



Giving kids with limited life unlimited possibilities

Lifelites 2016 #magicaltechnology Children's Hospice Staff Conference Report

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Lifelites – who we are

Lifelites provides specialist technology for over 9,000 terminally ill and disabled babies, children and young people using children's hospice services across the British Isles. These magical packages enable the young people to play, to be creative, to communicate and to take control of their lives, often for the first time and for as long as it is possible.

The hospices do not pay anything towards their Lifelites project and all of Lifelites' work is funded by donations: the equipment, ongoing technical support and training at each hospice costs Lifelites around £50,000 over four years.

Introduction

The 2016 Lifelites Hospice Staff Conference was held on the 19th May at the Hotel Ibis in Birmingham.

Our aim: To talk to 2017 hospice projects about new packages that may be available to them next year and to link the technology to the requirements of the young people at their hospices.

We brought together staff from children's hospices across the British Isles and gave them the opportunity to discuss the impact and difference the Lifelites technology makes to the children they work with.

We were also keen to hear from them what we could do to develop the equipment and services we provide to better meet the requirements of their children. Staff viewed equipment demonstrations and put in requests for some of the magical technology they thought would benefit the young people they care for.

Who attended?

The conference delegates were from a cross section of the children's hospice services: everyone from IT to care support workers, heads of care, therapists and play specialists were represented.

Fourteen staff attended from the following children's hospices:

Acorns in Birmingham
Acorns for the Black Country
Charlton Farm
Helen House
Little Bridge House CHSW

Little Havens
Naomi House & Jacksplace
Shooting Star CHASE
Tŷ Hafan

How the Lifelites technology is currently helping

Our conference is designed to get children’s hospice staff talking about their Lifelites equipment and the benefits it brings to the children they care for. It’s also helpful for staff to share their stories amongst one another and exchange ideas on how to use the equipment in different ways to achieve different outcomes.

Specialist iPad packages	<p>Staff from Acorns in the Black Country use the Facetime app to call home and allow the child to speak to their parents from the hospice. One child at the hospice can’t open their hands due to their condition but can still use knuckles on the iPads to draw and open apps - the hospice say that it’s great the touch screen is that sensitive.</p> <p>Staff from Acorns in the Black Country said that they have a child who comes to day care who had a tracheotomy – the Proloquo app gives him a voice. Although it’s not his voice it’s his words which enables him to type and communicate to tell staff what he wants.</p>
The Mobile Magic Carpet	Staff from Helen House said that the Mobile Magic Carpet is a focus point for families to come together and siblings to use the equipment to play games with each other sometimes for the first time.
Soundbeam	Vikki from Shooting Star CHASE uses Soundbeam for music therapy. She is able to create sensory stories by assigning a certain sound for each switch which she finds is great to help all the children to join in and interact with the story.
Large Touchscreen Tablet	Naomi House & Jackspace said they have a child who is completely blind in a wheelchair who uses the Touchscreen to make music. Huw says: ‘It made my day to see him with it’

Whole group discussion - “If money was no object...”

We asked hospice staff to discuss in groups if money was no object what they would like Lifelites to provide for the children they care for. Here are some of their responses:

- 3D printers and 3D cameras
- A giant hoverboard
- Magic tent to project images on
- Virtual reality – goggles/headsets
- 360° magic carpet – projective mapping with smells, wind, temperature, sounds, tastes
- 4G everything
- Drones and controls
- Waterproof equipment
- Eyegaze turning on TV, Radio, DVDs etc.
- More portable and compact equipment
- iPad per bedroom
- Sensory bus

Key discussion points

<p>Portable equipment</p> <p>We acknowledge that it's important for the equipment to be used around the hospice and in the bedrooms and, if possible, out in the gardens and especially to be taken into the children's homes.</p>	<p>Eyegaze – We now provide this technology with its own adjustable wheelie stand to enable the widest possible use around the hospice, even in the bedrooms.</p> <p>iPads – Our iPads have drop proof grip cases to protect the equipment from accidents . These can be taken anywhere around the hospice and into the children's homes.</p> <p>New Mobile Magic Carpet - Feedback about the old system concluded that although it was mobile, it was cumbersome to wheel around the hospice because of its height. Therefore together with Sensory Guru we have developed a new smaller, more compact version of the Mobile Magic Carpet. This includes a variety of new games and images and the ability to take it anywhere in and outside the hospice and into children's homes as well.</p>
<p>Training and development</p> <p>We repeatedly hear about the need for more training on the Lifelites equipment and that children's hospice staff still often feel 'afraid' of the equipment. We also hear that there is a high turnover of staff at hospices and therefore training is an on-going requirement so all staff can make the best of the equipment we provide. In response to this we will continue to offer more training services to give hospice staff the confidence they need to use the equipment to its full potential in the following ways:</p>	<p>Refresher training – We will continue to offer extra training for hospice staff on their Lifelites equipment when requested.</p> <p>Additional training staff – We now have trainer based in the north of England to facilitate the growing need for more training. This will help us to provide a more accessible training service from Lifelites for hospice staff around that part of the British Isles.</p> <p>Lifelites' website – We will continue to update the Lifelites website with information on how to use our technologies, signposting to other online resources and apps along with video and training guides. www.lifelites.org/hospicestaff</p> <p>Subject specific training events – We now organise national subject specific training days where hospice staff are able to focus on specific equipment and topics e.g. iPad to maximise the use of the apps and accessible options and Eyegaze training to learn how to calibrate or adjusting the stand.</p>
<p>Keeping in touch with hospice staff</p> <p>We gathered that staff felt they needed additional means of sharing and gaining information from us for them to make the most effective use of the Lifelites technologies.</p>	<p>Regular e-comms – We will continue to distribute bi-monthly e-newsletters to staff to inform them of training and installation news, latest apps and guides to help them with their equipment.</p> <p>Social media – Via Twitter and Facebook, we regularly post tips and advice from our Training Manager for hospice staff about the uses and applications of the Lifelites equipment.</p> <p>Lifelites' website – see above</p>
<p>Lifelites Champions</p> <p>Having a dedicated point of contact for staff in the hospice who understands how to use the Lifelites tech was an idea expressed at the conference.</p>	<p>Become a Lifelites Champion – If you'd be interested in becoming a Lifelites champion in your hospice please let us know. We may look at organising a conference or event to bring champions together for a joint training session on how to become the best tech support for your colleagues.</p>

Feedback from delegates after the conference

We aim to ensure that all delegates who attend our conference take a lot away from it. We organise the day so that it is informative in a fun, interesting and interactive way and take feedback on board in order to do our best next year. **Here's what the delegates had to say:**

100% of the delegates strongly agreed that the morning Lifelites equipment demonstration was enjoyable and informative	92% of the delegates strongly agreed that the afternoon equipment demonstration of the Magic Carpet and Beamz was enjoyable and informative
92% of the delegates agreed that the morning discussion was enjoyable and informative	92% of the delegates agreed that the if money was no object discussion was enjoyable and informative
92% of the delegates agreed that after the event they had a good idea of what their next Lifelites package will look like	58% of the delegates said that they would have preferred more interactive sessions with the equipment.

“Really useful to hear other people's experiences”

“Good ideas and a chance to look/hear what is new. Makes you think about what the hospice might need to support the children/families. All staff were friendly and helpful. Lots of information. Food and drinks also very nice, thank you!”

“Great day overall, the groups were small enough to feel like I had chance to express my views. Happy and helpful Lifelites team!”

Overall our delegates were happy with the event and next year we are aiming to make the equipment sessions more interactive. We will also consider extending the day by an hour to allow even more time, particularly for the interactive equipment sessions.



Key contacts

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