



For immediate release

Nottinghamshire cancer partnership gathers momentum with patients in the driving seat

A £3million partnership led by Macmillan to improve local cancer services is gathering momentum as more projects are announced – and it's patients who are driving the changes.

Patients and carers were first asked to help shape their future cancer services back in June. Since then, the Macmillan Cancer Partnership, which is made up of 15 individual projects and pilots all aimed at supporting the growing number of people surviving and living longer with cancer in Nottinghamshire, has added a further four projects to its portfolio and extended two others.

The new projects include a service to help lung and head and neck cancer patients better cope with the psychological impact of their condition, a research project to map the cancer support services across Nottinghamshire and a self help and support programme for people with advanced cancer of the larynx (voice box). A project which involves working with nurses and GPs in primary and community healthcare to ensure patients continue to receive ongoing support when treatment ends completes the list.

On 16th October, patients and carers in Nottinghamshire will have another chance to influence the partnership's work and share their views and experiences at an event held at the East Midlands Conference Centre.

Husband and wife Lis and Rod Lawrence, both 59, from Newark, have been diagnosed with cancer five times between them. They attended the first Macmillan Cancer Partnership event in June to have their say on how cancer services in Nottinghamshire should be run. Now they're encouraging others to do the same.

Rod has had skin cancer twice (aged 32 and 34) and was diagnosed with non-Hodgkin lymphoma on Christmas Eve in 2010 - the same type of cancer which had afflicted his mother. He was described as a medical marvel after being the first person in the local area to survive a reoccurrence of melanoma on the same spot, despite being told he might have just three months to live.

Lis was diagnosed with breast cancer in 2007 at her first routine mammogram appointment and then with endometrial cancer in August last year while Rod was still recovering from his own cancer diagnosis.

Rod said: "When I was first told I had cancer it was a massive shock. I was only 32, I was young, fit and healthy, I played rugby, I was untouchable. So to be told I had cancer was just unbelievable. My son was just 9 months old at the time and I thought this is history repeating itself. I thought my son is not going to know me. He's going to grow up without a father like I did."

Rod was treated for his cancer but two years later a doctor he worked with spotted a mark on his previous cancer scar and advised he go to the hospital immediately. Rod was diagnosed with melanoma for a second time and was told if the surgery was not successful and the melanoma was not contained he would have just 3 months to live. He survived against the odds only to be diagnosed a third time with non-Hodgkin lymphoma on Christmas Eve in 2010.

Rod said: "I was actually overjoyed when I was told it was lymphoma, because I thought, I can beat that. If they'd said it was melanoma again I'd have had it. That would have been it for me."

At the time of his third diagnosis, Rod's wife Lis was still on follow up care from her own breast cancer diagnosis. She'd had a radical mastectomy in 2007 after finding two lumps in her breast. Seven years later, cancer struck again and she was diagnosed with endometrial cancer which resulted in her having a full hysterectomy.

Reflecting on their combined experience, Lis said: "Rod and I are quite a formidable pair now. Having been through such a lot, it's brought our family closer together. The cancer has had a huge affect on us. The experience gave me the determination I needed to make my charity a success."

Talking about their involvement in the Macmillan Cancer Partnership, Lis said: "Rod could never talk about his diagnosis. He wouldn't talk to anyone except me about it – and then only when he felt like it. Being involved with the Macmillan Cancer Partnership has really helped him to open up as he's had the opportunity to talk to others going through a similar experience. When he came home from the Macmillan patient event he was buzzing.

"If sharing our views and experience will help to support others going through cancer and ensure they receive the best support possible, then we'll do everything we can. And I would strongly urge others who have had a cancer experience to do the same and come along to the next Macmillan Cancer Partnership event is on the 16th October to have their say."

Elaine Wilson, Senior Macmillan Development Manager, said: "This partnership puts patients firmly at the centre of the decision making process - they are the ones in the driving seat. We've listened to the views and experiences that were kindly shared at our last patient event in June and have responded accordingly with more investment and developed more projects which will help to ensure Nottinghamshire cancer services are amongst the best in the country.

“The partnership has already grown since we first launched in June with four more projects and pilots being confirmed which is very exciting. With so many partner organisations involved, we really can make an impact on local cancer services.”

The new projects include a Macmillan Psycho-Oncology Service run in partnership with Sherwood Forest Hospitals NHS Foundation Trust and Nottinghamshire Healthcare NHS Foundation Trust to help lung and head and neck cancer patients to better cope with the psychological impact of their condition and live a more fulfilled life. The 2 year pilot is the first of its kind in Nottinghamshire.

Macmillan are also funding a Cancer Insight and Intelligence Project which is being delivered in partnership with Self Help UK and involves mapping the cancer support services including self-help groups across Nottinghamshire to identify the gaps in service provision and examples of good practice. The findings will then be used to further develop cancer support services through the partnership to better meet local need.

The third project is being delivered in partnership with Mansfield and Ashfield Clinical Commissioning Group (CCG) and involves working with nurses and GPs in primary and community healthcare to ensure patients continue to receive ongoing support when their treatment ends.

The Macmillan Communication, Health and Wellbeing Group for Laryngectomees running at Nottingham University Hospitals Trust has also been brought under the partnership umbrella. The group supports people who are diagnosed with advanced cancer of the Larynx (voice box). The team consists of a Macmillan Speech and Language Therapist and a physiotherapist who help patients who have lost their natural speaking voice to manage their health and social needs beyond the hospital environment.

As well as launching new ways to support people affected by cancer, the Macmillan Cancer Partnership in Nottinghamshire has also extended existing projects and services including the Macmillan Radiotherapy Late Effects service at Nottingham University Hospitals NHS Trust which is now running an additional clinic each week to enable staff to support even more people affected by cancer. The Cancer Pathway Redesign Programme, also run at NUH, has recruited two additional team members to enable its work improving follow up support for patients to continue.

The next Macmillan Cancer Partnership patient event will be held on the 16th October at the East Midlands Conference Centre from 10am – 4pm. Local people affected by cancer are invited to help further develop local cancer services and also hear about the achievements of the partnership to date.

Places are limited, so contact us now to book your space. We can help you with travel, pay your expenses and will provide lunch on the day. If you can't make it to the session we still want to hear from you, so please feel free to get in touch. Call 07703 681206 or email eventmanagement@macmillan.org.uk

The Macmillan Cancer Partnership is comprised of Nottingham City CCG, Newark and Sherwood CCG, Mansfield and Ashfield CCG, Macmillan Cancer Support, Nottingham University Hospitals NHS Trust, Sherwood Forest Hospitals NHS Foundation Trust, Self

Help Nottingham, Nottingham CityCare, Notts County FC Football in the Community and Nottinghamshire Healthcare NHS Foundation Trust.

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For further information, please contact:

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Notes to Editors:

About Macmillan Cancer Support

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. At Macmillan, we know how a cancer diagnosis can affect everything and we're here to support you through.

From help with money worries and advice about work, to someone who'll listen if you just want to talk, we'll be there. We are millions of supporters, professionals, volunteers, campaigners and people affected by cancer. Together we make sure there's always someone here for you, to give you the support, energy and inspiration you need to help you feel like yourself again. We are all Macmillan.

No one should face cancer alone. Call us free on 0808 808 00 00 (Monday to Friday, 9am–8pm) or visit macmillan.org.uk