



## Lifelites Staff Hospice Conference 2018 Report

### **Who we are**

Lifelites is the charity which 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. 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 2018 Lifelites Hospice Staff Conference was held in Birmingham on Thursday 15<sup>th</sup> March.

Our aims were:

- To engage 2018 projects in the application process
- Remind all delegates about our free training offer
- Encourage hospice staff to share stories of how they have used Lifelites equipment creatively
- Provide networking opportunities
- Run a focus group on the use of virtual reality in children's hospice services

### **Who attended?**

Based on the success of last year's conference, we opened the invitation to all our projects across the British Isles. Delegates were divided equally into two groups: hospices due to apply for Lifelites donations in 2018 and non-applicants. The sessions were tailored for each group and the whole conference came together for the welcome, lunch and closing remarks.

We had an unprecedented response and were at full capacity. All the services due to apply for a Lifelites package this year attended with the exception of one. Two Lifelites trustees and two representatives from a new corporate partnership also attended.

The following hospices were represented:

Acorns Birmingham	Derian House	Noah's Ark
Acorns for the Three Counties	EACH Ipswich	Rachel House CHAS
Acorns in the Black Country	EACH Milton	Rainbows
Andy's Children's Hospice	Hope House	Rebecca House
Butterwick House	Jessie May	St Oswald's
Charlton Farm CHSW	Jigsaw	The Bridge, Murray Hall Trust
Children's Trust	Julia's House, Devizes	Ty Hafan
Claire House	Julia's House	
Demelza SEL	Keech Hospice Care	
	Little Harbour CHSW	

### **Aims and lessons from the conference sessions**

#### Session One, Group A - How to get the most out of your application and training

For the first time we ran a session on the application process with the aim of engaging hospice staff from the beginning and preparing them for each stage of the project delivery. We also emphasised the importance of training which is a vital part of delivering the new package. Delegates positively engaged in this session and shared ideas.

82.5% people strongly agreed with the following statement: "I feel confident about how to get the most out of the application process and training."

92% of people 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 emphasise the importance of training. It is particularly important that deadlines are met as we are running to a tighter schedule based on the financial year.

#### Session One, Group B - How to get the most out of your Lifelites equipment

This parallel session was tailored for delegates not applying for a new package this year. The aim was to enthuse delegates about their current Lifelites equipment and address any barriers to using the technology. We encouraged discussion about how to resolve these barriers and emphasised our offer of free refresher training, equipment maintenance and a variety of training resources.

90% of people thought the session was excellent.

This was an important opportunity to ensure hospices are using their equipment regularly and effectively.

#### Sessions Two and Three - Using Lifelites equipment creatively: Magic Carpet, Eyegaze and Switches, Beamz and iPads

This year we combined showcasing the equipment with discussions on using technologies creatively. The aim was to hear from the delegates and share different ways of integrating technology into care, education and play.

The delegate feedback illustrates that this aim was achieved:

- "We can take the ideas back and use the equipment with renewed confidence and creativity"
- "To go back to hospice and give another accessible IT push to staff. Always something new to learn/remember!"
- "Good ideas on how we can move forward and make better use of equipment"
- "Fabulous service and it allows us to share our experiences and broaden our use of the technology"

Over 90% of delegates thought these sessions were excellent.

#### Session 4 - If money was not object

The final session of the day was a short thought experiment where we asked delegates to use their knowledge and experience of hospice care to invent ground breaking technologies. Understanding what hospice staff view as useful technologies for children and young people, assists the projects team in researching new equipment and software.

Some of the ideas included: an implant so parents can experience their children's perspectives and dreams, a 360 degree waterproof projector used in hydro therapy/baths, a VR avatar experience so you can meet your favourite characters, an Artificial Intelligence "Brian" to live on site, a VR immersive room and a universal, wipe clean, multi-purpose, non-slip "super switch". It was highlighted that some of these ideas are in production for example VR avatars and the VR immersive room.

#### **VR Focus Group**

As part of our ongoing research into the suitability of virtual reality in children's hospices, we ran a VR focus group at the conference. The aim of the session was for hospice staff to try VR and to discuss the benefits and challenges of using VR with children and young people with life limiting conditions.

Due to the number of participants and the limited length of the session it was difficult to facilitate a group discussion. However, we provided a sheet of five research questions which delegates completed, providing excellent insights. The comments made during the sessions were also captured by Lifelites staff taking notes.

We invited the Managing Director of ImmersiCare to provide a short introduction and demonstrate their VR system so that hospice staff could experience virtual reality for themselves.

From the feedback it is clear that the majority of delegates were incredibly excited to see this technology and to consider the potential benefits it could have within a hospice setting.

#### List of research questions:

1. In what ways do you think VR immersive experiences could benefit young adults and children over 13 years of age using your hospice service? Are there specific conditions you think VR would be particularly suitable for?
2. Can you identify any risks? How would you overcome these risks?
3. In what ways do you think VR gaming could benefit young adults and children over 13 years of age using your hospice service?
4. Do you think the children and young people you work with could wear a bulkier headset and headphones?
5. What would be the top priority when considering a VR system for your service? Please number 1 – 5 in order of preference. 1 being the highest preference: cost, ease of use, widest use, personalisation, other?
6. Any other comments

VR would be potentially suitable for:

Duchenne’s Muscular Dystrophy and all degenerative conditions  
Cerebral Palsy  
Rett Syndrome  
Aicardi-Goutieres syndrome (AGS)  
Cancer  
Sanfilippo  
PMLD needs  
Tracheotomy  
Locked in Syndrome  
Friedreich's Ataxia

SMA type 1 and 2  
Spinal injuries  
“Most patients with cognitive understanding”  
“Children who are wheelchair bound, all children could benefit”  
“YP with more cognitive ability but limited physical ability”  
“Children who can no longer travel, have lost

their mobility, are house bound”  
“It could be suitable for so many of our children”  
“There is no one group/condition that may stop someone enjoying VR. It would be trial and error for everyone. Consent would be needed from family for people/children to try”.

Benefits of VR immersive experiences

<b>Medical and Physiological benefits</b>	<b>End of life care</b>	<b>Exploring new worlds/Escaping confines of hospice</b>	<b>Fun/Social experience</b>
We had a consultant from UCLH prescribe VR to a patient of ours for 20 mins a day. She is 18 years old with terminal cancer, severe depression and anxiety. He said he would prescribe to improve this	I think in end of life it would be really good as they can use it to experience wishes they may not be able to see otherwise. May help with depression in end of life as they can struggle with being bed bound	Freedom, new experiences, out of the box experiences, once in a lifetime experiences	Give them experiences they missed out on as kids or experiences they can no longer do. Great for families to see their young person "doing" experiences they have been unable to do
For distraction when feeding/medical procedures  To be used to distract from painful procedures	Good for a bucket list	Give them experiences that they wouldn’t ordinarily be able to do, in the safety of their homes/hospice	Could be a way of connecting children with others
Calming for children who have a lot of erratic movement	End of life when wanting an experience e.g. going to beach but too weak to go	Sense of freedom for those with deteriorating mobility. Experiences that they may never be able to do e.g. under water for those with tracheotomy	
On the ImmersiCare system it is possible to control the turtle on one of the experiences in order to encourage neck movements to improve strength		It would allow service user experiences that they were unable to access in daily life. It would give them a chance to escape and	

		relax. For some users it could bring back past experiences/memories	
It could help sensitise fears, exposing the user to something without it being real		To relax, immerse themselves in a different situation, escape reality and enjoy things they never thought possible	
It could promote exercise without children realising		Will enable them to experience a vast range of activities and situations that due to their physical limitations would be impossible	
		Enhancing their emotional wellbeing and potential to explore life	

Risks and how to overcome them

<b>Medical/Physiological</b>	<b>Solution</b>	<b>Mental/Emotional</b>	<b>Solution</b>
Over stimulation - too much too quickly Panic attacks due to experiences they've never had	Gradual introduction, staff using it first	Frightening children. Some children may not understand it and get frightened/anxious	Prepare and introduce gradually  Less confident children and young people can watch on the screen first
Nausea/vertigo/motion sickness	Start to use gradually  Alex Smale, MD: in his experience this is only with roller coaster experiences/games where your body isn't moving the way your brain expects. The frame rate of the ImmersiCare VR system is high which means it catches up quickly. It also monitors the user's movements and adjusts to it. There have so far been no cases of motion sickness	Confusion  Stress  Feeling overwhelmed	Work beforehand to prepare

Weight of the headset	Risk assessment and test for suitability	Upsetting a young person who has the realisation they are now unable to do any more	
Eye strain leading to headaches	Limit time  Alex: Any length of time. Just be careful of eyestrain. It would be like sitting in front of the TV for hours. Build it up. After 20 - 30 minutes people are usually satisfied	Unrealistic expectations - i.e. Unable to walk and never will be able to. Possibly lead to low mood/depression?	Training of staff, confidence of using the system
Falling over and bumping into/walking into things  Loss of balance i.e. standing up, claustrophobic feelings	Making sure it is staffed when used  Sitting only experiences/games	Those whose cognitive ability is limited may be alarmed  Communication deficits	Like how they would gradually be introduced to any new experiences – staff need to be sensitive to the child’s responses.  Images are purposefully cartoony rather than realistic
Seizures brought on?	More research  Parental consent  Trial and error  Close monitoring	Overuse - some of our children would become obsessive about it	Correct adult control and monitoring
Infection control	Risks have been minimised in the design  The Oculus headset is easy clean/can be deconstructed	Health and safety	Risk assessments Care plans

Benefits of VR Gaming

<b>Confidence and control</b>	<b>Social aspect</b>	<b>Sense of normality</b>
Confidence  Pride  New experiences	It could be a social activity, help them to engage with others, it would be an enjoyable experience, build their confidence, skills and give them something to look forward to	They feel like they can move again if not able to use generic controls
Help development/skills	Excellent group activity	Allowing them to be "in" the game

Reduce depression - take mind off degenerative condition when losing abilities. Provide a calming experience	Fun for siblings too	Used to online gaming
Would give them more control and to still enjoy things they are used to doing	Provide new experiences. Teenage weekends we have at hospice - VR gaming sessions	Gaming can keep them on the same level as their friends Able to continue with gaming activities
		A chance to do something the same as able bodied
		VR would benefit young people who are losing physical ability to continue to access something
		To enable them to interact with peers/siblings. Be "normal" and do what other teenagers are doing

### Headsets

Do you think the children and young people you work with could wear a bulkier headset and headphones?

Yes	No	Maybe
Most of them yes	Majority of teenagers in our service have big wheelchairs and very limited body control/head control so lighter and smaller I assume would be better	Not sure
On the whole yes	No, I think the ones we used today. Easier with head rests	Possibly not
Yes	Headrests may get in the way	Some of them could - difficult to know without trailing
Yes	Slimmer more comfortable headsets are better	This would depend on the children's physical limitations
If explained and modelled children will probably cope	No, most wear head cushions for support on wheelchair headrests	Depends on the positioning of their head
Yes, although not all obviously	Lighter the weight the better	Some yes. Personal preference and comfort should be taken into consideration
Yes	Need adaptable headsets	It depends on the individual child/young person and medical condition i.e. their head may be sensitive
Yes, although may be a problem if lying down	No	Some would tolerate but others not
As long as not too heavy, can't see an issue	The smaller headset would work better with the head rest	Depends on the child and their sensory preferences/needs

Yes some would tolerate these	Most could wear the Oculus headset	
	Head phones can easily be shaken off. May not sit well on head. Oculus head set would work better	
	Not much bulkier no	
	Not really bulkier no. This about the right size due to children in wheelchairs	
	No	
<b>10</b>	<b>14</b>	<b>9</b>

### Priorities

What number priority for most delegates?	Most important factors
1	Cost
2	Ease of use
3	Widest use
4	Personalisation

### Other comments and ideas

- “Amazing product! Mind blown!”
- “Providing stimulation, fun, distraction, age appropriate experiences”
- “I feel this would be invaluable to our children and young people”
- “Outreach for when families don't know what to expect from a hospice - could show a virtual tour”
- “Truly amazing and would benefit so many children and young adults”
- “Fantastic what you have achieved, endless possibilities”
- “What is particularly interesting is the after effects and how long this lasts”
- “Would be brilliant for our transition group/discharged young people who have lost so much function but still cognitively able - enhance wellbeing”
- “VR looks amazing with endless possibilities and experiences”

### Next steps – further research and piloting

The feedback from the focus Group was an invaluable part of our current and future research into the suitability of VR for children and young people using hospice services. This has been integrated into our collated research on VR and will be discussed by the projects team in April. We will continue to monitor and evaluate the Sony PS4 gaming and immersive experiences (now being piloted at Naomi House and Jackspace). The feedback will inform our decision on which VR systems will be offered as part of the pilot for 2018 – 19 projects.



## **Transition and Hospice at Home**

### Transition

Lifelites will continue to tailor its packages and training to cater for young adults, ensuring we provide age appropriate technologies that meet the needs of those transitioning to adult services. We received the following feedback on how technology can enhance this process:

- “IT *has* to be the way forward for supporting transition”
- Technology will “build confidence, provide different experiences, support their wellbeing and health. Something that would capture their interest when their ability is limited”
- It will “empower young people to help prepare them for adulthood”
- Technology can “enhance independence and the ability to experience age appropriate experiences and regain their motor skills”
- It “increases social activity and discussion. Motivational as well as relaxing”
- VR “would be brilliant for our transition group/discharged young people who have lost so much function but still cognitively able - enhance wellbeing”

### Hospice at Home

As care in the community increases, Lifelites continues to provide mobile equipment and more specialised training with a focus on family activities and technologies that enhance end of life care. We continue to research equipment that can be taken into the home environment such as iPads and apps, Beamz and the upcoming release of a mini mobile magic carpet. Delegates told us about how technologies have a positive impact on care in the home:

- “giving children enriched experiences and variety”
- “IT is becoming even more accessible by becoming more portable”
- “iPads and switches would be easy to take into children’s homes and improve access to activities and games”
- “Bringing fun/stimulation to the home environment”
- “Bring them a change to their usual environment”
- “Enhancing emotional wellbeing, allowing children to relax and enhance their experiences with their parents when in pain”

## **What Lifelites will be delivering in 2018/19**

The application process for 2018/19 projects has begun and we are looking forward to reading the application forms and discussing the new packages during the consultation period in May. Research and testing of VR systems will continue and we plan to pilot these with hospices due a package this year, should they request to be part of this trialling stage. From September 2018 – March 2019 we will be installing these new packages and delivering two days of training to each hospice.

We are continuing to develop our training remit, working on exciting new resources and tailoring our training for Transition, Hospice at Home and new equipment. Special courses are also on offer, for example on making memory books, 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 have created a new feedback form for those attending training sessions from April 2018.

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

We are planning to keep the conference open to all hospices next year. There will be a limit of 40 delegates, after which point we will run a waiting list. We have already booked two rooms at the same hotel (Ibis, Birmingham New Street) for Thursday 7<sup>th</sup> March 2019 (*this date is subject to change and will be confirmed when the invitations are sent at the beginning of next year*).

We will run a session on the application process for hospices due to apply in 2019/20 and tailor sessions for the non-applicant group. We would like to ask hospice staff to present on a topic and will contact potential speakers in advance. Any external speakers we invite will be non-commercial, for example it may be possible to have a specialist session on using technology to create music or art. Based on delegate and staff feedback we will keep the sessions short but provide more time in between sessions for refreshment breaks. We will also look into a virtual ideas board via Mentimeter or Kahoot so delegates can make suggestions throughout the day on dream technologies, how to use equipment creatively or stories they want to share about their work.

The aims of next year's conference will be to:

- 1) Showcase equipment
- 2) Initiate the application process for 2019 projects
- 3) Provide important research and consulting opportunities
- 4) Revitalise and enthuse hospice staff about using Lifelites equipment
- 5) Share stories, hear from delegates, network

### **General feedback from the day**

- 92.5% said that the sessions seemed well planned and the event was enjoyable
- 88% of people strongly agreed with the statement "after today, I have some new ideas of how to use my Lifelites equipment"
- "Great to meet the Lifelites team and network with other children's hospices. Has been invaluable in planning equipment for our hospice build and make the most out of our current Lifelites iPads"
- "This has been a fantastic conference and inspired me to return to the hospice and make the most of our Lifelites equipment. To also encourage other staff to become involved"
- "The Virtual Reality equipment was truly amazing and would make such a difference to so many of the children and young people we care for. We loved it"
- "A great day, feel inspired and fired up to try and use all the equipment with more confidence. Thank you. p.s. loved the milkshake and cookies! :)"
- "Extremely enjoyable day - very inspiring!"
- "All the equipment will benefit the majority of our children and young people"
- "Really enjoyed today. Amazed by the technology. Excited by the possibilities of VR"
- "Love these conferences to enthuse me again. VR looks awesome!"



### Key contacts and resources

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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 and presentation slides from the conference take a look here:

<https://www.lifelites.org/hospicestaff/lifelites-hospice-conferences/lifelites-hospice-staff-conference-2018/#.WsdpTC7waUk>