



Yorkshire Cancer
Community

Autumn Edition 2022



The voice of those affected by cancer in Yorkshire and The Humber

www.yorkshirecancercommunity.co.uk

Welcome

Welcome to our autumn newsletter. We are a support and information network for patients, carers, families and healthcare professionals in Yorkshire and the Humber.

Our aim is to enable the views and experiences of cancer patients and carers to be heard and used to improve the quality of cancer care in our region.

I hope you will enjoy reading patient stories and learning about new opportunities within the Yorkshire and Humber Cancer Community. If you would like to tell your story, please get in touch. Always look forward to hearing from you.

Best wishes

Jill

Chair's Blog

I hope you have all enjoyed the excellent weather this Summer. I have spent several weeks in the USA with my American family and they came back with us to meet up with friends and family.

I continue to Volunteer at fundraising events with my local Hospice St Gemma's and myself and another YCC Trustee, Louise, manned the plant stand at their Open Day in July.

I mentioned in a previous Blog that I see my main role as Chairman of our Charity to act as an ambassador engaging with different groups and being the voice of Cancer patients in Yorkshire. This has become increasingly important due to the delays and backlog in the NHS post Covid.

Last week I had a meeting with an Oncology Professor in Leeds and we are looking at ways we can work together with different group to promote our CANCER SMART message and enlist CANCER CHAMPIONS.

I am presenting our Cancer Smart talk to my local GP practice at a meeting of their Patient Participation Group. Hopefully this will lead to involvement with other GP practices.

Dr Stewart Manning
Chair



Stewart and Louise volunteering

I've had cancer twice – but I was very lucky they both could be treated when caught early – Richard Seddon's story

Keen sportsman Richard Seddon arrived for our interview in Leeds on one of the hottest days of the year looking a picture of health despite having cycled 12 miles from his Yeadon home. As temperatures hit 33 degrees C, Richard laughed off the heat, as I beat a hasty retreat into the air-conditioned café.

Richard, 57, a member of the West Yorkshire & Harrogate Cancer Alliance Community Panel, has survived and been given the all clear for two different forms of cancer – Prostate Cancer in 2018 and more recently Throat Cancer in 2021. His throat cancer was caused by the Human Papilloma Virus (HPV), which we all carry and which teenagers (boys and girls) are now being vaccinated against, so hopefully it will ultimately be eradicated in the UK.

He is determined to raise awareness by encouraging people, particularly men, to speak up about changes in the body as soon as you notice anything different. On results day in June when he told his followers on Twitter, that he was cancer free, this time for his throat cancer, his tweet went viral attracting 40,000 likes and his story was then picked up and shared in the Mirror Online alongside an article about Bowel Babe, Dame Deborah James.

"I've been very lucky twice over, as both times the cancer I've had has been curable when caught early," he told me. "Age and relatively good overall health have also been on my side".

The fantastic result he was given was that he has a 'complete metabolic response', which at this stage, means he is cancer free, although he will face regular ongoing follow ups for the next five years.

Richard had been all too aware of cancer after losing his mum to ovarian cancer when she was just 52, and his dad died as a result of prostate cancer aged 72.

Back in 2015 before Richard had cancer himself, he had cycled from Liverpool to Leeds in memory of his mum and dad and raised £1,500 for Cancer Research UK and Prostate Cancer UK.

Prostate cancer diagnosis

Armed with some knowledge and being aware of his own body, Richard was alert to the tell-tale signs that something wasn't right – blood in his semen. (See information on prostate cancer symptoms below) In November 2018, he was diagnosed with prostate cancer and had a Radical Robotic Prostatectomy in June 2019, as he was told it was slow growing. The procedure involved biopsies and then removing the



whole prostate and checking there had been no spread of cancer cells.

After being cured of prostate cancer and to try and help others, he took part in a genetic testing trial in 2020 at the Royal Marsden in Surrey, a national genetic cancer research centre.

"The result was that I was told I had a predisposition for prostate cancer but my older brother, who also underwent the same testing, was not," Richard said.

Looking back, Richard concluded he had wonderful treatment but felt he was discharged after surgery too quickly. He also didn't get the all-clear for twelve weeks rather than the four weeks it should have taken. This led him to join the WY& H Community Patient Panel so he could try and change information, systems, help re-write prostate cancer pathways locally and nationally and to make it easier for patients understand what happens and when, if they are unlucky enough to get prostate cancer in the future.

Throat cancer (Oropharyngeal) diagnosis

After his successful prostate cancer treatment, he returned to cycling/sport but several years later, he noticed he didn't feel on the top of his game and he was told by professionals it was probably down to him getting older. He adds that he was only 56!

In October 2021, he found a lump on the right side of his throat. He described the lump to his GP over the phone and was prescribed two separate courses of antibiotics, which did nothing to reduce the swelling and it was at this stage that he suspected it might be something more sinister.

When his GP examined him, he was referred to the Ear, Nose and Throat department at Leeds General

Infirmery, who, after examinations and biopsies, confirmed the lump was throat cancer (Squamous cell carcinoma) which they confirmed was caused by the HPV virus.

He was then offered two options:

1. Surgery plus radiotherapy and perhaps chemotherapy
2. Radiotherapy and chemotherapy

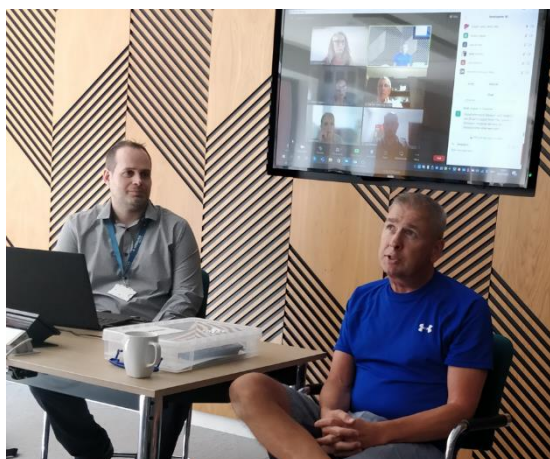
When he asked which was best and which the experts would recommend, he was told both options had similar outcomes but that he had to make the decision himself.

“I spent the next two weeks agonising over my decision. I stayed calm, but you know it’s a tough call to make especially at a time of such turmoil (again)”.

Richard remembered he spoke to a fellow patient from Yorkshire Cancer Community and a friend of a friend who had had a similar diagnosis 18 months previously after which he eventually went for option 2. radiotherapy and chemotherapy. This involved 35 fractions, one daily targeted dose of radiotherapy for 35 days as well as two chemotherapy treatments on days 1 and 17 (of 35).

“Other than the odd occasion, the schedule was very manageable. I had the weekends off and to my surprise, radiotherapy treatments only lasted 5 minutes so I was in and out quickly and didn’t feel anything.

“The Bexley Wing staff were also fantastic. We have one car and I needed to get my wife to work, so they adjusted all the sessions and all other varied appointments to suit me. I feel they were all fantastic, flexible and very patient led, a real blueprint for what the NHS should be,” added Richard.



Richard tells his story at the WY&H Cancer Alliance Community Panel, seen here with facilitator Fraser Corry

After effects of treatment

While Richard had no initial unpleasant side effects during treatment such as ulcers, sore throat or burnt skin, he did lose his sense of taste just before

Christmas, which is hopefully just beginning to return.

“No matter what I was eating or drinking, everything started to taste like gulping seawater. It was so unpleasant I stopped eating and drinking completely and lost three stone (20% of my body weight) in total which is now fantastic for self-esteem, confidence and general wellbeing. People can’t believe how well I look, and I also feel great and have bought a whole new wardrobe and have sent all my old clothes to various cancer charities. You’ve got to be positive, and I always try to look on the bright side”.

In early January and with very little food and drink in him for nearly two weeks, Richard admitted to staff that he felt awful and exhausted. They were totally on the ball and Richard was quickly hooked up to a drip and had a nasal tube (NG) to feed him. Within 24hrs he was feeling much better and for the next four months it was kept in place to ensure he had the right amount of nutrients on which to survive.

Four months after the end of treatment, Richard underwent a second full body PET/CT scan which revealed there was no evidence of cancer in his throat. In fact, there was no sign of any Cancer in any other part of his body, which not many people get to know!

In that four-month period and for the foreseeable future he also has a number of other manageable but well documented side effects, such as dry mouth (always has a bottle of water with him), lymphoedema, anaemia (aching body), brain fog, constipation, burning throat, fatigue, loss of taste etc. many of which it is hoped will come back to normal over time. He was also told that his new ‘norm’ should be established after the first two years post treatment in 2024.

On results day, Richard and his wife went for a symbolic celebratory drink even though his beer didn’t really taste nice and still doesn’t, and this is when he sent out a tweet to his handful of followers sharing his fantastic news. To his amazement, it went viral.

Said Richard: “I just want to get men talking about their bodies as we all know our own bodies best and men are known for not talking. Two old friends got in touch after seeing the story in the Mirror, and perhaps as a result, they may raise their concerns with their GP, who will either put their minds to rest or point them in the right direction. If I can help or prevent just one person going through what I’ve been through twice, then that’s brilliant. If I can get that message to hundreds or even thousands, then even better. That’s my aim!”

Prostate Cancer Symptoms - www.nhs.uk

Prostate cancer does not usually cause any symptoms until the cancer has grown large enough to put pressure on the tube that carries urine from the bladder out of the penis (urethra).

Symptoms of prostate cancer can include:

- needing to pee more frequently, often during the night
- needing to rush to the toilet
- difficulty in starting to pee (hesitancy)
- straining or taking a long time while peeing
- weak flow
- feeling that your bladder has not emptied fully
- [blood in urine](#) or [blood in semen](#)

These symptoms do not always mean you have prostate cancer. Many men's prostates get larger as they get older because of a non-cancerous condition called [benign prostate enlargement](#).

Throat cancers - www.nhs.uk

Doctors do not tend to use the term "throat cancer", as the throat (pharynx) includes many different parts that can be affected by cancer.

The main areas that can be affected are the:

- oropharynx – the part of the throat at the back of the mouth
- hypopharynx – the part of the throat connecting the oropharynx to the gullet and windpipe
- nasopharynx – the part of the throat that connects the back of the nose to the back of the mouth

The most common symptoms of cancer in the oropharynx or hypopharynx include a lump in the neck, a persistent [sore throat](#) and difficulty swallowing.

West Yorkshire & Harrogate Cancer Alliance Community Panel

Would you like to know more about this cancer community panel and use your experience to improve cancer care services for all across West Yorkshire and Harrogate?

The panel brings together an enthusiastic group of cancer patients, carers and others who are passionate about ensuring the voice of people affected by cancer influences the development of cancer care and services in the region.

Meetings are held in central Leeds and also via digital conferencing.

Contact coordinator Fraser Corry to find out more. Email: fraser.corry@healthwatchwakefield.co.uk or telephone 07597 801623 or [click here](#) to access the webpage.

Inspiring Women of Yorkshire

Sara Williamson from Wakefield, founder of the MY (Mid Yorkshire) Breast Cancer Support Group was diagnosed with grade 3 stage 3c invasive breast cancer with three tumours in December 2015, aged 46. 14/17 lymph nodes were also affected. She underwent mastectomy, chemotherapy, radiotherapy, and Herceptin, which was halted on two occasions due to heart failure. She completed treatment at the end of 2019 with Zoladex injections to shut down her ovaries. She had numerous surgeries due to surgical site infections and sepsis. If she could complete treatment, then she was given life expectancy of forty percent of living five years.

After chemotherapy, she developed neuropathy – a condition affecting the nerves that can cause pain and loss of sensation. She had to learn to walk again and takes medication to manage pain and assist with mobility. She is on heart medications for life, but nothing holds back her determination.

Jacqui Drake was diagnosed with Melanoma in 1993 where a mole was removed from her leg. The lump returned again in 2009, which found that she had secondary cancer which is very rare. By 2011, the Melanoma had spread to her lungs and she received oral chemotherapy for two years to remain stable as a terminal cancer patient. In 2015 the tumour was removed along with her right lung. Normally life expectancy averages out at one year, but Jacqui is not your average person. Whilst still on lifetime treatment she is grateful for the staff at St James's in Leeds, who keep her alive. She made it her goal to raise one million pounds for the Bexley Wing to assist all cancer patients.

Both ladies have raised hundreds of thousands of pounds for Yorkshire Cancer Charities. They met whilst having treatment, and also raising funds separately within the hospital. The two have an amazing friendship, and feel like sisters on the same wave length. Sara believes that nothing is impossible and Jacqui oozes positivity. Together they are a force to be reckoned with.

Last year Sara and nine breast cancer patients completed the Leeds 10K raising £5,147 for "Jacqui's Million". Sara struggling with neuropathy, broke a foot, so completed it in a wheelchair assisted by these determined women.

This year there were thirteen ladies. One had to drop out due to Covid. Nine were breast cancer patients and three were Jacqui's friends. Sara completed it with walking sticks just a few weeks out of bowel surgery. She is due an MRI next week to determine further surgery. Who knows how she will complete it next year? In the current climate it is pretty amazing that these ladies raised just under £4k. They wanted to show other cancer patients that anything is possible, and that exercise can reduce the risk of recurrence by 30%. Sara says, "It has been a privilege to be part of the 15th Jane Tomlinson Race for All 10K. What a legacy she has left behind. It's also a gift from the heart to the hospital where we have all received treatment that saved our lives. We can all make a huge difference to support our local communities!"



If everyone could donate just a pound to Jacqui's legacy, the people of Yorkshire would benefit greatly. Funds are directed into the Leeds Hospitals Charity Cancer Centre. This time it is to fund a bereavement nurse, a role that is vital and needed for patients, their families and loved ones.

You can pledge a donation at www.justgiving.com/jacquismillion and quote 10K as the reference.

Sara Williamson

Taking the Cancer SMART message out and about this summer

We've been running Cancer SMART – an awareness raising project - in partnership with West Yorkshire and Harrogate Cancer Alliance since 2020.

The pandemic meant we couldn't take the message out on the road until this summer. Here are some of the highlights from the past few months.



I picked up a few tips from the **Adult Cuppa & Craft** session organised by Tina Dransfield of Spectrum People at **Tieve Tara Medical Centre, Castleford**. In return they listened to the Cancer SMART message while they decorated empty spirits bottles to make into beautiful lamps.



Fraser Corry who coordinates the Community Panel for the Cancer Alliance and volunteers Gill and Yorkshire Cancer Community trustee David, hit on the idea of a hook a duck for their stall at a **Family Fun Day at Northfield Hall, Huddersfield**.

Families took home prizes of fruit as well as finding out why it's important to know what is normal for you and your own body.

The event was organised by the BAME (Black, Asian and Minority Ethnic) Forum, Kirklees.

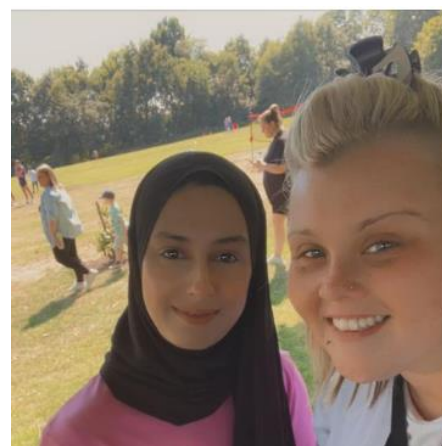


The BAME Forum also organised the **Women's Health Awareness event** held at **Zakaria Education Centre, Savile Town, Dewsbury**. Various partners including Macmillan (Calderdale & Huddersfield NHS Foundation Trust), the Kirkwood and ourselves presented information about where to find support if you are diagnosed with cancer. Rehana (pictured left) did an amazing job of translating our presentations. Mandy, Jill and Kulsum, who spoke about her experience of caring for her husband, are pictured at the event.



Gemma visited a **Slimming World** session held at **Cleckheaton Methodist Church**. Pictured is Carol Rayner who also runs sessions in Scholes.

Gemma also helped to publicise cervical screening at an event organised as part of a series of roadshows by the Cancer Alliance. Here she is seen at **Wibsey Park, Bradford** with Cancer Alliance colleague Fatima.



Cancer Champions Bob and Julie, (who is also from Bradford and Pennine Breast Screening Services) are seen here enjoying a breather at a very hot **Airedale Show** in **Ferry Fryston, Castleford**.



We took lots of colouring pictures, quizzes and word search taken from *Adventures In the Sun* by Jacqui Drake. Jacqui, who has stage 4 skin cancer, devised the book to raise awareness of safety in the sun, along with fellow cancer patient Sandra Hudson, with funds going to Jacqui's Million. Email Jacqui.drake1@btinternet.com to find out more.

Seen here are two sisters enjoying colouring in pictures to take home later. We also supplied Factor 50 sunscreen throughout the day.



Finally, we made another visit to **Portobello Gala at Castle Grove Park, Wakefield**, following last year's success. Cancer Champions Bob, James and Ric (pictured) volunteered all day chatting to visitors, giving out leaflets and helping children gown up in protective clothing to decorate cloth bags. We ran out after 40 bags, up on last year's figure of 25 bags.



Yorkshire Cancer Community Trustee Paul (pictured below) came to visit the stall and one lady proudly displayed her finished decorated bag. She said she hardly ever got a chance to get crafty and loved dabbling in paint again.

All visitors to the stall were interested to hear the Cancer SMART message and took away lots of helpful information leaflets supplied by Macmillan and Cancer Research UK, as well as hearing the personal accounts from our volunteers who have all had their own cancer journey.



Cancer

Screening saves lives by prevention and early detection

Making cancer an everyday conversation

Awareness of unusual and persistent changes

Reduce risk with a healthy active lifestyle

Take action now against cancer

Welcome back Support Groups – you’ve been missed

Here at Yorkshire Cancer Community, we keep a directory of support groups in the region, and have seen the number shrink, at a time when patients need peer support more than ever.

It’s been so delightful to visit two Support Groups this month – groups who I first visited when I was newly in post in 2017 - with what was then Yorkshire Cancer Patient Forum.

I’m happy to report that both groups are thriving and are stronger than ever, despite having to take an enforced break during Covid-19.

In the case of The Hub, Crossgates, Leeds, the group meet the first Monday of the month, from 11 am – 1 pm at Crossgates Methodist Church on Austhorpe Road, LS15 8QR. Meetings only recommenced in July, so this is still early days.



The Hub is an informal cancer support drop-in, and anyone who has experienced cancer, is welcome to call in, either regularly or from time to time. The group aims to provide a warm, friendly environment where people can build friendships, share experiences, build peer support, access listening services and hopefully share laughter and fun, over a cuppa and snack.

Hazel, who with a team of volunteers, leads the group, said people affected by cancer, need the support of other patients more than ever. “Just being able to chat with others who have experienced something similar, is so important. They don’t need a medical appointment,” she added.

Yet many of the groups that used to be run by Clinical Nurse Specialists were put on hold for the pandemic, and there are no longer the members of staff available to start the groups again.

A head and neck cancer patient said it is so reassuring to talk to other patients to ask them about symptoms and treatment. “How do we know what is normal if we can’t ask anyone else with this particular condition?” he said.

You can find The Hub Crossgates on Facebook or at their website:

www.thehubcrossgates.co.uk



Pontefract & District Breast Cancer Support Group have a wonderful new home with a sunny patio outside for their meetings the first Thursday of every month. They are now at the Red Lion, Market Place, Pontefract, from 10 am until 12 noon, usually followed by lunch at a local pub.

The group is led by Rachel who also offers one to one support over the phone. The group have continued to meet when possible, during much of the pandemic, and also offer a closed Facebook group where members can ask for advice or helpful tips.

They had just returned from their annual trip to Scarborough and were looking forward to a night out at a local Italian restaurant.

Rachel said the number of members is growing all the time. On the day I visited, there were four new ladies, and Rachel thoughtfully offers to meet each one beforehand, so they don't have to walk in on their own. It can be so daunting visiting somewhere new for the first time.

Members come from all over the region, from Scarborough to Selby, and can access phone support, if they can't attend group meetings or outings.

The group has just taken the decision to welcome women with any cancer – Rachel recognised that many groups that used to meet before Covid – will not be opening their doors again. Men affected by cancer can also receive telephone support.

Pontefract member Janette recalls when she was new. "I was so scared to attend, but I went for it. Now I would recommend it to anyone. It's been like a second family. Everyone is so friendly."

Another member says: "I just don't know where I would be without Rachel or our group."

To find our more contact Rachel on 07891 908641 or emailbrachel779@gmail.com

Yorkshire Cancer Community also continues to offer an **online Support Group** the second Tuesday of each month on zoom from 11 – 12 noon. This is a small, informal and chatty group. We talk about anything and everything but anyone who does need to find out where to go for help can also get their questions answered. Contact Jill for a zoom link. You will be made very welcome.



Transforming the diagnosis, treatment and care for cancer patients in our area

New breast pain clinics launched

Clinics have been set up to help women experiencing breast pain without other symptoms in North Lincolnshire, North East Lincolnshire, North Yorkshire and York.

Breast pain alone, where there are no other symptoms, is rarely a symptom of breast cancer but can understandably cause a lot of worry.

Historically GPs have referred people with breast pain to an urgent appointment, called a two week wait, which carry out more in-depth assessments of symptomatic people displaying signs of breast cancer.

The wait for a scan to detect or rule out cancer can be an anxious one and, in the case of patients with breast pain symptoms only, the underlying problem remains undiagnosed even when cancer is ruled out.

However, alternative options, such as breast pain clinics, now offer more appropriate approaches for people experiencing breast pain alone.

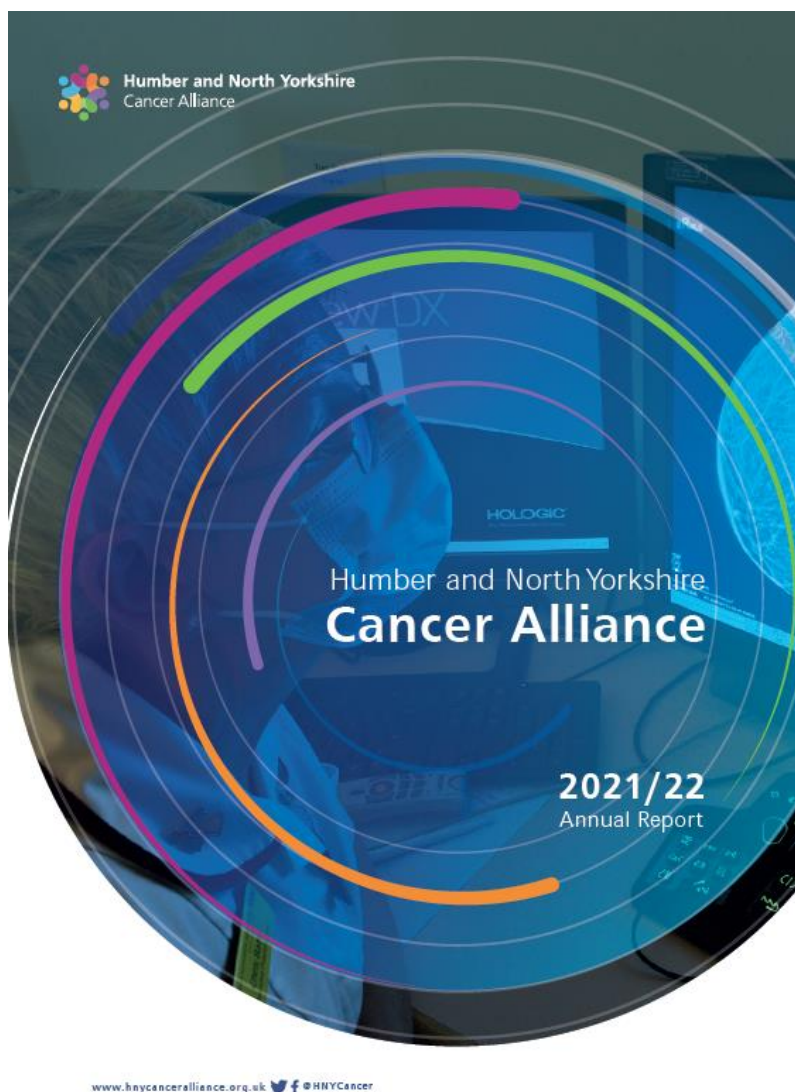
The breast pain clinics offer examination, guidance and support to patients who are referred by their GP. Patients with a family history of breast cancer can understandably become anxious when they experience breast pain, so their family history will be reviewed and they can be referred to specialist services if required.

The Cancer Alliance has worked with York and Scarborough Teaching Hospitals NHS Foundation Trust and Northern Lincolnshire and Goole Foundation NHS Trust to develop these community-based clinics.

The York and North Yorkshire clinic, based in Malton, started treating patients on 20th June and the North Lincolnshire clinic in Scunthorpe and the North East Lincolnshire clinic in Grimsby opened their doors on 4th July.

Find out more [here](#).





Cancer Alliance annual report captures 2021/22 achievements and plans for the future

The 2021/22 Humber and North Yorkshire Cancer Alliance [annual report](#) has been published. The last 12 months has seen many challenges and there's been a lot of hard work to ensure cancer services are prioritised. The report outlines how the Cancer Alliance has and will continue to work with the [Humber and North Yorkshire Health and Care Partnership](#) (integrated care system) to ensure people who are referred for suspected cancer are seen and treated promptly.

Successes include:

- Improving earlier diagnosis of cancer via the [Rapid Diagnostic \(RDC\) programme](#).
- Continuing [Targeted Lung Health Checks in Hull](#), to help identify lung cancer and other respiratory diseases at an earlier stage
- The increased the use of teledermatology to rule out or diagnose skin cancer faster.

The Cancer Alliance also remains committed to raising awareness of cancer prevention. The free [Cancer Champion awareness sessions](#) have now trained over 3,500 people.

Read about these achievements, and many more accomplishments, in greater detail in The Cancer Alliance's [2021/22 annual report](#).

Would you like to help improve cancer services in our region?

Humber and North Yorkshire Cancer Alliance is recruiting more patient and public representatives to work with the Alliance and its partners to improve cancer services in our region.

Patients and the public play a crucial role in helping to develop and improve local cancer services, as they have been through these services and can use their knowledge and experience to shape them for the better.

Leo Stevens, the Cancer Alliance's Communications and Engagement Lead, said: "We want to ensure that patient and public voice is at the very heart of the Cancer Alliance's work. If you're a patient, family member, carer or friend, we would love to work with you.

"By sharing your experiences and opinions, you can help make sure that cancer patients get the care they really need. There are many different ways to get involved, and you can give as much or as little time as you would like."

If you want to join the Cancer Alliance's growing list of patient and public representatives, please provide your details by completing this [contact form](#).



Major milestone for NHS Targeted Lung Health Check Programme

[Hull's NHS Targeted Lung Health Check Programme](#) has reached a major milestone – having now carried out more than 10,000 assessments and 7,000 scans since the programme started in the city in January 2020.

Past and current smokers aged between 55 and 74 who live in Hull and are registered with a Hull GP are invited to a free lung health check, to identify potential lung problems early so effective and early treatment can be provided.

The Lung Health Check mobile scanning unit recently relocated from north Hull to Morrisons supermarket on Holderness Road offering approximately 19,000 people in east Hull a lung health check within their local community.

Stuart Baugh, Clinical Director, NHS Targeted Lung Health Check Programme in Hull, said: “The majority of scans and assessments find no abnormalities or signs of lung cancer. In the small percentage where lung cancer is detected, many have been found at an earlier stage, meaning better outcomes for local people.

Gavin Anderson, Responsible Clinician for the NHS Targeted Lung Health Check Programme in Hull, said: “Early intervention can make a huge difference with a CT scan three times more likely to diagnose cancer at an early stage. If you're invited to have a lung health check, we strongly advise you to take up the offer.”

Find out more about lung health checks in Hull at lunghealthcheck.org.uk.



**Humber and North Yorkshire
Cancer Alliance**

Cancer has affected me and my family – and now I want to give back

Wakefield woman Karen Kilcommons spotted our flyer appealing for Cancer Champions and decided she would like to volunteer.

After being diagnosed with breast cancer in December 2018, Karen learned it had spread to her lymph nodes and liver, meaning she will be on treatment for the foreseeable future. "It's something I have learned to live with, and if I can help other people I'd really like to," explained Karen.

One of the key messages behind Cancer SMART – to be aware of your body so you spot anything unusual and persistent – struck a chord with Karen.

Aged 49, she had attended an appointment for her first mammogram, which are usually offered to women aged 50 -70. The results came back clear, but Karen

instinctively knew something was wrong. "I couldn't feel a lump, but I'd noticed a couple of times that one of my nipples would become inverted and then go back to normal." Although Karen's GP couldn't see anything, she referred her to a breast clinic where they diagnosed HER2+ breast cancer.

For Karen, although this was disturbing news, she was reassured that she had been taken seriously, and that while mammograms pick up the majority of cancers, there are some that can be missed.

Unfortunately, this wasn't the end of the bad news. Further tests revealed the cancer had spread to her lymph nodes, and a full CT scan detected three tumours in her liver.

Karen's treatment included chemotherapy, surgery and radiotherapy but she will be on Herceptin and Pertuzumab for the foreseeable future and has regular scans to see if the cancer has spread.

During the pandemic, Karen continued to receive her regular scans but appointments with the oncologist were carried out over the phone. It was when appointments had returned to being delivered face to face, Karen received news that was completely unexpected. An oncologist who was standing in from another hospital had reviewed Karen's notes before the appointment and suggested there was a possibility that she may not have cancer in her liver after all. She explained the diagnosis had been taken from an MRI and CT scan, so no biopsies of the liver had been taken. The tumours in her liver looked suspicious, and two have now disappeared. However, this could be due to treatment.

For Karen this is such a difficult dilemma. The treatment she receives could be doing more harm than good, but equally it may be responsible for keeping her well. To consider ending her treatment is not a decision she can make alone. "I've never seen the same oncologist twice so I can't ask their opinion," she explained.

Options may include asking for further scans, a review from another hospital or for her case to be referred to a MDT (multi-disciplinary team meeting).

While dealing with this bombshell, Karen feels fortunate to work for a caring employer who provide support for employees experiencing cancer. First Direct, who are based in Leeds, partnered with Maggie's as they were developing a new centre for people affected by cancer, in the grounds of St James's University Hospital, Leeds. First Direct now offer support via zoom or the intranet to anyone affected by cancer. They also raised more than £400,000 for the charity.

It's been helpful for Karen to be able to talk openly about her cancer journey and also feel supported by her employer. "I had to take one year off because of the treatment. By the time I returned I had lost two stones in weight. The help we receive at work includes signposting to sources of help and support for managers who may be dealing with an employee affected by cancer for the first time," she added.



Karen has continued to visit Maggie's beautiful centre in Leeds and helps to give back by fundraising for this worthwhile charity. Now she would also like to offer her time raising awareness as part of our Cancer SMART initiative.

Said Karen: "If I can 'do my bit' and raise awareness to help others then I'd be more than happy to volunteer my time."

Cancer Support UK

Cancer Support UK provides practical and emotional support to people with cancer, during and after the treatment period. We support people with all kinds of cancer across the UK. Our services, including our Cancer Coach support groups, our Cancer Kits and our Cancer Support Training, are designed and delivered by people who have experienced cancer themselves to improve the experience of others.



Cancer Coach

Cancer Coach support groups are available to anyone who has completed their physical cancer treatment and is experiencing low mood, anxiety and worry, and doesn't know how to move forward in their recovery. The course takes participants through a series of weekly facilitated group sessions, run for a six-week period over the telephone or online video. The sessions take participants through a series of strategies, techniques and exercises that aim to furnish them with the tools, support and coping strategies that can help them on their recovery journey. The course is free and completely confidential, accessible via the telephone or online video, from the comfort and privacy of home.

Cancer Kits

Cancer Kits include a range of practical items for adults and children currently experiencing cancer. They provide handy items that people will find genuinely useful during their treatment. We have Cancer Kits, Chemo Kits, Comfort Kits (for people over 65) and Kids' Kits, which we supply free of charge and can be ordered directly from our website.

Cancer Support Training

Coming into regular contact with customers and colleagues living with cancer is a common occurrence for many private, public and third sector organisations. Our experience has shown that many staff feel ill-equipped to have conversations about cancer. We know that a basic knowledge of cancer and its treatments can be helpful in being able to communicate effectively with clients and colleagues affected by cancer. Developing these communication skills demonstrates that a business strives to be a 'cancer aware' organisation, which really cares about their colleagues and their customers. Cancer Support UK has developed a series of training workshops to help employers communicate about cancer in the workplace and we are now actively rolling out these courses to organisations across the UK. These courses include:

- Communicating about cancer workshop
- Online learning resources
- Cancer Support Ambassador training

For more information, please visit: www.cancersupportuk.org or contact us at hello@cancersupportuk.org or phone 020 3983 7616.

If you would like to hear more from us about our news and updates including Cancer Kit and Cancer Coach announcements, fundraising and research campaigns, and how you can help support adults and children with cancer, please sign up to receive our newsletters.



"Cancer Coach enables me to give something back and make a difference." - Jane's Cancer Coach story

Jane is one of Cancer Support UK's amazing Cancer Coach volunteers. An experienced coach, she lives in Dorset and facilitates our Cancer Coach courses remotely for the benefit of people across the UK who have completed their cancer treatment.

"I became a Cancer Coach volunteer thanks to an advert I saw on Facebook during lockdown. I thought, this is perfect for me. It utilises my background in oncology together with my coaching skills. Having empathy and listening skills is also key to being a Cancer Coach.

"Most importantly though, it's an opportunity for me to give something back and to make a difference to people who really need some support.

"I don't have personal experience of having cancer, but I have worked within the cancer and oncology environment for the past 12 years. In addition, like many people, I have friends and family who have had cancer, which is quite a driver to wanting to help people affected by cancer.

"I did four weeks of training to prepare for Cancer Coach, as well as shadowing an existing course. I then ran my own course, which entails weekly sessions, lasting between an hour to an hour and a half, across six weeks, either in the afternoon or the evening, and there's usually a check-in period. The course is very professionally organised and run by Cancer Support UK.

"Cancer Coach is aimed at people who are adapting to life after cancer, having completed their treatment. These people are trying to get back to some sort of normality or a new normal after the experience they've been through. The course, which is usually run in groups of around ten people, enables individuals to take responsibility for self-management and to set goals for the future. The course also helps them to understand their feelings and what causes their emotions.

"A really powerful benefit of Cancer Coach is that it offers peer support in a safe, confidential space, where people can talk about their experience with other people who understand what they are going through. I think that's really important.

"In each session, we find out how people have got on during their week and then we guide them through specific topics, which are also covered in a handbook everyone is given.

"I really like the way the six-week course is structured. We start with a getting to know you session, which is a good bonding experience. For some, it's the first time they are able to talk about their feelings and emotions.

"Then we look at why the emotions are there and how these are absolutely normal given the experience that they've been through. Everybody's story is different and there's no set time frame for feeling that you're recovered and back to normal. After all, how can you go through that experience and be exactly the same person that you were before?

"We have little exercises and techniques that we use with the participants, which I try out on myself. We also do a session on breathing techniques and mindfulness, and a session on goal setting.

"It's good to talk through with people about the expectations they have of themselves, as well as other people's expectations of them, and to discuss relationships, rest and recovery.

"From a coaching perspective, it's very much about being grounded in the present. But we also look at the future and how we can take back a little bit of control in our lives by setting a few achievable goals. With this strategy, we aim to build forward momentum and to start looking positively at the future.

"It's lovely connecting with people and seeing them taking control of their lives. During the session, they become just a little bit lighter, as a few of their worries disappear. As a coach, that's really rewarding.

"I've definitely benefited from becoming a Cancer Coach volunteer with Cancer Support UK and I would really recommend taking part in a Cancer Coach group."

Cancer Coach support groups are completely confidential and are available free to anyone over the age of 18 who has completed their physical cancer treatment. The groups provide practical and emotional support in a safe space to those who are experiencing low mood, anxiety and worry, and who don't know how to move forward with their lives. The course takes participants through weekly facilitated group sessions, run over the telephone or online video. The sessions cover a series of coping strategies, techniques and exercises, which can help individuals on their recovery journey.

If you've just completed cancer treatment and are wondering how to cope, then please apply to join the course. Simply complete the application form online.

If you have any questions, please email cancercoach@cancersupportuk.org or call: 020 3983 7616.

Carer Lanyards – helping carers to be recognised and supported in health and care settings

Earlier this year, Healthwatch Kirklees launched the carer lanyard campaign alongside other partner organisations.

This project came about after one of their volunteers, Lynne, who is also an unpaid carer, said they are often asked: 'who are you and why are you here?' They do not feel that their role as a carer is always recognised and understood.

Their YouTube video shows how unpaid carers feel when they visit a health and care setting: [YouTube Carer Lanyard](#)

To help address this issue, Healthwatch Kirklees, distributed carer lanyards to many health and social settings throughout Kirklees to tie in with Carers Week. Carers can then wear the lanyard when they visit health and care settings, or they can use the separate card if they prefer. This will help staff working in health and care services to recognise unpaid carers, to support them and to signpost to carer information and support services.

If you are a carer in Kirklees, you can ask any health or care service for your lanyard. If they don't have any available, please contact Healthwatch Kirklees on 01924 450379 or email info@healthwatchkirklees.co.uk

If you are a carer in Kirklees and you need advice, support or information, you can contact the following organisations:

Carers Count
0300 012 0231
info@carerscount.org.uk
carerscount.org.uk
<https://www.facebook.com/carerscountkirklees/>

Carers Trust Mid Yorkshire
01484 537036
info@CTMY.org.uk
carerstrustmidyorkshire.org.uk
<https://www.facebook.com/carerstrustmidyorks/>

Carers: we see you, hear you and support you



We recognise and support carers in this setting

When we see this lanyard...

or this card...



...we know that you are a carer

Carers are family members and friends who are relied upon to provide essential care and support to someone who has a physical disability, long term health condition, learning disability, mental health issue or who is frail. If you are a carer and would like a carer lanyard, please speak to a member of our staff.



Healthwatch Kirklees - info@healthwatchkirklees.co.uk - 01924 450 379

The Ella Dawson Foundation – helping young adults live well with cancer

When Jane Dawson lost her beautiful daughter Ella aged 24 to cancer, there was no doubt in her mind, how she would honour her memory.

She and her family set up the Ella Dawson Foundation to help young adults diagnosed with cancer to have the support they need to live well.

Said Jane: “It was the most natural thing to us to continue the work that Ella had started. We wanted to fill the gap she had identified, she handed us the baton, and we ran with it.”



Ella was diagnosed with Acute Lymphoblastic Leukaemia (ALL), a rare cancer of the blood cells, which can cause symptoms very quickly. Around 800 people each year in the UK are diagnosed with ALL.

She graduated from Newcastle University in June 2019 with a BA Honours degree in Fine Art, and was diagnosed in August when she was travelling in Columbia.

She returned to her Huddersfield home, where mum Jane became her main carer and she underwent often gruelling treatment for her cancer, first at St James, Leeds and then at the Christie, Manchester, where she accessed CAR-T therapy – a highly complex and innovative new treatment which involves collecting and using the patients’ own immune cells to treat their condition.

Jane remembers: “She received the very best medical treatment; there is no doubt about that. The NHS were amazing. But it was in terms of helping Ella meet her physical, emotional and nutritional wellbeing there didn’t seem to be much help.”

Ella scoured the internet looking for charities or organisations who could help but she felt they fobbed her off with leaflets. There seemed to be a reasonable amount of support for young people affected by cancer, up to the age of 24. After that, the support was mainly focused around London, which for Ella with increasingly poor health, wasn’t a possibility.

She started blogging, two months after her diagnosis, and found it empowering, to be able to tell other young patients it was possible to live well.

Her parents found her private psychological support, as waiting lists for NHS services were lengthy. While she didn’t necessarily need a shoulder to cry on, she wanted the tools and techniques she could use to develop resilience. Ella also made strong friendships with other young cancer patients via Instagram, since there was nowhere she could meet up locally with anyone going through something similar.

The Ella Dawson Foundation has prioritised meet ups for young patients and is organising a calendar of events to include meetings at locations such as the Yorkshire Sculpture Park or learning paddleboarding.

“Ella always wanted to meet other people like herself. We want to make that happen. Not so they all talk about cancer, but about anything and everything,” added Jane. Ella loved to run, hike or practice yoga and her family could see how movement, even on really bad days when she could scarcely leave her bed, left her feeling energised.

Younger sister, Tasha, who has just graduated from University of Leeds after studying Sport and Exercise Science saw how exercise helped Ella and went on to become a CanRehab Level 4 Accredited Cancer and Exercise practitioner. She is heavily involved in the charity, and like Ella, is a passionate advocate of mental and physical wellbeing, currently preparing to undertake a PhD. Tasha hopes to be able to help close the research to practice gap and help to bring exercise and movement to all young people with and beyond a cancer diagnosis.

Prehabilitation (prehab – getting ready for cancer treatment) and rehabilitation (given by trained professionals during treatment, follow up care and survivorship) are now offered more widely and there is a growing body of evidence to show how effective they are in aiding recovery.

Ella died on 11 July 2021 and the family held an event to celebrate her life on 5 August 2021. By 23 August, they had put in the application to set up the Ella Dawson Foundation.

When asked if the charity had been Ella's idea, Jane replied: "Ella never talked about dying. She was always positive and hopeful and lived each day with gratitude. There was never an overt discussion about her legacy. However, within only a few weeks of Ella's diagnosis she began to layout her vision of a wellbeing blue print for young people with cancer through her blog alongside her contributions to other cancer support charities. Over the two years of treatment Ella became a passionate advocate for and practitioner of the importance of wellbeing support during and beyond a cancer diagnosis and we saw how much that helped.

In Ella's own words 'I just want to show that all is not lost as a young person with cancer and I want to put something out there that there I was missing'.

And so, it was the most natural thing for us to do as a family, to continue Ella's work, and to play our part in delivering the blueprint to help other young adults live well with and a beyond cancer diagnosis which Ella felt so passionately about and where there is such a need. "

How the charity can help

Around 50% of young adults in the UK struggle to access the psychological and emotional support they need during a cancer diagnosis.

The Ella Dawson Foundation provide funded access to experienced Clinical and Counselling psychologists who can talk through how you are feeling and providing tools and techniques to help reduce emotional distress and enhance psychological wellbeing and resilience.

To find out more email info@elladawsonfoundation.org.uk to receive a referral support pack and next steps.

Support for family and carers

Having a child, sister, brother, or partner diagnosed with cancer is a traumatic and frightening experience as routines, relationships and daily life are turned upside down and fear, anxiety and relationship worries can set in. The family focus switches to looking after the person with cancer, which is a scary place for parents, carers and siblings, with little support available to them.

Jane and Ella had a loving and supportive relationship, and Jane admits how fortunate they were.

"This can be a tricky space to navigate for parents and families. The young person affected by cancer still needs support but doesn't want to be drowning in it. They still need to retain independence and it's about getting the balance right. That's why I am passionate about reaching out to other parents and carers, for a space for them to come together."

The charity is providing regular meet-ups for peer to peer support, somewhere to talk to others who are going through something similar.

There's more information on the website www.elladawsonfoundation.org.uk about moving well, eating well and living well and as the charity grows, more courses and activities will be offered.

The charity is also looking for people interested in becoming a trustee and joining their board.



An Open Letter to Death – if you could say one thing to Death...what would it be?

“It’s not something the average person thinks about, but death is one of the few things that connects us all. Whether you’re bereaved, having intrusive thoughts, have just received a scary diagnosis or are simply scared of facing your own mortality, it’s one of the few things that affects literally everyone” says Olivia Hyde about her first solo project.

Inspired by losing her dad at the age of 21, Olivia, a singer, musician, artist, director and workshop facilitator from Huddersfield, has teamed up with bestselling author Joanne Harris, to explore the many faces of death. Both are pictured below.

Funded by The Arts Council and supported by the prestigious Lawrence Batley Theatre, the project which will go ahead this Autumn includes:

- Free workshops in singing, performance, self expression and creativity
- Free online events
- An album
- A dynamic multi-arts show at the Lawrence Batley Theatre
- Live and online exhibitions of work created by participants

Game of Thrones actor Clive Russell plays the role of Death in the video for Olivia’s single which inspired the project.

To find out how you can take part either online or in person please visit the website below to register your interest:

[An Open Letter To Death - Register www.anopenlettertodeath.co.uk](http://www.anopenlettertodeath.co.uk)



In Thyroid Cancer Awareness month here's Catherine's story

Up until this year, I had no idea really what a Thyroid did. I knew it was in your neck, I didn't know what it looked like, but I knew that a lot of people suffer with thyroid related problems and that it can be quite debilitating. September is Thyroid Cancer Awareness Month and that's why I wanted to tell a little bit about my story, what this month means to me and to raise people's awareness about Thyroid Cancer.

In 2020, I was one of the unfortunate people to catch Covid and now over a year later, I'm actually really glad that I did. After I had Covid, I noticed that the glands in my neck were really swollen, something that I and my GP figured was normal following a virus. I didn't think anything of it and sure enough by the summer the swollen glands had gone. In the Autumn I was getting ready for work and noticed that the right side of my neck was swollen again, I felt fine just tired, which I just put down to being a Mum to a very lively 4-year-old and having covid earlier in the year.

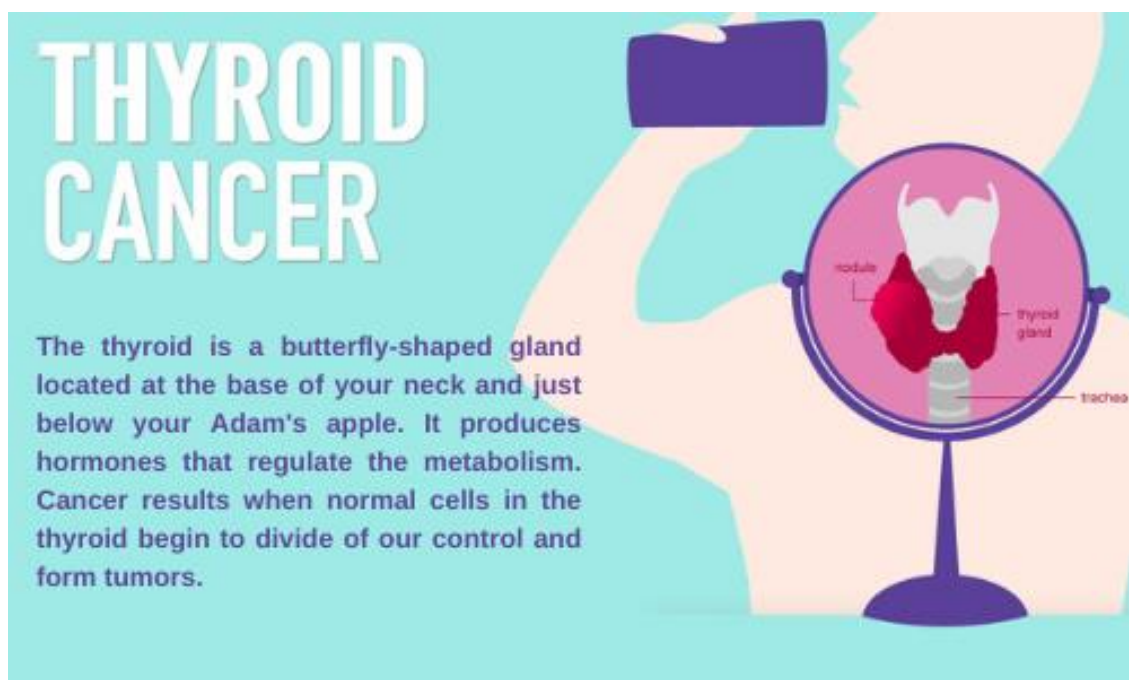


Because the swelling often changed from day-to-day, I didn't think anything of it, but by Christmas I noticed it looked a bit bigger. My friend had just been diagnosed with Lymphoma and she very bravely shared her symptoms and diagnosis on social media...I'm so glad she did because it was the push I needed to get my own symptoms checked out, which were vaguely similar to my friends. I sat on it throughout Christmas but in my mind, I knew I needed to get checked. I was packing away the Christmas decorations and I suddenly thought, what if it was bad and that this was the last time, I would pack the decorations away?

On New Year's Eve I went back to the GP, had routine blood tests (which all came back fine) and was fast-tracked to ENT (ear, nose, and throat specialist). I was reassured that given I had no other symptoms, and my blood results were normal everything should be OK. My appointment came through two weeks' later and then began months of scans, biopsies, and more tests to determine what was wrong.

Thyroid Cancer can be quite tricky to diagnose and each test and scan failed to diagnose what was wrong with me. So, I was referred for surgery to remove the lump. About a month after my surgery, I was finally diagnosed with Hurthle Cell Carcinoma, which is a rare type of Follicular Thyroid Cancer. This meant further surgery to remove the remaining thyroid and treatment known as radio-iodine therapy.

Here's what I found out. Thyroid Cancer is very different to other cancers, it is slow growing, many people can live with it undetected for years and pass away from other causes. Follicular and Papillary Thyroid Cancer are the most common Thyroid Cancer's and Anaplastic and Medullary are less common but more aggressive. Most importantly though it can come with very few symptoms, the most common symptom is a swollen neck or a visible lump, but many people don't have any noticeable symptoms at all.



There are many misconceptions about Thyroid Cancer, such as that it is mainly the middle-aged or elderly that are affected, but recently a young reality star from Love Island was diagnosed at aged 22. Thanks to her speaking out about her diagnosis and treatment more young people have come forward and the NHS reported a significant increase in referrals to investigate neck lumps.

I wanted to speak out about my cancer and urge people to check for any signs or changes in their neck and please, please do not hesitate to contact your GP if you do notice anything suspicious.

Despite having an amazing support network of family and friends around me, a cancer diagnosis and its treatment is still an isolating and lonely experience. But it doesn't always have to be; since speaking out I've connected with people going through the same illness and the same treatment or who have been through it in the past. I can't tell you how much that has helped me so I would urge anybody to speak out and get checked.

I completed my treatment and received my scan results a week early and found out that my scan showed they had successfully got all of the cancer and there has been no spread! I have to have follow ups now and I've still a little way to go before we can establish that the treatment saw off any remaining thyroid tissue, but my consultant said that it was very unlikely it would return. I have now been left with Hypocalcaemia and Hypothyroidism as a result of my surgery, which means I now have to take 9 tablets a day...possibly for the rest of my life, but this is a small price to pay to still be here.

Signs of Thyroid Cancer can be a sore or hoarse throat, a lump or swelling and tight feeling in your neck. I had none of these signs, just a slightly raised area in my neck. This is why Thyroid Cancer Awareness Month and the "[Check Your Neck](#)" campaign are so important to raise further awareness of Thyroid Cancer. You can also find information and [follow my journey on my blog](#).

Thank you for taking the time to read my post.

For more information, visit [butterfly: the thyroid cancer trust](#)

Catherine Oinonen, Learning Disabilities Team, Kirklees Council

Catherine has now joined Cancer SMART as a Cancer Champion to help raise awareness.



Catherine (first left) and friends fundraising for the Butterfly Thyroid Cancer Trust

Sovereign Health Care support

We are delighted to announce that the **Sovereign Health Care** Community Programme is supporting the costs of our newsletter for one year.

Sovereign is proud of its long history of charitable giving, supporting charities and voluntary groups who are tackling problems, improving the lives of disadvantaged and vulnerable people and providing opportunities and facilities that can transform the quality of life for all of us, or as they like to describe it 'positively touching people's lives'.

In the past 15 years, they've donated over £9.7 million to health and wellbeing good causes both large and small.

They're also proud supporters of the NHS, donating over £2 million to the NHS in Yorkshire over the last 15 years.

Their donation will mean we can continue to tell the patient stories from across the region and update you on any new charities or services you can access. We believe ours is the only newsletter of its kind in the region, which is aimed at cancer patients and carers living in Yorkshire and the Humber.

We know from work we did earlier this year that the newsletter gets forwarded to more than 14,000 people. It is also accessed by several thousand more on the Yorkshire Cancer Community website.

Once hospitals and GP surgeries are ready to receive printed documents, we would like to start providing the newsletter in printed format as well as the online version.

For more information about Sovereign Health Care visit www.sovereignhealthcare.co.uk



Meet Cancer Champion Sue Hartup

When you're looking for inspirational stories of people who battle adversity to complete their studies, you don't get much more inspirational than Nurse Research Fellow Sue Hartup (pictured with her youngest daughter Grace, below). She did a PhD while raising three children, one of whom has Asperger's, as a single parent, caring for her father who had dementia, working as a breast cancer research nurse, and part of this was during the pandemic.

Sue who works at St James' University Hospital, Leeds explained how she coped: "Juggling the stress of trying to analyse results and write a thesis whilst going through a Covid pandemic, as well as the girls doing their GCSEs and A-levels was definitely interesting! It has taken a lot of determination, juggling, frustration, stress and sheer bloody mindedness to get through it."

Her PhD is aimed at helping people with breast cancer manage their long-term pain. Whilst working as an oncology research nurse, she saw patients for follow-up whose biggest long-term issue was persistent pain. She realised that if they could provide better support for acute pain then fewer patients would go on to develop persistent pain.

She chose to do her PhD part-time so she could continue to work as a senior breast cancer research nurse and team leader for two days a week, as well as being a single parent raising her three children who were aged 19, 13 and 11 at the start of her PhD. However, a year after starting her PhD, her job-share went on maternity leave meaning Sue chose to work full-time as well as continuing her PhD. She was also looking after her Dad who had advanced dementia during the first three years of her studies. Sadly, he died shortly after her colleague returned to work which she said knocked her for six.

Sue began her career as a student nurse in 1989 after announcing at the age of seven that she was going to be a nurse! She qualified as a Registered General Nurse in 1992 and worked on a general surgery ward at Seacroft Hospital – this included working with Ear, Nose and Throat (ENT), vascular, minor surgery and breast cancer surgery. She did a specialist course at Hull University in ENT nursing, and Teaching and Assessing in Clinical Practice which she started when her son was six months old. She then did a degree in Biosciences and Health at Leeds Beckett University.

Unfortunately, she then suffered a brain tumour and had to take time off for recovery. Fortunately, the tumour was not cancerous, but needed to be removed because of its size.

Her most recent role is as a senior breast cancer research nurse at St James's Hospital in Leeds which she has been doing since 2001. Whilst here, she joined the National Cancer Research Institute Breast Specialist Group – this fuelled her desire to do her own research as well as working on research designed by others. Sue explains the research she has done to help breast cancer patients: "The web-based

intervention involves patients logging on daily after surgery to report their symptoms and pain scores. This provides them with personalised feedback and advice based on what they report. It even signposts to other sources of help such as support groups and charities. Patients can track their own results and clinicians can review the results as they are linked to the patients' hospital electronic records. This means appointments can be tailored to discuss problems and issues as well as provision of appropriate support and advice."

Despite having a lot to deal with already, during the pandemic Sue put her PhD on hold for six months so she could help: "As one of the more experienced members of the team, I was happy to take on additional workload and new roles. I felt it was important as a senior nurse to be willing to do whatever was needed, support those around me and always stay positive."



“It was very hard as in the first six months of the pandemic, I could see things that the general public couldn’t, and I felt that we were unable to do our job as well as we would normally. This made me very emotional especially as we knew what the long-term impact may be for patients diagnosed with cancer.”

Despite everything, Sue completed her PhD and has provided some invaluable advice for others: “Only do a PhD in an area that you truly believe in or have a passion for. When things get hard, if you have a strong motivation for doing the research, then you will find a way through it. My patients have always been my motivation and no matter how hard things got for me I would always find a way as I knew it could help them. Like my Mum used to say, ‘there is always someone worse off than you’. Always remember that research is about trial and error, learning constantly, and adapting. If we knew everything in the first place, we wouldn’t need to do research. I think that having a supportive, honest and realistic person guiding you is a must. Without, Mark Johnson, Professor of Pain and Analgesia and Director of the Centre for Pain Research in the School of Health, I would not have finished my PhD. He kept me grounded, calm, supported and enthusiastic. I can’t thank him enough. Having the right support team around you is vital; be it work colleagues, family, friends or academics.”

Next steps for Sue are to try to get her research funded to run a full-randomised trial working with other hospitals across the country.

Sue joined Cancer SMART as a Cancer Champion at the start of the project, as she is passionate about promoting cancer awareness. “I wanted to help people reduce their risk and do more to help. There isn’t always an opportunity or the capacity in the day-to-day role, so I was happy to do something as a volunteer, even if it is just helping one person.”

Now Sue is looking at ways of tailoring the Cancer SMART message to a younger audience using contacts gained while bringing up her children.

If you would like to know more about Cancer SMART please visit

www.yorkshirecancercommunity.co.uk/cancersmart/ or contact Jill jill@yorkshirecancercommunity.co.uk

Asbestos related cancer and benign diseases - could our group support be useful for you?

By Laura Hogarth of Yorkshire & Humberside Asbestos Victims Support Group (also known as SARAG)

Our support services

In 2021, SARAG developed my role of Activity and Support Co-ordinator to enable the charity to provide a range of support and information for people who have been affected by asbestos related diseases. You can access this support whether you have a diagnosis yourself, are supporting a family member with a diagnosis, or have sadly been bereaved by an asbestos related disease. I offer both one-to-one and group support services.

I run a fortnightly **Zoom Social Group** which was developed for those with an asbestos related diagnosis, as well as a fortnightly **Zoom Bereavement Peer Support Group** for those who have lost a loved one to an asbestos related disease.

We also have a monthly **Zoom Carers’ Support Group**; this is for carers (official or unofficial), spouses, partners, family members or friends of those with an asbestos related disease (some may also have additional health conditions which require a level of care). We understand how challenging, and often isolating, this role can be. Please get in touch if you are interested in joining this group.

Could I benefit from joining a support group or social group?

A good support network is essential during stressful times. It is useful to have a range of support sources you can call upon; from talking things over with family and friends to contacting community and charity groups for more focused forms of support. Asbestos related diagnoses can often raise specific questions, feelings and topics for discussion. This is where our groups can come in.

Being a member of a group gives you the opportunity to speak with people who understand what you’re going through. Through the sharing of experiences, members are able to offer support, advice, encouragement and comfort, and to receive the same in return. This can help you to feel more confident, informed and in control.

We understand that it can be daunting joining a group for the first time, whether it's online or in person. Our groups are informal, friendly and supportive. We can chat to you beforehand about what to expect and how the group could be helpful for you personally. There is no pressure to commit to every session; just drop in as you please!

If you are interested in joining one of our online groups (or if you have an idea for a new one!) but don't feel

confident using Zoom, I can provide one-to-one support to get you up and running. The majority of our Zoom group members were completely new to this form of communication before joining our groups!

Take it from them...

"I was very reluctant to use Zoom at first but once I tried it a couple of times, I felt comfortable. It opened up a whole new way of communicating at a time when many of those other opportunities were denied us."

"I was very wary of Zoom but it's easy and just a matter of clicking on a link. It was great to see people we would not otherwise meet and much better than just chatting on the phone. Discovering there was nothing to it, I was motivated to join in SARAG's Zoom meetings and found it really beneficial. Give it a go!"

"I would like to say to anyone interested in joining the Zoom meetings, it is quite straightforward. If you can get emails, it's only a case of opening the email from the group facilitator and clicking on to the link provided. I've found the Zoom meetings interesting, finding out how others are coping. We've also had coffee mornings and a pub lunch and it's good to meet up."

Online groups also offer the opportunity to access support from the comfort of your own home. One of our group members tells us:

"I can quickly and easily join from the safety of my own surroundings, without needing to travel anywhere. I've not wanted to be out and about following the loss of my husband over a year ago and the pandemic has increased these feelings of anxiety. It's a convenient way to have that important face-to-face contact and support from others who understand what you're going through. The Zoom groups can also be a gradual stepping-stone to feeling ready to get back out in person."

A return to face-to-face meetings

Following the lifting of covid restrictions earlier in the year, we were able to go ahead with our monthly social lunch groups and support groups in-person.

We will also continue to run and develop our Zoom groups, in order to provide choice and accessibility within our support services.

We now have monthly social lunch groups in Sheffield, Doncaster and Leeds and a monthly Mesothelioma Social Group in Sheffield.



Sheffield social lunch group



Doncaster social lunch group

If you would like to have a chat or to find out more about the various means of support available, please contact me on laura@saragasbestosupport.org or 07783510265.



Some of the friendly team you will find at the Rosewood from left to right: Kim, Catherine (creative therapist), Vicky (oncology bookings clerk), Marie (Nurse manager) and Nat (oncology healthcare)

New Service for cancer patients in Dewsbury

The newly refurbished Rosewood Centre, at Dewsbury and District Hospital, has now opened its doors again to oncology and palliative patients, as well as their families.

The pleasant and airy centre just off Halifax Road now offers a Macmillan Information and Support Centre in addition to the existing Information Hub on Level D at Pinderfields Hospital, Wakefield.

I was shown around by Kimberley Priestley, Macmillan Information Manager, who will spend her time between Dewsbury and Pinderfields.

Patients and their families from the local community will be able to access Upper & Lower Gastrointestinal and Breast oncology clinics as well as palliative care physio and occupational therapies, palliative care nurses and wellbeing services at the Rosewood.

Talks are in place with Mid Yorkshire Hospitals NHS Trust, The Kirkwood and other local community groups on how best way we can support and enhance the patient experience. New services will be developed alongside this conversation.

The Macmillan Information Centre offers a peaceful environment for chats with patients and families as well as lots of well planned information displays.

Services they offer at both Pinderfields and Dewsbury include:

- Benefits and finance
- Emotional support
- Local and national support group information
- Blue badge/disabled bus pass
- Travel insurance advice
- Hair loss support and headscarves

Both centres open Monday to Friday 8 am – 4pm (excluding Bank Holidays)

Callers can drop in - no appointment is needed. You can also call 01924 546072 or Dewsbury 01924 512204 or email:

midyorks.macmillan.infocentre@nhs.net



Kim (left) and Marie, The Rosewood Centre Nurse Manager meet in the new Macmillan Information Centre

I hope you enjoyed this edition. If you would like your story to feature in the next edition, please contact me jill@yorkshirecancercommunity.co.uk or telephone 07715 217845. Please find more information, including updates on all our projects on the website: www.yorkshirecancercommunity.co.uk