

SPOTLIGHT

ISSUE 4: Autumn 2015



HELLO!

Welcome to our Autumn newsletter. As ever we have been busy here with BRIGHTLIGHT.



BRIGHTLIGHT collects information from young people at five different timepoints. We have now carried out all the face to face interviews and very soon we will be able to do some number crunching to provide you with some exciting results.

In the meantime this issue will give you a brief summary of what's been happening with the study, what the YAP have been up to, some emerging findings and share a young person's story.



NEW Website

Check out our new website. Using our YAP's feedback we have improved the look creating a fresh, simple design that includes all our current research. It is simple and easy to navigate helping you to find the information you require a lot easier. Please take a look and let us know what you think. We hope you like it!

www.brightlightstudy.com

Emerging Findings

Being diagnosed with cancer may have come as a huge shock at the time. For many people it is an overwhelming time as you start thinking about the affect it will have on your life. We recognise it is a difficult time to take in all the information you receive from your healthcare team about your diagnosis, treatment and the next steps.



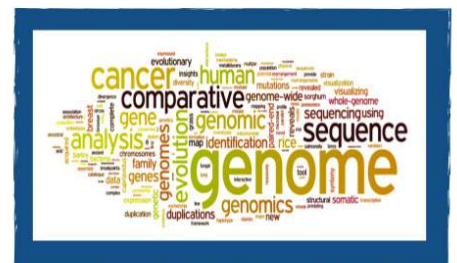
80%

BRIGHTLIGHTER's told us they can 'always' speak privately with the cancer specialist if needed



70%

of young people found information is 'always' provided in a way they can understand



30%

of young people found the cancer specialist 'sometimes' uses terms they cannot understand

In September we held our annual workshop and things got a little bit TWISTED!

Our workshops are always fun and different but even the YAP didn't see this coming! Using the original Twister game board we made some changes to reflect different areas of the BRIGHTLIGHT survey. This generated group discussions between randomly chosen topics of the survey to encourage or explore any associations that we as researchers had not thought of.



Twister allowed the study team to gather new research questions and think of new ways to analyse our data from all the information you provide in your surveys. This will give us a deeper understanding of issues relating to your care so please continue to complete the survey online or over the telephone. We are now working on these ideas and hope to have some results for you shortly. Keep an eye on our website.



A HUGE thanks to our YAP for making this another fun day and giving us lots of new ideas to work with!

Being a mum

Sarah, 23 is one of our YAP members and mum to Khloe. We hear her experience of learning she had Thyroid cancer and her concerns about her young daughter.



Khloe is like every other 4 year old girl, she loves swimming, dancing and is very energetic! Before being diagnosed my days were filled with the usual stuff a mother does **raising a child** but noticing a lump in my throat I knew it wasn't normal so I went to the doctors for the second time who referred me to the hospital straight away. Learning I had cancer immediately scared me as I was forced to think about the future at such a young age- but I had Khloe to think of and the thought of her having a life without me made me feel awful. My thyroid cancer treatment path was very straightforward, surgery then radioactive iodine.

Coming home from the hospital after my surgery was difficult. All I wanted was a cuddle from my little girl but the stitches and scar across my neck made her scared of coming near me, this was worse than the surgery itself! She was too young for me to explain the cancer to her; all she understood was that I had sore neck. My parents were **lifesavers** and looked after her during this time, I was worried how she would cope on her own with them as Khloe had never spent a night away from me since being born but she was fine.

I was lucky to have my parents as my **main support** which meant they could take the weight of my shoulders and look after Khloe. I was able to **focus on recovering** from my surgery/treatment without having to worry about her. I also had the support of my healthcare team who were amazing and kept me informed all along.

Life hasn't changed for me much since finishing treatment. physically I am much more tired which makes activities with Khloe sometimes challenging and I find it hard to motivate myself to do things. The one thing cancer has changed is my perception on life. I definitely appreciate every little thing now, and I look forward to the **future**. This has made my relationship with Khloe a lot stronger and I look forward to spending everyday with her.



Sarah & Khloe

ARE YOUR DETAILS UP TO DATE?

You originally agreed for the BRIGHTLIGHT team to keep your contact details for 3 years. The study is taking longer than we expected so our NHS Research Ethics Committee has approved us keeping your details until the study ends in 2018. This is so we can keep you updated with all the emerging results. If your address or telephone number has recently changed, or you would rather not be kept updated please let us know and we will remove your details from our database.



Want to share your story? Please get
in touch:



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