



## Lifelites children's hospice staff conference report

### **Who we are**

Lifelites is the charity that donates and maintains assistive technology for children and young adults at every children's hospice service across the British Isles. Our aim is to give these children and young people the opportunity to join in with activities around them: to play, be creative, communicate and control something for themselves, whatever their abilities. At Lifelites we never just install a package and walk away. We research the best items for children in hospices, fundraise for it, install it, train staff on how to use it and commit to maintaining it in good working order. Every four years we aim to donate a new package of assistive technologies. The ongoing relationships we have with each of the children's hospices we work with are very important to us because they help us share great ideas and encourage innovation across our network of projects.

### **Introduction**

The Lifelites hospice staff conference was held in Birmingham on Thursday 7 March 2019.

Our aims were to:

- Engage 2019/20 children's hospice projects in the application process.
- Remind all delegates about our free training offer and provide a training session on making memories with iMovie.
- Encourage children's hospice staff to share stories of how they have used Lifelites equipment creatively.
- Provide networking opportunities.
- Run a focus group on accessible gaming in children's hospices with special guest speakers Hector Minto (*senior technology evangelist (accessibility), Microsoft*) and Stephen Woodgate (*marketing lead (accessibility), Microsoft*).
- Discuss the challenges and solutions to providing care in the community and collect feedback on the new Lifelites tech trunk initiative.
- Treat hospice staff to special guest speakers – Vicki Garrity (RLDN, Butterwick House) and Sarah Ezekiel (Eyegaze artist and Lifelites patron).

### **Who attended?**

The conference was open to all our projects across the British Isles. Delegates were divided equally into two groups: those due to apply for Lifelites technology donations in 2019/20 and non-applicants. Within one month of the invitation we were at full capacity with a waiting list. Lifelites trustee David Strudley also attended. The following 30 hospices were represented:

Acorns for the Three Counties	EACH Milton	Little Harbour CHSW
Acorns in the Black Country	EACH Quidenham	Little Havens
Alexander Devine	ellenor	Noah's Ark
Brian House	Forget Me Not	Pepper Nurses (Rennie Grove)
Butterwick House	Haven House	Rachel House CHAS
Children's Trust	Hope House	Rebecca House
Christopher's	Jessie May	Robin House CHAS
Claire House	Julia's House, Dorset	The Donna Louise
Demelza SEL	Keech Hospice Care	Tŷ Gobaith
EACH Ipswich	Little Bridge	Tŷ Hafan

## Overview of conference sessions

### Session One

#### How to get the most out of your Lifelites application and training

**Session leads: Daisy Powell (head of operations) and Katherine Bentley (trainer, north)**

The aim of the session was to engage hospice staff from the beginning of the application process, preparing applicants for each stage of the project delivery. We discussed the importance of training which is a vital part of delivering the new package of assistive technologies. We also demonstrated the following equipment to spark ideas about what to apply for:

- Mobile Magic Carpet
- Eyegaze
- Touchscreen and special mice
- Virtual Reality
- Beamz music
- iPads with special adaptations and apps
- Go Pro camera

94% of applicants strongly agreed with the following statement: "I feel confident about how to get the most out of the application process and training."

96% of applicants thought the session was excellent.

We hope the session will have a positive impact on this year's application forms, facilitate the smooth running of the projects and encourage engagement with the Lifelites training.

### Session one (parallel)

#### Making memories training and the impact of Lifelites technology

**Session lead: Caroline Jellyman (training manager)**

This parallel session was tailored for delegates not applying for a new package this year. The delegates received a short training session on making memories with iMovie (software on all Lifelites iPads) before breaking out into groups and creating their own movies.

'Making memories' training is integrated into Lifelites' training on iPads so 2019/20 applicants will have the opportunity to learn these skills as well. This training can also be requested as part of the Lifelites free refresher training offer.

96% of the delegates thought the session was excellent.

We hope this provided the ideas and confidence to use iPads creatively and capture special memories for families to cherish.

## Session two

### **Accessible gaming focus group with Hector Minto, *senior technology evangelist (accessibility)* and Steven Woodgate, *marketing lead (accessibility)* - Microsoft**

Lifelites is committed to ensuring that all children and young people with disabilities and life limiting conditions have access to gaming. We have seen first-hand how accessible gaming facilitates co-play between peers, siblings, parents and carers, as well as enhancing inclusivity and building self-esteem and confidence. To find out more about our developing work in this area, please click the link below to read a recent Guardian article about Lifelites' work with Microsoft:

<https://www.theguardian.com/games/2018/dec/18/childrens-hospice-video-games-adaptive-controller>

The Microsoft Xbox Adaptive Controller (<https://www.lifelites.org/latest-news/microsoft-announce-new-accessible-gaming-controller>) has revolutionised Lifelites' accessible and portable gaming offer. The controller can be easily adapted for different individuals and for those with degenerative conditions. We were delighted that Hector Minto, senior technology evangelist (accessibility) and Steven Woodgate, marketing lead (accessibility) were able to lead two excellent sessions on accessible gaming, co-pilot and the Xbox Adaptive Controller, and we are so grateful to Microsoft for donating an Xbox Adaptive Controller to every children's hospice represented at the conference.

#### **The key objectives of the session were to:**

- Enthuse the hospice staff about the impact of accessible gaming for the children and young people they care for.
- Demonstrate the Xbox Adaptive Controller using a number of difference switches and the co-pilot function.
- Give hospice staff the opportunity to play games with the Xbox Adaptive Controller and co-pilot and to build their confidence.
- Collect feedback on the importance of gaming for children and young people accessing children's hospice services.

A massive thank you to all our delegates who shared their thoughts and provided a wealth of positive and useful feedback:

- "I loved Hector's enthusiasm, so glad to hear social model of disability talked about"
- "I had personally feared the complexity but now that I've trialled it I do not fear!"
- "I am extremely excited to introduce our young people to the accessible controller - it will be life changing! Truly amazing!"
- "Fabulous insight. Eye-opening and much appreciated. Thank you for your time, knowledge and gift"
- "Amazing technology. I myself would happily join and play with our clients knowing I can be in charge of one element of the game!"
- "Very interesting and the interaction by playing was amazing"
- "A child I see loves gaming and normally only watches his dad play which upsets him. He will love to play with dad"
- "Really innovative – I'm excited about this"

**In what ways do you think accessible gaming will benefit the children and young adults using your hospice service?**

- “It will open lines of communication, giving opportunities for difficult conversations to happen”
- “Gaming together, communication between peers, starting conversations, families playing together”
- “This will take so much pressure and frustration off our children who are desperate to play but just physically find it too challenging”
- “This would help nurses to interact and join in”
- “We will be able to be more inclusive, particularly with the younger children who want to be involved, the older children normally give them an unplugged/old controller, now they can play together”
- “This is a life changer!”

**Are there children or young people with specific conditions that you think would especially benefit?**

- “Many youngsters, especially Duchenne's boys, do a lot of gaming when they become restricted to their wheelchairs but eventually using a standard controller becomes impossible and so they lose friendships as well as ability”
- “It will benefit children who need some social confidence building”
- “It is an all-inclusive technology with no limitations”
- “Any child will benefit (...) the controller is universal and can be adapted to individual children”

**What impact do you think the Xbox co-pilot function will have for the children, young people and their siblings/families?**

- “Being a gamer is really important in children's lives, it gives children an identity”
- “Co-pilot can bring families together. This doesn't exclude any members of the family or children, everyone plays a part”
- “I think it will build bonds between peers, family and friends without disabilities”
- “The child/young person is dictating who does what! It gives them control when in other areas they have very little”
- “Inclusion, socialisation, entertainment, empowerment - boost in mood and emotions, building positive relationships, improving communications”
- “It opens up a new dimension of accessibility regardless of any conditions or generational aspects”

In addition to donating an Xbox Adaptive Controller to each children's hospice represented at the conference, Lifelites has donated ten accessible gaming bundles in 2018/19 and our fundraisers are working hard so that we are able to continue this important work in 2019/20.

### **Session three**

#### **Providing hospice care in the community: challenges, solutions and getting the most out of your Tech Trunk**

Starting in 2019/20 Lifelites is planning to pilot the Tech Trunk, an initiative to ensure children and young people receiving hospice care in the community have access to assistive technologies. This bespoke bundle of portable technologies will be specifically allocated for children's hospice community teams and services. As always we will consult with each individual service and aim to respond to their specific needs and requirements.

The aim of the session was for hospice staff to identify the main considerations of using Lifelites technologies in the community, developing solutions and providing feedback on the Tech Trunk prototype:

- "It is a brilliant idea, it would be great to bring variety into homes"
- "A really good idea. We are always looking for portable, versatile, easy to use equipment"
- "This is a great idea. Thank you for thinking about how to get Lifelites into the home"
- "It will be a good experience for families to see how the children communicate using the devices"
- "If everything is in one place then coming up with ideas for individual children might be easier"
- "Something for children to do whilst parents are chatting and ability to offer something for children as part of home visit"
- "Offer more choice to our families - bring children and their siblings together"
- "Variety of options and able to respond to individual needs. If more children are beginning to use Eyegaze as a method of choice and communication in schools, we should be allowing them to do the same with their choice making for play and leisure"
- "Community care seems to be the way forward - so the tech trunk idea seems brilliant"

The fundraising team will continue to work hard to raise funds so we can donate Tech Trunks to every eligible project. Children's hospices applying for packages in 2019/20 will discuss their specific hospice at home needs during the consultation process. Through this work, we aim to reach more children and young people receiving hospice care within the community.

### **Session four**

#### **Guest speakers**

##### **Our journey with Lifelites – from the hospice staff conference to now, Vicki Garrity (RNLD, Butterwick House Children's Hospice)**

We'd like to say a huge thank you to Vicki for talking about Butterwick House's Lifelites journey. Highlights from Vicki's speech included:

- The value of learning about the application process and new technologies at the 2018 conference.
- How Vicki was encouraged to put together her ultimate wish list for the children and young people at Butterwick House, and how thanks to the Lifelites fundraising team, they were able to receive everything on it.

- The fun they had on the two installation and training days, learning how to use all the equipment.
- The photos and stories Vicki shared of children using the new Lifelites technologies.
- The offer of refresher training which Vicki has taken up and is looking forward to in September 2019.

### **Communicating and creating with Eyegaze, Sarah Ezekiel (Artist, Eyegaze user and Lifelites patron)**

We'd also like to say a massive thanks to Sarah for her truly inspirational speech about life with motor neuron disease. Sarah kindly shared her story with humour and compassion, talking about the value of Eyegaze technology to enable communication and creativity, whilst showing her amazing artworks which can also be found and purchased here -

<https://www.etsy.com/uk/shop/EzekielArtShop>

### **What Lifelites will be delivering in 2019/20**

The application process for the 2019/20 projects has begun and we are looking forward to reading the application forms and discussing the new packages during the consultation period in May. Alongside these conversations we will be researching and testing new assistive technologies, and working hard to raise the money to fund these projects. From September 2019 to March 2020 we aim to install new packages and deliver two days of training to each children's hospice.

At the conference we announced the exciting news that we have recruited a new part-time trainer based in the South: Daniel Brand. Lifelites is delighted that we are able to increase our capacity to provide ongoing free training for hospice staff. With this additional resource we will continue to develop our training remit, working on exciting new resources and tailoring our training for transition, hospice at home and new technologies. Special courses are also on offer, for example on making memories with iMovie, using music apps or creating art. We will continue to run the account call programme, contacting all hospices to check how everything is going and offering refresher training. We are also happy to be contacted any time to request further training. We will continue to monitor and evaluate all our projects and collect regular feedback from those attending training sessions.

### **Next year's conference**

The next conference will take place in March 2020 and the email invitation will be sent before Christmas.

We will run a session on the application process for children's hospices due to apply in 2020/21 and tailor sessions for the non-applicant group. Based on the success of this year we would like to ask hospice staff to present and will contact potential speakers in advance. The aims of next year's conference will be to:

- 1) Showcase Lifelites assistive technologies
- 2) Initiate the application and consultation process for 2020/21 hospice projects
- 3) Provide important research and consulting opportunities
- 4) Revitalise and enthuse hospice staff about using Lifelites assistive technologies
- 5) Share stories, hear from delegates and provide networking opportunities

### More feedback from the day

- 98% of delegates said that the sessions seemed well planned and the event was enjoyable.
- 96% of delegates strongly agreed with the statement “after today, I have some new ideas of how to use my Lifelites equipment”.

We collected an abundance of wonderful feedback from the day. Below is just a selection of the brilliant comments received.

#### **About the impact of Lifelites technologies and hospice staff training:**

- “I am going to aim to utilise the excellent equipment and resources more”
- “This would bring a new dimension to play and communication for our children”
- “The new technology increases the scope for giving new experiences to our children and young adults”
- “To enable and give the children empowerment to achieve their full potential”
- “The equipment will break up the day and allow the children's siblings and family to engage”
- “Interaction, inclusion, and fun for all. Promotes independence and access to all equipment, even tech they may not have thought they could use”
- “Access to play on games ALL children their age play on”
- “Using the equipment we have seen today will impact our children massively. It will help our children interact in a way they have never been able to do. It will give our children an opportunity to express their emotions and feelings, within our base and out in the homes”
- “This conference always gives us new ideas and refreshes our memory about how we can best use equipment”
- “Going back excited to show the various iPad uses. It will benefit our new communication group and bereavement group”
- “Gaming will help promote inclusion and build friendships, not only between children but staff and children too”
- “This will help children to access the world around them and to interact with the nurses who spend time with them and communicate to their families after visit has finished”

#### **About Lifelites and the conference:**

- “Informative sessions, ideas to implement and to facilitate. You all seem very happy and enthusiastic (in your yellow shirts). Delicious food and refreshments. Thank you. Interesting to share difference hospices' dynamics and to meet with other professionals. Thank you for reigniting my interest. I will make the most of it. Amazing as to what interactive technology can do. Enlightening, fantastic new technology. Unlock a child's/young person's capability and potential”
- “Motivational speakers at the end, sharing how successful the equipment is in a hospice. Inspirational and looking forward to making our wish list”
- “Thank you this was another amazing conference. The guest speaker at the end of the day was so inspiring”
- “Thank you I have found today enlightening and supportive”
- “Wonderful staff, the possibilities are endless”
- “I've really enjoyed today's conference and gained a lot more knowledge on the equipment. Thank you”
- “Thank you so much for all your hard work :)”
- “It was good coming here as a team – it promoted great discussion among us - lots of good ideas - very inspirational”

- “Staff have been very welcoming and informative”
- “Thank you very much for all the wonderful work you do”
- “Such an enjoyable event - really got me thinking of best uses of equipment and new application ideas”
- “Brilliant day as always, thank you!”
- “Very interesting conference, will definitely recommend to colleagues”
- “Very enjoyable day, good networking and finding out what others do and how they use equipment. Thank you for hosting the day and giving us the opportunity to attend”
- “Thanks for helping us network and share our experiences alongside learning from you”
- “Thank you all - very well planned and informative. Such a fabulous conference – I really enjoyed it and got a lot from it!”
- “I cannot imagine doing my job without Lifelites equipment. Lifelites is amazing”

#### Key contacts and resources

Name	Role	Email	Phone
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Take a look at the hospice staff section on our website for helpful tips and useful guides on your Lifelites equipment: <http://www.lifelites.org/hospicestaff>

To see a video round up of the day take a look here: <https://www.lifelites.org/latest-news/the-biggest-lifelites-conference-to-date#.XLRW-jBKiUk>

If you would like to see the presentation slides from the day and/or the iMovie videos created by conference delegates, please contact  
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