Cancer Connect

The St George's newsletter for people affected by cancer

Issue 2, Winter 2018

Cancer patients benefit from role of support workers at St George's

Patients are continuing to benefit from a partnership between St George's and Macmillan Cancer Support.

This includes increasing the time patients are able to spend with a Clinical Nurse Specialist (CNS). These are highly trained nursing staff who can address patients' complex needs.

Macmillan has funded six support workers, who can assist and compliment the work of a CNS, freeing up the nurses to be able to spend more time with patients.

Mark Langston, a Wandsworth resident in his 60s, was treated at St George's for prostate cancer. He's now in remission, but feels that having a support worker on the ward gave him more quality time with his CNS.

He said: "My CNS was marvellous and I really valued the contact we

had. She had the time to go above and beyond her expert clinical role. After I was discharged she would continue to ring me at home to ask how I was feeling. It made such a difference."

Janice Minter, Lead Cancer Nurse for Urology at St George's, said: "A lot of a CNS's time can be spent on administrative tasks and so their specialist skills are not being used.

"We're delighted that the partnership has appointed six motivated Macmillan Cancer Support Workers in urology, colorectal, haematology, lung, skin and upper gastrointestinal areas."

The six support workers were funded through money raised by the Merton Committee of Macmillan Cancer Support.

St George's and Macmillan: Cancer Care Partnership for Patient Experience includes four improvement pilots and will run until December 2018.

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Beyond the diagnosis

"Two years of treatment and surgeries has left me with a new body, new hair and a new outlook on life. The result of my reconstruction is far better than I could have ever imagined and I feel extremely lucky to be one of the many success stories."

Jo Bailey



Jo Bailey, age 38, talks about her experience of genetic testing and recovery after breast cancer.

Jo's mother was first diagnosed with breast cancer at 36 and once again before dying at 47. It wasn't until Jo had her first child that she thought about genetic testing. However, she didn't qualify because she had no living relative with cancer.

Breast pain in 2015 prompted her to think again about genetic testing and as her grandmother had since died of ovarian cancer in 2013, she was finally referred to St George's cancer genetics service.

Jo was diagnosed with the BRCA2 mutation and was considering risk reducing surgery when two weeks later, she found a breast lump and was referred to the breast clinic.

"My cancer diagnosis was the scariest moment of my life," said Jo. "All I could think of was how much I wanted to see my children grow up. After a lot of tests and tears I turned the fear into fight – I rallied my amazing family and friends and together we faced it head on with positivity and even a little humour."

Chemotherapy was followed by radiotherapy and double mastectomy and reconstruction. The treatment Jo received, together with her optimistic outlook and support from family and friends, has enabled her to be where she is today – wife, mother and back at work. Her sons will be able to request genetic testing when they reach adulthood.

After cancer treatment – *Listening Event*

Together with Voice, our patient and carer user group, we held a themed Listening Event in November for people who had finished or were finishing cancer treatment.

It was an opportunity to learn how St George's is working with local GPs in the community to deliver the different elements of the Recovery Package. This was followed by table discussions around the experiences of the participants, which has helped clinical staff to better understand their concerns when finishing treatment.

35 participants came to the afternoon along with 12 clinical staff and 5 Voice members. One participant commented that she had 'Learned so much – I wasn't aware of what was available or could be so, was brilliant. Great to see GPs.'

The learning from the participants will help clinical staff prepare their patients for when they finish treatment.



Physical activity scheme gets locals with cancer moving



Getting over fatigue was a huge issue for Lloyd, aged 59, when he finished treatment for chronic lymphocytic leukaemia in December 2016. Physical activity can play a huge role in cancer recovery and the Move More programme in Wandsworth, Merton and Sutton, helps people living with a range of different cancers to get active in a way that's right for them. Following an informal chat to discuss people's personal reason for wanting to become active, the service helps motivate them to make individualised plans.

For Lloyd, taking care of his own health and being active is now a priority for his two daughters and two grandsons. He said: "Once my treatment was over, I was really motivated to get back into fitness as I knew it would help me get my energy levels back. However, it was a big mental challenge."

To take part in the scheme, or to find out more, please contact Beth Brown, Macmillan Move More Coordinator for Wandsworth on 020 8871 6756 or email waccg.movemorewandsworth@nhs.net.

The 100,000 Genomes Project



Patients at St George's are taking part in the 100,000 Genomes Project, which aims to transform the treatment and care of people with cancers and rare diseases.

The project aims to sequence 100,000 genomes from around 70,000 people. It is the largest national sequencing project of its kind in the world at the moment.

Genetics looks at the way particular features or diseases are inherited through genes passed down from one generation to the next.

Cancer patients at St George's are identified by their team of clinicians, and a member of the project team then explains the process to them. If they are in agreement, blood samples are taken, and possibly a sample of tissue if the patient has had a biopsy.

Their genome will then be sequenced, and links established to that patient's medical condition. This may help them to receive the most appropriate treatment, which is called personalised care.

In the future patients could be offered a diagnosis when previously there wasn't one, or a more effective treatment could be available for a disease we do know about.

The project is run by Genomics England and funded by the Department of Health.

For further information, or if you would like to get involved, go to: https://www.genomicsengland.co.uk/

Treating the whole person

"I felt like a human being again," says Maddy. "Like there was more to me than just my illness."



As the healthcare staff help you through your illness, the greater challenge often lies beyond the clinical treatment. Quality-of-life charity Full Circle Fund Therapies supports patients on haematology and oncology wards (and beyond) during the most difficult times through a range of complementary therapies. Haematology consultant Dr Fenella Willis is Chair of the Trustees.

"I first encountered Full Circle on a particularly bad day for me with the chemo," says West End actress Maddy, who was given her diagnosis of stage 4 Hodgkin lymphoma on the day of press night for a show.

"The nurses couldn't find a vein and I was really upset. I was in lots of pain and felt like a pin cushion. Then a lovely man called Nick, one of the Full Circle therapists, asked if I'd like some reflexology. From that day on, Nick gave me reflexology during every chemo session.

"Full Circle helps to connect you to who you really are, and for that I will be forever grateful," says Maddy, now a patient ambassador for the charity. "They played a huge part in helping me to feel positive and strong enough to fight cancer and make a full recovery."

Find out more about Full Circle Fund Therapies at www.fullcirclefund.org.uk

Photograph credited to Paul Martin

RESOURCES

Macmillan Information and Support Centre

Ground Floor, Grosvenor Wing, St George's Hospital **Tel:** 020 8725 2677 **Open:** Mon – Fri, 10am – 4.30pm **www.stgeorges.nhs.uk**

Information and support

Paul's Cancer Support Centre 20 – 22 York Road, Battersea, London SW11 3QA Tel: 020 7924 3924 www.paulscancersupport.org.uk

Offers individual and group support (including Asian and African-Caribbean support groups), complementary therapies and a home visiting service. South East Cancer Help Centre

2 Purley Road, Purley, Surrey CR8 2HA Tel: 020 8668 0974 www.sechc.org.uk

Offers individual and group support, complementary therapies and information.

Macmillan Cancer Support Help Line: 0808 808 00 00

(Mon – Fri, 9am - 8pm) www.macmillan.org.uk

For details of information and support centres and cancer support groups, benefits advice and practical, medical, financial and emotional support.

The Cancer Connect editorial team would love to hear your comments about our newsletter.



Beverley van der Molen

If you would like to make a comment, want more information about any article or have a suggestion for a future article, please email Beverley van der Molen, Macmillan Patient and Public Involvement (PPI) Co-ordinator at **beverley.vandermolen@stgeorges.nhs.uk** or contact the Macmillan Information and Support Centre on **020 8725 2677**.

You can also drop in at the centre, which is on the Ground Floor, Grosvenor Wing, St George's Hospital.

St George's University Hospitals NHS Foundation Trust, Blackshaw Road, Tooting, London SW17 0QT Tel 020 8672 1255 www.stgeorges.nhs.uk



Voice Cancer patient and carer user group



WE LISTEN. WE CHANGE. WE CARE. Driving excellence in cancer care, together