

BRIGHTLIGHT Newsletter



SUMMER 2016

HELLO

Welcome to the summer edition of the BRIGHTLIGHT Newsletter. Filled with the latest updates of what has been happening here are BRIGHTLIGHT headquarters. Wave 2 data collection is now complete and we would like to thank all of you who took part. We are now pulling all of this information together and will provide you with a summary of the findings soon.

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IMPORTANT ANNOUNCEMENT



Our Young Advisory Panel (YAP) asked us for an Instagram account and so we are pleased to introduce our Instagram profile at @brightlightstudy. If you have an Instagram account, follow us. Let us know if you have any ideas of what you would like us to post or any ideas for hashtags that we can use. We hope you like it. #BRIGHTLIGHT #BRIGHTLIGHTStudy

HOW TO CONTACT US:



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BRIGHTLIGHT RESULTS: Healthcare professionals caring for young people

As well as interviewing young people about their cancer experiences. Another part of BRIGHTLIGHT is finding out what qualities and characteristics make a good healthcare professional **caring for young people with cancer**. We carried out an **international survey** with nearly **200 experts** from all round the world. The key results are in this box 

KEY CHARACTERISTICS FOR HEALTHCARE PROFESSIONALS CARING FOR YOUNG PEOPLE WITH CANCER

- Identify the impact of cancer on young people's life
- Know about side effects of treatment and how this might be different to those experienced by children or older adults'
- Honesty
- Listen to young people's concerns

So what will we do now?

Delivery of care to young people with cancer aged 15-24 years in England is provided by a multi-disciplinary team (MDT) involving lots of professional groups. We believe these groups should be trained to provide specialist cancer care for teenagers and young adults with cancer.

There was a lot of agreement between professionals that education and professional training could be improved for professionals wanting to work with young people with cancer.

We will be having a workshop later in 2016 for healthcare professionals to decide how best to take these results forward to improve training and education for future professionals.



If you want read the full report you can click here:
<http://bmjopen.bmj.com/content/6/5/e011361.abstract>

INFORM_ME: SUMMER YOUNG ADVISORY PANEL WORKSHOP

We held our sixth annual workshop with our YAPPERS in Leeds looking at how young people use the internet to look for information and support about their cancer.

WHAT websites/apps have you used for information and support?

WHEN did you look for the information?

WHY did you need it?

The YAP workshops are open to any one taking part in BRIGHTLIGHT. We will be having similar workshops in the autumn and **if you would like to come along email us:** brightlight@uclh.nhs.uk



MEET ANTONIA FROM OUR YOUNG ADVISORY PANEL (YAP)



Antonia is one of our **YAP** members and was diagnosed with Non-Hodgkin's Lymphoma in 2014. Here Antonia discusses her story.

“ My name is Antonia Young, I am 22 years old and work full time between two jobs. From a young age I've always studied and worked so life has been busy. August 12th 2014 I celebrated my 20th birthday, just another year older, I never knew shortly after my life would change forever.

Christmas was approaching and the overtime piled up. Demanding customers, more work, the pressure was on. I developed a chesty cough, lost my appetite, lost weight and suffered night sweats.

From what I remember this all started around September 2013. I was backwards and forwards to the doctors with the same complaints. They told me it was laryngitis. In November I was on my way to work. It was a busy afternoon and the trains were packed. I couldn't get a seat, felt really hot and noticed I was sweating. Finally, I arrived at my stop to get off and thought fresh air would make me feel better. As I walked out of the station I felt really **sharp pains** down the right hand side of my body. I called my boyfriend and told him what had happened and he came to meet me. He was asked a nearby security guard for help. They decided to call an ambulance for me.

I was taken to Hammersmith Hospital where I was reviewed by doctors. I had blood tests and an X-ray. I was told that my bloods were fine but my X-ray seemed to have a shadow appearance. But I still was discharged. Little did I know this was the **beginning** of my cancer journey.

I continued working over the Christmas period, dealing with the busy Christmas rush. However, I was still suffering with **symptoms and pains**. I put that all aside as the hospital confirmed nothing was wrong. Christmas day arrived, I remember opening my presents surrounded by family but couldn't stop **coughing**. I wasn't going to let that ruin my day!

I booked a week or so off work to try and settle the cough and to make time for some driving lessons.

1st February I returned to work. The shop floor was really quiet and I was putting out some stock. All of a sudden I became **dizzy**. My colleague asked if I was okay and said I looked pale. I went to the back office to sit for a couple of minutes. I didn't want any questions or any fuss so instead I went to the toilet and sat down. At this point the room was spinning, worse than ever. Everything after this moment was a **blur**. My store manager came in and lifted me off the floor. I had never fainted before. I was going in and out of consciousness. I don't know how I got from the toilet floor to the office.

Sitting in the office I could see the cameras on the shop floor and could see it was busy. I wanted to go and help my colleagues but my manager told me to stay. I was aware that an ambulance had been called. The office became very crowded and I was taken to Chelsea and Westminster Hospital for further investigation.

On 4th February 2014 I was diagnosed with Non-Hodgkin's Lymphoma. I never knew cancer was ever possible at 20 years old. Old people get cancer! Not me? My life had just started. From this moment I knew my life would change drastically, that's if I get out alive! Treatment began 28th February and after eight long cycles of chemotherapy and two scans I was glad to be done on the 27th July. I got the 'remission' news and was expected to get back on with normal life. I had so much attention and concerned friends during my illness that as soon I was okay again nobody really wanted to know. It was a big shock to the system.

Being diagnosed with cancer at any age is hard, but to be young and have cancer is even harder. Even though I'm in remission, I still think about cancer and live in constant fear of it returning. I'm back to full time work and working on my career goals. I am hoping to attend university in September. ”

WANT TO GET INVOLVED?

If you are interested in helping shape future research projects and also help us spread BRIGHTLIGHT results as far as possible then get in touch. If you contacted us previously and did not hear from us, please do get back in touch. We have experienced some technical errors here and not everyone who has contacted us may have got a response.

- Do you have creative ideas that can benefit the BRIGHTLIGHT study?
- Are you interested in learning more about what the BRIGHTLIGHT team do?
- Do you want to take part in developing more research for Teenagers and Young Adults?
- Do you want to meet other young people with cancer?
- Do you want to join our **YAP group**?

We are looking for people to join our YAP group; YAP is short for Young Advisory Panel. If you took part in the BRIGHTLIGHT study and would like to help with future research ideas like the one above, or with future plans for the BRIGHTLIGHT study then get in touch. We have a workshop once a year, usually in London, where we come together to work on research topics.

This is not taking part in a research study it is working alongside researchers helping to shape current and new research studies. Click [HERE](#) to see more photographs of previous workshops



Contact BRIGHTLIGHT HQ for more information

**Do you want to provide us with feedback on our newsletter or send us your story?
Our find our contact details below**



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