What’s inside

Could you support Lifelites at work?

How technology has changed Macsen’s life
Welcome to our 2018 Highlites newsletter

It is estimated that there are 49,000 children living in the UK with a life-limiting condition. We are determined to reach as many of these children as possible with our magical technology, because we know that it can change lives.

In this newsletter you can read about six year old Macsen, who – despite his complex disabilities and needs – is able to use the Lifelites technology to play games and have fun, just like any child. You can also read about Eyegaze, an incredible piece of technology that can open so many doors to a child with disabilities.

We couldn’t do any of this without you, and we’ve lost count of the number of supporters who have helped us, but there is always more we could do and more children we could reach. If you’re able to help Lifelites in any way, please do get in touch.

Thank you.

Magical memories for children with cancer

In 2017, Children with Cancer UK continued their generous donation to help Lifelites provide support to children with cancer using hospice services.

The technology we donate provides an essential part of many aspects of care for children with cancer and their families. One member of staff at a hospice told us about her experience with Lifelites technology and palliative care: “A family whose child was dying of Leukaemia used iMovie on the Lifelites iPad to create a film of the things she enjoyed at the hospice during her last few days and her sister wrote a song to accompany it. Memories might fade, but the family will treasure that forever.”

Thank you so much to Children with Cancer UK, for helping to make these magical moments possible.

Run Forrest Run!

One of our most dedicated supporters, Ewan ‘Forrest Gump’ Gordon is embarking on what looks to be his most demanding fundraising challenge to date!

Ewan and his friend Kenny will take on “The Great British Duathlon,” which involves running from John o’ Groats to Land’s End, and then turning around to cycle back again.

They are hoping to complete the 900 mile run in 30 days, running a minimum of 30 miles a day and then cycling back over two weeks.

We’re aiming for £20,000

Ewan has completed several running challenges to raise funds for Lifelites to date. He said: “I’ve been thinking about this challenge for a while, and we think we’re going to be the first people to ever do it in this time, so we’re hoping to be able to raise lots of money. We’re aiming for £20,000.”

If you’d like to follow their progress or sponsor them, visit their Facebook page – The Great British Duathlon.

Lifelites donates 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

@LifelitesOrg  @Lifelites  @Lifelitesorg

Registered charity number: 1165791
Macsen has a number of complex disabilities, but loves using the Lifelites technology which gives him the chance to play and provides a welcome distraction for him and his family from the challenges they face.

Macsen is six and has a rare genetic mutation causing severe cerebral palsy-type symptoms, extreme feeding issues and pain, as well as visual impairment and epilepsy.

He has visited Tŷ Hafan children’s hospice in Wales with his family since he was three and uses it for short breaks, play and music therapy.

Macsen is unable to talk, which makes it very difficult for him to communicate with his parents or his carers. He can’t tell them when he wants something or if he is in pain.

Dad Matthew says: “Macsen loves playing with the Soundbeam to make music and really enjoys using the iPads with a special mouse, but his favourite is definitely the Eyegaze. It gives him a way to express himself and interact with the world in a way he couldn’t before. He loves using it to draw pictures with his eyes, which is just amazing.”

As well as making a difference to the lives of children like Macsen, the technology can also be a fantastic benefit to their brothers and sisters.

Macsen’s brother is supported by a sibling group and loves using the touchscreen computers to play games. Matthew says: “He loves them. It’s the first thing he asks for when he gets there. It’s really important to us that he’s getting support as well.”

Thanks to donors, the technology we donate has benefitted the whole Williams family. Matthew said: “This technology makes a huge difference to the children here, distracting them from their challenges and difficult lives. Thank you for supporting Macsen, the whole family and everyone at Tŷ Hafan.”

What do children’s hospices think about the Lifelites technology

“The Lifelites package is a fundamental part of the resources available to our carers and therapists. The Magic Carpet has provided so much fun, for children of all ages. All of the equipment is so valuable and we’re so delighted to have received such great support from Lifelites.”

Julia’s House children’s hospice

“I wish there was a bigger word than thank you to show our appreciation for the support that Lifelites give us. We are incredibly grateful for all the work they do because it really does change the lives of our children. It gives them their independence back, which is something that you can’t put a price on.”

Demelza hospice care for children

“The children we work with are so full of joy. Play is one of the most important things in a life where they have so many procedures and clinical requirements. That’s what the Lifelites technology helps us do. It can be used by children of all abilities and really allows them to take part and express themselves. We’re able to enter their worlds so much more.”

Alexander Devine children’s hospice
Spotlight on our magical technology – Eyegaze

For this issue of Highlites, we want to shine a light on one of our magical pieces of technology – Eyegaze.

What is it?
Eyegaze is eye tracking technology which enables a child to use a computer just with the movement of their eyes.

How is it used?
Eyegaze enables whoever’s using it to be able to do anything you could normally do with a mouse. They can paint a picture, play a game and even use it to communicate, all with the movement of their eyes. This is life changing for a child who may not be able to control anything for themselves.

How much does it cost?
The Lifelites Eyegaze package is specially collated for children’s hospice audiences. It comes together with an amazing package of games and communication software for all levels of users. It also comes with a special stand which helps the children to use it wherever they are, whether they are sitting in their wheelchair, or lying on a bed. Including a days training for hospice staff, it costs Lifelites around £4,000.

What do the hospices and families say?

“1 cried when I first saw my daughter use the Eyegaze so easily. She can finally play games by herself without worrying about coordination or a spasm. Incredible.”
Parent, Claire House

“Parents are absolutely blown away when they see what their children are able to achieve with the Eyegaze from Lifelites. It’s incredible to be able to give them that opportunity to unlock their full potential.”
Tŷ Hafan

I cried when I first saw my daughter use the Eyegaze so easily

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 year in numbers

We’ve achieved so much in the last 12 months, but don’t just take our word for it, have a look at the figures:

4,210 miles travelled by car, bus, boat, train and plane to deliver our magical technology

14 hospices that received brand new packages of technology from Lifelites

820 pieces of equipment, games and applications donated

57 training sessions delivered by our training team for hospice staff across the country

60 children’s hospices in the British Isles; all are supported by Lifelites

10,000 children and young people using the children’s hospice services that we donate to and continue to support

And the number of supporters who have helped make it possible – we’ve lost count!

These numbers are impressive, but we could do more, and can only do so with your help. If you want to help us increase these numbers next year, why not fundraise for us? Find out how you can get involved on our website: www.lifelites.org
The children we want to support in 2018

Here’s a map of all the hospices we hope to deliver new technology to this year. Is there a Lifelites project at a hospice near you which you could support?

2018 projects

1. Andy’s, Lincolnshire
2. Butterwick Children’s Hospice, Durham
3. The Children’s Trust, Surrey
4. Derian House, Lancashire
5. EACH Milton, Cambridgeshire
6. Francis House, Lancashire
7. Hope House, Shropshire
8. Jigsaw, Cumbria
9. Keech Hospice Care, Bedfordshire
10. Rachel House, Kinross
11. Rainbows Children’s Hospice, Leicestershire
12. Robin House, West Dunbartonshire

Support Lifelites at work

Could your workplace or club help Lifelites support children in hospices in your area? We spoke to two organisations which have chosen Lifelites as their corporate charity partner to see what made them pick us, and why you should too:

Ruth Staunton is Head of Corporate Marketing at the British Medical Journal. Staff at the respected medical publication selected Lifelites for a two year fundraising partnership. As well as fundraising, they are also using their professional skills to help Lifelites in a variety of different volunteering roles.

Ruth said:
“Working with Lifelites has given our BMJ colleagues the opportunity to make a real and positive impact on the lives of children in hospices. As a values-driven company, inspiring colleagues to take part in (fun!) activities to raise vital funds is very much part of our working culture. We’re all looking forward to the exciting partnership developments in the future.”

Alan Burnip is a member of the Remington club in Mablethorpe. After hearing about the work of Lifelites he encouraged other members to help fund Lifelites technology at their nearest children’s hospice. To date they have raised over £5,000.

Alan said:
“I was so pleased that everyone at the Club agreed to support Lifelites. We are all determined to raise as much as we can to support children in our local children’s hospice where Lifelites donates their technology. Our community worked together, had fun, and showed support by taking on lots of activities and events. We know that the technology will make such a difference to these children’s lives, and that’s why we’ll continue to support this fantastic charity.”

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.
Our fundraising stars

Our fundraisers are our heroes; we simply wouldn’t be able to do what we do without them. Here’s what some of them got up to in 2017:

Nigel and Andy from Hampshire took on the fastest zip wire in the world, raising £2,054

Rachel Thompson braved a tandem skydive and raised £1,100

Matt Altass raised £2,268 by cycling from London to Brighton

Amo Basra raised £2,000 by cycling all the way from London to Paris

Born to ride
A group of motorcyclists covered 12 counties in one day, raising £10,000

£2,054  £1,100  £2,268

Sarah Clemence took on an Ultramarathon in the Lake District, running an incredible 100 miles. She raised £890

£2,000  £890

The Provincial Grand Lodge of Hampshire and Isle of Wight (above) and The Provincial Grand Lodge of the Isle of Man (below) both raised a staggering £50,000 for the Lifelites projects in children’s hospices in their respective regions

£50,000

If you are inspired to do something this year to help Lifelites support children in hospices throughout the British Isles, please take a look at the challenge events on our website. Just go to www.lifelites.org/challenge or contact Max on 0207 440 4200 or email info@lifelites.org
Yes, I would like to help children like Heavenly 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 below if you prefer not to receive these postal updates.
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.
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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.

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