further. Please indicate your contact preferences below:

Please do **not** send me updates via post from Lifelites

From time to time we would like to get in touch with you electronically.
Please indicate your preference below.

Phone Yes No **Email** Yes No **Text message** Yes No

Use Gift Aid to boost your donation by 25p for every £1.

I want to Gift Aid my donations to Lifelites (Charity no. 1165791), including donations that I make in the future and have made in the past four years.

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations, it is my responsibility to pay any difference. I will notify Lifelites if I wish to cancel this declaration, change my name or home address, or no longer pay sufficient tax on my income and/or capital gains.

Signature _____ Date _____