

Cancer Connect

The St George's newsletter for people affected by Cancer

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Cancer Don't Let it Win

Jeff Thompson's prostate cancer support network

CDLW, Cancer Don't Let it Win, stands out as a remarkable support network for individuals battling prostate cancer, offering solace and guidance to those diagnosed or in recovery.

The brainchild behind this initiative is Jeff Thompson, a prostate cancer survivor who underwent surgery and grappled with the challenging physical and emotional aftermath, that led him to attempt to end his life.

Jeff's moving account, which he recently shared with the St George's Trust Board, laid bare his struggles with issues like incontinence and impotence, evoking deep emotions among his audience. Reflecting on his own journey, Jeff highlighted a pivotal moment when a candid conversation with a friend facing similar challenges provided him with much-needed comfort and prevented him from succumbing to despair.

Motivated by this experience, Jeff resolved to create a supportive community where individuals could openly discuss their experiences, find comfort, and glean insights. Thus, the group "Cancer Don't Let It Win" was born, spearheaded by Jeff with minimal financial backing.

Today, this initiative has branched out to places like Birmingham, Vauxhall, Brixton, Croydon, Lewisham, Bermondsey, and Brighton, offering a welcoming environment for individuals and their partners to connect, share, and empathise.

In addition to hosting regular meetings, Jeff and his team extend a warm invitation to anyone seeking support, having already assisted over 2000 men and their families since the group's inception in 2020. Furthermore, Jeff has devised a tailored exercise regimen designed to cater to the specific needs and abilities of individuals affected by cancer.

Jeff actively engages with numerous organisations to advocate for the importance of men getting tested and to raise awareness about the prevalence of cancer in men. Statistics show that 1 in 4 men from a black African or Caribbean background, 1 in 8 white men, and 1 in 13 Asian men in the UK are affected by cancer.

Despite facing financial constraints, Jeff has been able to carry out his advocacy work through the support of small donations, which cover expenses for venues and administrative tasks. His successful surgery at St. George's Hospital has inspired him to establish a support group in Wandsworth, and he is optimistic that many individuals will rally behind his cause.

For more information, visit Jeff's website at:
www.cancerdontletitwincic.com



Living with and beyond cancer

Improving our support for patients and their loved ones

Dealing with cancer and its many treatments can sometimes bring with it a range of different challenges.

Helen Ricketts, living with and beyond cancer lead physio, has been running a series of projects under the banner of 'Living with and beyond cancer' aimed at enhancing St George's services to better support patients and those around them, thanks to the generous funding from the St George's Hospital Charity.

The VOICE group has played a crucial role in shaping these projects to ensure that the trust cater to patient's needs effectively.

Here is a glimpse of some of the projects currently underway.

Supporting people with pelvic and abdominal consequences of cancer

We understand that topics like incontinence, pelvic pain, sexual dysfunction, prolapse (and many more) can be difficult to discuss.

We are designing a service and resources to support people facing these consequences of cancer. Our aim is to make it easier for you to access the help you need.

Cancer website

We hope to centralise information for patients, primary care and St George's colleagues to make it easier to access support and information related to treatments. Additionally, we are establishing a network of colleagues with cancer related expertise to support people throughout the Trust with the different cancer related health issues that can arise.

Week of Wellbeing

In partnership with AFC Wimbledon Foundation, we are developing resources to support people with different wellbeing activities to try every day of the week. Our goal is to wellbeing, whilst having some fun along the way.

Training and Education

We continue to deliver training for different teams in the hospital and community settings to increase awareness of the different types of cancer and the many treatments, to ensure staff are better equipped to understand the needs of people living with cancer.

Prehabilitation

We have a partnership with the Move More team to support people to be physically active prior to being admitted to hospital for their stem cell transplant. We are going to pilot a digital healthcare App to support people to prepare for lung cancer treatment.

Understanding how cancer impacts quality of life

To help us to develop our services further, we will be collecting some information in several clinics to help highlight areas of concern for our patients and indicate what next steps to provide support should be.

Patient involvement and feedback will be invaluable as we move forward with these projects.

Please do participate in any of the groups or feedback sessions that we advertise to help us better serve you.



Carl Tubb's Story

One minute I was going to the gym regularly, practicing boxing and playing rugby – the next I was put on emergency bedrest and being informed I had a tumour on my T12 vertebrae, compressing my spinal cord and nerves.

I knew the cancer statistics, but still thought I was untouchable. I'd just turned 30, was reasonably healthy and was planning things to enjoy my second summer in London. During a workout in November 2022, I got a little distracted and heard a crunch in my back while using weights, by that evening I was in awful pain.

The months following were a struggle, until in May 2023, I paid for an MRI to be carried out privately (my GP was convinced I was just overweight and that it was a pulled muscle). The result was a stress fracture in my T12 vertebrae. The pain continued to get worse and on 31 May 2023, I had to call 999. I couldn't sleep and had become numb around my lower back. The pain had become so severe that I couldn't put weight on my legs or pass urine. I was rushed to hospital and had an urgent MRI scan.

They found a mass in my back, and I was immediately put on bed rest. Every movement risked causing permanent damage to my nerves, or possible paralysis. On 3 June, I was rushed into emergency surgery to have a laminectomy to reduce some of the pressure in my spine and to reduce the risk of nerve damage, a biopsy of the mass was taken. The operation went well and within a few days I was back at home. However, on the 11 June, I was rushed back to hospital as the pain once again was so severe that I couldn't put weight on my legs. I spent the whole night in A&E. Whilst sitting in a bay, on the morning of the 12 June, a consultant said the words "The results of the biopsy have come back, the mass on your back is malignant. You have non-hodgkins lymphoma."

My world stopped in that second. I froze – was I having a nightmare? Did they have the wrong person? I called my dad and close friends – their worlds also stopped. Those statistics we all skimmed over in the past; well I was now one of those who had cancer. On 14 June, after my initial PET CT, I was informed that I had a second tumour on the right side of my pelvis – which was a further shock.

I was kept in St George's for a month because my pain was so severe, and the specialists were trying to find the right balance of medications that worked for me.

During my stay I started chemotherapy, POLA-R-CHP. Two weeks after starting, I woke up one morning and discovered lots of hair on the pillow, then it started coming out in clumps. During a shower the plug got blocked due to the amount of hair falling out. I asked some friends to visit a few days later and shave my head – I wanted to keep some control over something!

My cancer 'journey' wasn't as straightforward as I'd hoped it would be. Each cycle of chemo resulted in a hospital admission due to infections, ranging from COVID-19 to neutropenic sepsis. Each cycle knocking a little bit more out of me, until I just wanted to give up and stop. If it wasn't for the support of my friends, nurses and CNS, I don't think I would have pulled through. Speaking of friends, one of the positives of my diagnosis is that I got to see who my true friends are. Cancer is a hard thing to be around, I get that, but using that as an excuse for not seeing your friend who is fighting for their life is a rubbish excuse. I lost a few 'friends' during my 'journey', but it's their loss.

They haven't got to witness how strong and determined I've been to beat this. True friends stick to your side no matter what; they attend appointments where they take notes for you, they bring you food when you're struggling with fatigue, they joke around with you when you're struggling to stay positive, they shave your hair off before the chemo takes it – they show up when you need it. This year has been hard, yet I've found ways to keep smiling and remain positive. I've surprised myself with how determined I am, how strong I am and how resilient I am. Even on the days where I really struggled – I found little ways to keep positive. I know even once I'm in remission, the fight won't be over – there's plenty of side effects from the treatment, medication, and the tumours themselves, but I'm determined to stay alive. Not just for myself, but for all those other individuals I've met along the way who didn't make it.

Cancer is a horrible word and a vicious disease – but on the 30 May 2024, I won the fight!



Jenny says hi!

Jenny Wainman is the new co-chair of patient voice

Hello, I'd like to introduce myself. I'm Jenny Wainman, the newly appointed co-chair of Patient Voice. VOICE is the cancer patients / carers user group. We work with the hospital's Cancer Division to improve services.

I have been a patient at St George's for over 30 years and am glad to say I am living with and beyond cancer thanks to the treatment I have received. Patient Voice has given me the opportunity to share my experiences along with fellow Voice members to help and enable the cancer developments being put forward at the trust.

There are several exciting new activities that Voice members are assisting with in the 'Living With and Beyond Cancer' series.

The Lymphoedema management workshops for advice on self-management and building resources to support people experiencing Lymphoedema or pelvic and abdominal consequences of Cancer.

We are also looking to develop and provide appropriate information for patients in pre-treatment/surgery, including informative workshops for those starting or having treatment. We are looking to develop a specific group or 1-to-1 support for those who will benefit from it.

We are always eager to welcome new Voice members. Some of the best suggestions for supporting cancer services come from conversations during meet ups with fellow patients and carers. One such suggestion is the George's green Club.

The club is still going strong, holding monthly gatherings in differing green spaces around the hospital to enjoy talks, walks, drinks, snacks and conversation. They are held at 2pm on the fourth Wednesday of every month.

Resources

Macmillan cancer information and support centre
Ground floor, Grosvenor wing, St Georges hospital
Tel: 0208-725-2677

Macmillan Cancer support
Help line: 0808-808-0000
Mon-sun, 8am-8pm

Macmillan community cancer link worker Support services
Tel: 0300-1000-200
Macmillan.org.uk

Other advice services

Citizens advice
Tel: 03444-111-444
www.adviceguide.org.uk

Turn2us (Financial support)
www.turn2us.org.uk

National debt line
Tel: 0808-1565-3800
www.nationaldebtline.co.uk

Step change (debt service)
Tel: 0808-138-111
www.stepchange.org

Law centres Network
(free legal advice)
Tel: 020-3637-1330
www.lawcentres.org.uk

ACAS (Advise on workplace rights)
Helpline: 0300- 123-1100
www.acas.org.uk

Age UK
Tel: 0800-055-6112
www.ageuk.org.uk

Voice is our cancer patients/carers user group. We work with the Hospital's Cancer Division to improve the services. Are you interested in representing your community and influence future cancer care at St George's Hospital? Why not join a community to help make a positive impact. Membership of Voice ensures you will always be up to date on the latest information on cancer services, be invited to health and wellness events and be able to share your views and experiences. You can also help with fundraising and have a hand in designing new services. **Interested in joining? visit the Macmillan information and support centre or contact:** Tel: 0208725-2677 Email: cancer.information@stgeorges.nhs.uk

