



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

Welcome to our winter 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

Reflecting on 2022, I feel the Yorkshire Cancer Community is finally starting to make progress in its core objective, which is acting as the 'Voice' of cancer patients in Yorkshire. Post Covid we have now been able to attend more events, meetings and workshops. We have managed to target different groups to deliver our Cancer SMART message.

Having delivered the talk to my Patient Participation Group at Alwoodley Medical Centre in September, I am now working with a female GP Registrar from the Practice to deliver the presentation to a group of South Asian women in December.

I would be delighted to extend this model across Yorkshire in 2023. We have had positive feedback when other members of our team have given the talk to a variety of groups, and we are hoping to engage with schools in 2023. Fellow Trustee Louise and myself continue to volunteer for St Gemma's Hospice at their events, and this enables us to talk to different people about the Yorkshire Cancer Community and find other ways to be the Voice of more cancer patients in Yorkshire.

I am very conscious of all the articles in the Press, TV and social media about NHS problems and delays in cancer treatment, but I would not let this deter or delay you from seeking help if you believe you have a problem. I am proud of the achievements of our Charity. However, this could not be reached without the hard work of all our Trustees, Cancer Champions, Digital Champions and Gemma.

I would also like to thank Hayley Snowden, Tracy Holmes, from the Cancer Alliance and Fraser Corry (who has just left his role as Community Panel coordinator) for their continued support, encouragement and involving me in several projects.

Finally, my greatest thanks go to Jill Long our Charity Administrator who manages to keep everything under control and well organized, without whom we would not have made our progress to date.

I send each and every one of you Festive Greetings and my Best Wishes for a Healthy, Happy and Peaceful New Year.

Dr Stewart Manning
Chair



Stewart and Louise volunteering at St Gemma's Ball

Bare All For Cancer

Many of you will already be familiar with Jacqui Drake, a terminally ill cancer patient who set up her Jacqui's Million appeal to raise funds to support Leeds Cancer Centre. Here Jacqui explains how she came up with the concept of her latest musical extravaganza which was staged at Yeadon Town Hall in October.

"I have staged and hosted so many events for Jacqui's Million since the charity was founded in March 2016, and I have worked most of my life in theatre, but nothing could have ever prepared me for this incredible experience! I wanted to raise more awareness of this terrible disease and also more funds towards funding a Bereavement Nurse at the Bexley - Leeds Cancer Centre, which is a cost of £53,000 for just one year. A role that is vital for patients, their families and loved ones.

I had seen the professionals & celebrities strutting their stuff in The Full Monty TV show and that gave me the idea, but with a difference. I wanted my people to actually be cancer patients or have a close connection with the disease. So I set to work on it and it should have happened, but Covid hit, and everything stopped including theatre.

Once I was able to, I put the call out on social media and was delighted by the response. So on Sunday 9th October we finally stepped up to do "Bare All For Cancer" at Yeadon Town Hall Theatre. It was a full packed evening of entertainment, Carl Ashington singing Soul/Motown and Lionel Richie with comedy by Steffen Peddie.



The cast of Bare All For Cancer keep everything under wraps during rehearsals

Then the finale...13 very brave & courageous people joined me on stage and it was so very well supported, you could certainly feel the love from the minute you stepped on the stage. These people are patients who came together through cancer and became a family in just three rehearsals, all wanting to make a difference using their story to help others and give hope too about living a "Positive" life with cancer.

Everyone's journey so very inspirational, ladies who had had mastectomies and no reconstruction, a lady with a stoma bag, a guy who had had testicular cancer and two of us still on active treatment and so many more!

I have choreographed productions all over the Yorkshire but taking these wonderful people who I call "family" into a theatre and putting them for the first time on stage and then having to bare all is truly something else indeed, but incredibly precious. Everyone's emotions were totally raw, heart on sleeve but knowing that we were all doing it together for the greater good made it so worthwhile and they have all said they would do it again in a heartbeatso watch this space for next year!

The event in total raised a staggering £5136! This now means Jacqui's Million stands at £326,508 due to everyone's continued support and generosity. I really do feel truly honoured and humble to be Jacqui's Million. I will bring in that well needed million that is for sure with all your help."

To make a donation to my appeal simply visit: <https://www.justgiving.com/fundraising/jacquismillion>



Glamming it up for Bare All For Cancer

Moving Forward

We know it's not always 'back to normal' when you finish hospital treatment for primary breast cancer. Coping with the shock of a diagnosis, treatment and side effects, and worries about recurrence can make it difficult to readjust to the everyday. Finishing treatment at your hospital can sometimes mean leaving behind the routine and support you've become used to. It may have left you feeling alone.

That's why Moving Forward is here. Through supportive, open conversations in a safe, confidential space, you'll connect with people who understand. And you'll find the tools you need to feel more empowered, confident and in control. Ready to move forward with your life. You can attend a face-to-face or course or join an online course.

The courses are run in conjunction with the NHS, over two weeks, with two, 3.5 hour sessions run by one of our expert facilitators. Groups are kept small, with no more than 12-15 people attending. We also have our trained volunteers on hand to

welcome you and share their own experience of a breast cancer diagnosis and treatment. Everyone is encouraged to participate in a way that suits them. The course is supported by online resources and our Moving Forward journal.

Week one: Looking back to move forward. A chance for the group to share common ongoing concerns and discuss the impact of diagnosis and treatment.

Online content: Activity and energy, Mental wellbeing, Lymphoedema, Menopausal symptoms, Recurrence, Eating well and breast cancer and Adjusting and adapting

Week two: Setting intentions within a wellbeing framework, we look at the Five Ways to Wellbeing, and what people need to move forward. Supported by a Q&A session with a healthcare professional, and content from your Moving Forward journal.

You can join courses in Sheffield, Barnsley, Rotherham, Doncaster, Worksop, Chesterfield, York, Scarborough, Scunthorpe, Grimsby and Northallerton.

We also have our new online courses run over two weeks, with two three-hour sessions and are facilitated by our expert staff.

What people have told us:

'Just didn't realise how much I needed the time to be able to reflect and acknowledge what I had been through. Thank you for providing this time and expertise to help complete my cancer journey.'

'Excellent couple of days met fabulous people, put everything into perspective. The future looks so much brighter. Thank you'

'The course was fantastic, really informative especially regarding diet, exercise and lymphoedema. The whole course helped me feel more empowered and in control. The body awareness section was extremely helpful.'

'Hearing from others was reassuring that I wasn't alone or the only one who was scared.'

'I think the course would be very helpful for anyone who is anxious and frightened about their life after their breast cancer diagnosis.'

Please contact us Telephone number: 0345 077 1893 Email: movingforward@breastcancer.org



In this edition, we bring you news of two Prostate Cancer groups which have set up in West Yorkshire

Retired Police Officer Craig Ward was diagnosed with prostate cancer in December 2021, which resulted in him having his prostate removed the same month. Here he talks about his experience and why he formed the group:

This diagnosis came out of nowhere. I only attended at my doctor's for a regular blood test after just one symptom which led to my doctor referring me to a Urology Consultant. Then after an MRI and Biopsy, I was given the news. Devastated was an understatement, why me? How did I get it? The questions go on and on. I have since come out of the 'dark' place and I have found that you can get back up and continue with your life with only a few changes...with help from others who have been there and got the T-shirt.

Why have asked for this to be publicised? Well I made enquiries in order to receive counselling but discovered that there wasn't any specific counselling for Prostate Cancer. There were trained counsellors but they had not gone through the trauma that I had gone through which wasn't good enough for me. This is a 'taboo' subject amongst men and they/I won't just speak to anybody about it. Men know what I'm talking about.

So after advice and liaison with my local charity Cancer Support Yorkshire, I have been given the go-ahead to facilitate my own Prostate Cancer group specifically for Prostate Cancer patients.

So if you have any questions or fears, believe that you may have symptoms, already diagnosed, pre-op or post-op, come along and meet people who have all experienced this cancer in some form or another and share your concerns, doubts and experiences.

We're an open group of people and although it's a difficult subject, we always manage to end up laughing. I'm definitely getting something out of this and I hope the other members are too.

We meet on a fortnightly basis at 7pm, the first Wednesday and the third Wednesday of the month at: The Idle Draper, 28 The Green, Idle, Bradford BD10 9PX

You can also contact me at wardcraig777@gmail.com or 07800 637567

Breaking news: members have decided to call themselves The Green Prostate Cancer Support Group based on the address of the venue and the traffic light system.

Red - It can't happen to me

Amber - Do I really want to know

Green - Go and get checked



Lights, Camera, Action!

We've had some fun filming footage for a patient video **Patient Power** which has been made possible with funding from the West Yorkshire and Harrogate Cancer Alliance.

Clips of patients will also be used in a series of videos being made focusing on specific cancers including skin, lung, breast and bowel.

The theme is around what help is available for patients following cancer treatment. Patients often tell us that their lives are taken over by medical appointments, but once treatment is at an end, they feel they are forgotten.

Often described as 'falling off a cliff, patients are not sure where they should go for further help and support as they come to terms with their 'new normal'.

Yorkshire Cancer Community patients, carers and healthcare professionals responded to a shout out for advice and some of those ideas will appear within the videos.



Ric, one of our Cancer Champions and Sandra are filmed at the Sir Robert Ogden Macmillan Centre, Leeds

We will also make a compilation of the top tips and post on both social media and our website to help anyone currently facing this dilemma.

Thank you everyone for responding with your top tips and for volunteering to be part of the videos.

The videos which are being made by Deadline Digital, will be available in the New Year.



Cancer Champions Mariam and Karen and YCC Chair Stewart enjoy the calm surroundings of the Macmillan Information Centre at the Rosewood Centre, Dewsbury District Hospital, before filming begins

Heaven Can Wait

Head and neck cancer patient Eric Bailey, chair of Heads Together Support Group, Sheffield, has many hobbies including writing poetry. Here he reflects on his cancer diagnosis.

Heaven can wait, I told myself when I suffered Cancer.
Recovered and survived, why I asked, but could not find an answer

Heaven can wait. The good lord thought it best to keep me here, to serve my fellow man

He needed me to help others, wherever and whenever I can.

Heaven can wait. For other sufferers, I am here to help them find their way and hopefully give some peace of mind.

I have to be here for them, I don't want to leave them behind

Heaven can wait. I have to be here to listen and to respond
To answer their questions on my experience and create a bond.

Heaven can wait. I am the leader and run a support group
Its purpose to meet with other patients, to keep them all in the loop.

Heaven can wait, I feel the need to help all who are suffering with this disease
To be ready when called by the many to help them find their hope and peace.

Heaven can wait. To guide others through this illness. I count a privilege and pleasure and hope to do so, till my life here is over.

As long as the good lord can spare me, I plan to continue his work helping the many to cope and keeping them above the clover.

Eric Bailey
March 22nd 2016



Eric pictured at the Christmas meeting of his support group Heads Together, Sheffield

Barnsley CaPS

Prostate cancer is the most common cancer for men in the UK, with more than 52,000 diagnosed every year on average. Living with Prostate cancer, can bring physical, practical and emotional challenges. The treatment options alone, are varied and each brings different side effects to manage.

Barnsley CaPS was born out of a local need of support, for the men of Barnsley, diagnosed with Prostate cancer. The group has grown from the original six men (pictured below) to seventeen.



They recently agreed on the name Barnsley CaPS; CaPS being an acronym for Cancer Prostate Support. The support in the group comes from their WhatsApp group, face to face informal meetings and the friendships formed as a result.

The CaPS WhatsApp group is used to share meeting invitations, post messages and ask serious questions for comment. The men in the group are kind, give each other encouragement and there is lots of humour. The aim in this space is to share experience and information in a supportive way.

CaPs also meet the second Wednesday of each month. The venue has frequently been Barnsley Market

Kitchen, chosen for the large meeting tables and also the delicious breakfast they treat themselves to! Meeting each other puts a face to a name, develops the support from the WhatsApp group and helps bond the connections made.

One or two meetings in the year are planned to include a speaker. Recently the group had Dr Jason Alcorn from the Mid Yorkshire Trust to speak about treatments for erectile dysfunction, which may be one of the concerns for men with Prostate cancer. Last year, members booked a Christmas lunch and Santa Steve came bearing gifts (see photo).

The group has helped the men feel they're not on their own and that someone else understands. They've been able to share knowledge, experience and give moral support, when it is needed. Private contact can also occur freely as group members make individual connections to deepen that feeling of support. Wives and partners have also set up their own supportive group.

New members are continually being added and welcomed to the group.



For any details about Barnsley CaPS, please contact Amanda Prout, Macmillan Cancer Support Worker, Urology, 07565 201437

Brainstrust

Hi, I'm Mariel and I'm the new Support Specialist for brainstrust in North England. brainstrust is a brain tumour support charity and our mission is to make sure that people with a brain tumour and their loved ones are involved, resourced, confident and connected. We support you to live the life you want, to the best of your potential, because you are a person first, and a patient or carer second.

brainstrust provides personalised one-to-one coaching and support, a virtual events calendar of community groups and informative webinars and a growing range of resources made in consultation with the community (please see the links below). I am here to help you navigate your brain tumour journey and make sure you have the support you need to make the decisions that are right for you.

We have a 24/7 helpline as well – contact us at 01983 292 405. I come to brainstrust from the NHS where I worked as a Neurology Nurse during which time I gained vast experience of patient care. I am an advocate for support services having worked with numerous organisations and seeing the benefit they bring to one's wellbeing. I'm passionate about supporting people. In brainstrust, I can blend my patient centric approach with modern technology platforms, ensuring everyone can access our services.

Patients with brain tumours and their families should never have to feel alone, no matter where they are. Please do get in touch with me at mariel@brainstrust.org.uk to talk about how brainstrust can support you and your family.

For coaching and support: www.brainstrust.org.uk/thrive

Online resources: <https://brainstrust.org.uk/brain-tumour-support/resources/downloads/>

Online events: <http://brainstrust.eventbrite.com/>

To request a brain box: <https://brainstrust.org.uk/brain-tumour-support/resources/downloads/the-brain-box/>

To join our private Facebook group: <https://www.facebook.com/groups/braintumoursupportbrainstrust/>



br  instrust
the brain cancer people

How Nadia took up walking

When it comes to exercise - we can all come up with the excuses for not getting started.

- The gym's too expensive
- I don't have time to join a class
- I don't have any equipment

One Huddersfield woman found the motivation to start a new daily walking regime and has stuck to it through thick and thin.



Nadia Sethi admits she was in a bad way when she decided she needed to change her ways.

"I'd been through a divorce; I had a long-term health condition and was constantly in pain. I was taking up to 40 pain killers, I was unable to walk and I even had a blue badge," she remembers.

Working as a Care Coordinator for a number of GP practices in Calderdale, Nadia talked to patients about their health and wellbeing. "I could see how much difference physical exercise makes to mental health and how much fitness impacts on health. I realised that instead of giving out advice I should be taking some too!"

Nadia decided to walk around her Huddersfield hometown and during lunch breaks in the beautiful Calder Valley where she is based. "It was something I could fit into my life. I'm an early riser, I get up for morning prayers, so I walk before the sun rises. I even pace during phone calls.

"I started off with just walking around 6,000 steps a day, I'm now on around 15-20,000 per day. It's been a slow and steady journey for me but the only pills I'm taking now are vitamins and I have the energy to live a full life. I've almost lost 3 and a half stone and I'm not stopping yet."

Earlier this year, she shadowed the Macmillan teams at Calderdale and Huddersfield NHS Foundation Trust where she saw first-hand the work of the charity in supporting people with cancer. This inspired her to want to fundraise for Macmillan, she said: "As part of my role in the Primary Care Network working with the medical practices, I shadowed Macmillan teams to get a better understanding of the issues that matter to people when they're diagnosed with cancer. The experience opened my eyes to the range of support Macmillan provides - financial, emotional, practical - the charity does whatever it takes for the people they support. Because I was on a mission to get fitter, I spotted Macmillan's '100 miles in October' fundraising challenge and it caught my attention. I started the challenge on 1st October and I enjoyed it more than I thought I would."

She went on to walk 202 miles and raised more than £500. Not bad for someone who couldn't walk to the shops before last summer.

Nadia is loving life, eating healthily and looking for a new fitness challenge. At work she will lead on a new pilot scheme for Care Coordinators to carry out patients' cancer care reviews, a role which was traditionally carried out by GPs.

"I'll have more time to spend on a review, so I hope patients get something out of it. I'm so blessed to have a role where I can help people. My fitness has had a huge impact on my life. I feel like a different person, and much more confident."

As a Muslim, Nadia has found another benefit because of her improved fitness. "I pray five times a day but I had to sit on a chair, but now I can bow down and kneel and that means so much to me," she added.

New study launched at Leeds Breast Clinic



A new study has started at the Leeds Breast Clinic based at St James Teaching Hospital. Patients who have received a cancer diagnosis will be asked to give their opinion on the introduction of computerised technology to assist pathology doctors in making a diagnosis from tissue biopsies.

Originally, this process was achieved by examining tissue slices under a microscope but, more recently, microscope slides have been replaced by digitised images on a computer screen.

Whilst pathologists make diagnoses, they have no patient facing role, such that their reports are relayed to patients through other clinicians, such as general practitioners or oncologists.

Postgraduate Student and Senior Research Technician Angelene Berwick (Women's Health Research Group, University of Leeds), together with her PhD supervisor Dr Nic Orsi, are interested in including patients in their early-stage research focused on the implementation of Artificial Intelligence (AI)-based technology in breast cancer diagnosis and the prediction of long-term clinical outlook (also known as 'prognosis').

Patients that meet the criteria, will be invited to attend 30 minutes to 1 hour meeting, based around a set of topical questions on this subject. There are no right or wrong answers to the questions, this is purely an opportunity for patients to share their opinions and ask any questions they may have.

Indeed, whilst much emphasis has been placed on gathering pathologists' opinions on the acceptability of AI in assisting diagnoses, patients' opinions have been entirely overlooked. This study therefore aims to understand patients' views so that future digital pathology/AI-based diagnostics can be more patient-centred.

This is particularly relevant given that the adoption of such new technologies promises to speed up diagnosis times and improve prognostic accuracy, both of which are key concerns for the end beneficiaries - patients.

For further information please contact Angie Berwick at: a.berwick@leeds.ac.uk, or Dr Nic Orsi at: N.M.Orsi@leeds.ac.uk

It's full steam ahead for Platform 1 Prostate Cancer Support Group

The second of our prostate cancer support groups only started six months ago at Platform 1, a unique and diverse mental health charity in central Huddersfield. Already they're looking to expand the number of sessions to keep up with demand.

Platform 1 Chief Executive officer Gez Walsh has seen the numbers grow steadily to the point where he is considering setting up a second group, as a group of more than 14 or 15 members squeezes the time for everyone to have their say.

Platform 1 started as a men's mental health charity and grew rapidly to meet the needs of not only men, but the whole community. The charity started in a railway yard at the side of Platform1 in Huddersfield Railway Station, which is now used as a support and therapy site.

When many support groups are struggling for members, I asked Gez what was the secret of their success?

"We have an arrangement with the urology departments at

Huddersfield and Calderdale Hospitals where everyone who is diagnosed with prostate cancer receives a copy of our leaflet with details of the support available at Platform 1 – both the meetings and individual counselling.





“Staff from the Urology department regularly attend our meetings for Q and A sessions. This is an opportunity to find out more in a more informal and less clinical environment.

“Lots of the guys have become advocates and talk about the need to get a PSA test, and then invite their friends to join them at the group”.

The meetings are facilitated by Gez and Chris, a retired counsellor who was diagnosed with prostate cancer last October, and subsequently treated. Chris had received a lot of support from friends in the medical profession and was concerned that others might not have the same access to specialist help, particularly when recently diagnosed.

Gez and Chris both felt that a peer-led support group would help men cope with their individual situations – both in terms of making decisions about treatment options – but also in dealing with the anxiety and concerns that surround the topic of cancer.

Gez discovered one of the regular problems for group members was getting a blocked catheter. With nowhere else to turn, men were waiting in A & E for hours on end to get the problem resolved. However, now specialist nurses attend the group to demonstrate the solution, which Gez reckons must be saving the hospital hours of time and money.

“Men who have just been diagnosed that day turn up and you can see the fear written across their faces, as they believe they are going to die. Then our guys start to talk about how they are still living with prostate cancer after many years, and how they have a good life,” said Gez.

The group members come from all walks of life from factories to general practice.

“It’s so moving, they are all brothers with one enemy. They have one thing in common, and nothing else matters. Cancer doesn’t care, and it’s completely indiscriminate. The guys are there for each other and it doesn’t matter if they come from different worlds” explained Gez.

Right from the start, it was clear the men did not want the group to include wives and partners, so they could express themselves without embarrassment or inhibition.

Added Gez: “It’s funny, we all have the same ‘bits’ but we’re so bad about talking about stuff. We feel we can talk about erectile dysfunction or whatever we need to talk about. It’s often funny, rude or bawdy.” So wives and partners are not left out, Gez has arranged a one off session for them.

“When a loved one is a cancer sufferer, their wives and partners are sufferers as well, and it’s good for them to talk.”

Gez wants the group to go into different communities offering support, not expecting people to come to them. He is particularly keen to make connections in the South Asian community in North Kirklees. If anyone is interested in working with Platform 1 please contact him.

The Prostate Cancer Support Group meets the first and third Thursdays of each month from 6.00 -7.30pm at 7 St George’s Square, Huddersfield, HD1 1LA (First Floor)

Contact Gez on 07512 018940 or email:

gez.pfm1@gmail.com

Prostate Cancer

...You don't have to face it alone

Support
Chat
Information
Tea and coffee

Join our
Prostate Cancer
Support Group
First and Third
Thursdays
of each month
6.00-7.30pm

PLATFORM 1

If you would like to join the group or would like more details, call Gez on 01484 535960 or email: gez.pfm1@gmail.com

The Support Group meets at 7, St George's Square,
Huddersfield HD1 1LA (First Floor)

Macmillan Walking Group

Sometimes I have to pinch myself – yes, I actually get paid to go for a gentle walk – and then sit with some of the loveliest people you could wish to meet while having coffee and cake!

The Macmillan Walking Group offered by Macmillan Information Services at Calderdale and Huddersfield Foundation Trust hospitals is now up and running again following an enforced closure for Covid.

The group, led by qualified walk leaders, meet the first Thursday of every month at 10.30 am in the Conservatory at Greenhead Park, Trinity Street, Huddersfield HD1 4DT.

Anyone joining the group needs to fill out an application group beforehand, so arrive a little early to allow time. The walk goes at the pace of the slowest participant, so don't worry about keeping up. It's a lovely opportunity to explore what is a beautiful park, and the group is warm and welcoming.

For more information about the walking group call the Macmillan Information team on 01422 222709 or 01484 343614 or email cancer.information@nhs.net

Don't attend if you have Covid symptoms. Car parking is available at both the café car park and anywhere on the park perimeter.



The walking group captured on a lovely autumn day with walk leaders Shaz and Kajal, both far right of the picture.



Colleague Stephanie Wilson, Advanced Clinical Practitioner at Trinity Medical Centre, alongside the new information display.

Bringing cancer information to the GP surgery

New Cancer Champion Caroline Kearford, is keen to raise more awareness of cancer and screening.

As a Wellbeing Team Leader at the large Wakefield city centre practice, Trinity Medical Centre, Caroline hit upon the idea of focusing on the cancers in the Cancer Awareness Calendar.

Utilising the large waiting areas, she organised a display for Breast Cancer in October, and currently has information on lung cancer and pancreatic cancer for November's awareness month.

With the help of Kimberley Priestley, Macmillan Information Manager at Mid Yorkshire Hospitals, she was also able to obtain a Macmillan Information Point which displays a wide range of Macmillan leaflets.

Changing roles for Fraser Corry Community Panel Coordinator

It's goodbye to Fraser, Coordinator of the West Yorkshire and Harrogate Cancer Alliance Community Panel... but hello to Fraser as new Macmillan Engagement Lead covering West and South Yorkshire and Harrogate.

Many of you will already know Fraser in his role supporting the Community Panel. It's a role which is close to the heart of Yorkshire Cancer Community. Our founding member Phil Kelly came up with the idea of a patient panel to act as a sounding board for the newly created Cancer Alliance back in 2017.

Together with Healthwatch Wakefield, who employed me at that point, we came up with a job description and project plan and were fortunate when Healthwatch won the Cancer Alliance contract to develop the role.

The Community Panel was launched in Leeds at our Annual General Meeting in June 2018 and Fraser is pictured signing Ronnie up to become one of the first members. Ronnie is still actively involved today, and now brings along his granddaughter Elisha.

Under Fraser's careful stewardship the Panel has flourished and now has 50 members who meet in Church House Leeds every few months or connect remotely. Even during the pandemic, Fraser kept in regular touch and meetings were held online.

The panel brings together an enthusiastic and committed group of cancer patients, carers and others who are passionate about ensuring the voice of people affected by cancer is influencing the development of cancer care and services in their local area.

Last year the Community Panel were winners in the Helpforce Champions Awards in the category Partnership and Systems Working in Volunteering.

Many of the Yorkshire Cancer Community are actively involved in the Community Panel and I have always felt confident to recommend membership to patients and carers as I know they will be valued and offered rewarding engagement opportunities.



Fraser shares a joke with YCC trustee David at an information stall in Huddersfield.

Fraser has always taken the time to get to know members and offer support where necessary so they can share their expertise and participate in discussions as fully as possible.

He has also been a supportive colleague both when I worked at Healthwatch Wakefield, and now that I am employed by Yorkshire Cancer Community.

I will keep you updated about Fraser's new role with Macmillan, where he takes over from another great friend and supporter of Yorkshire Cancer Community, Ian Margerison, who takes up a new role within Macmillan as Partnership Quality Lead.

Jill Long

North Lincolnshire Patient Involvement Group closes the doors

One of the first groups I went to visit when newly appointed to my role in 2017 was this Patient Involvement Group, affectionately known as PiG. They met in the market town of Brigg and included cancer patients and carers as well as professional staff working in cancer services.

Over the years, I've been pleased to attend several of their meetings and visited their cancer awareness events, but Covid meant the group had to be paused for quite some time.

Although they reinstated their regular meetings, the core group of members felt their work had been completed. Dr Ann Moore, chair said: "It is with mixed feelings that the Northern Lincolnshire & Goole Cancer Services Patient Involvement Group (NLGPIG) announced that it ceased operations as of Tuesday 18th October 2022, when an Extraordinary General Meeting agreed that its objectives had been met as far as possible.

"We would like to thank all those who have worked with us over the 20 years that NLGPIG has been in existence. We have had some successes, including the waiving of the (then large) tolls on the Humber Bridge for cancer patients who had to cross for treatment, and we had strong input into some publications to make them more understandable for patients. We had considerable input into the developments of the Oncology Ward, the Radiology Unit and the Macmillan Information Centre at Scunthorpe General Hospital. We supported NHS staff at meetings and events, but times have changed.

"Patients requiring a voice to put their point of view regarding cancer care will still have Patient Participation Groups and individual, site-specific support groups to speak for them, along with groups such as Healthwatch, and websites such as NHS have far more information available now than when we began our work in 2002".

Thank you to the group for their involvement and commitment and for helping to improve cancer services in their region.

Here the group are pictured at one of their monthly meetings at the Buttercross in Brigg Marketplace in 2019 with chair Ann, pictured back row, first left.



Your stories

In the last edition we told Catherine's story and her diagnosis with thyroid cancer. Her colleague, Huma was also diagnosed with thyroid cancer when she was just 25-years-old. Here's her story:

"I noticed a swelling on my neck one day and arranged an appointment with my GP. He had a feel of my neck stated that I had an oversized thyroid gland, so he took some blood tests, and all my thyroid blood tests came back normal.

After this I never went back to the GP. Two years later I ended up in A&E after feeling suffocated in the night. I was then fast-tracked and referred for a scan. The scan showed a small nodule within the gland.

I had a biopsy, and on my 25th birthday, I went to see the consultant who told me it was cancerous. I had a six-month-old baby and I sobbed in the consultation room. It was very hard to digest, and I had a million worries in my mind - how was I going to tell my family? What would happen to my baby? The anxiety was making me feel sick.

It was a really difficult time but I became stronger as the days went on. On my son's first birthday I had my surgery (the timings were not great), the nodule along with my whole thyroid gland was removed as the cancerous cells had spread outside of the nodule.

I had my treatment planned soon after, I had radio iodine therapy. I was in isolation for one whole week at the hospital - isolating is normal in the covid world but a few years ago, I was dreading it!

The hospital and staff were great at St James Hospital, but the whole experience was bizarre. As I was radioactive, I was in a room on my own, there was a line drawn at the end of the room where my food tray would be left, no visitors, I had a TV and an en-suite and a window, I took plenty of things to keep me busy.

Once discharged I had to stay with my aunt, as I was not allowed to be next to my baby. Two weeks later I finally went home!

My follow up scan after this was going to be in nine months' time. This is because it is a slower growing cancer which is also slower to kill, so the treatment inside continues to work and after nine months I had a smaller dose of radio iodine before a scan in one of them scary machines!

I was then referred to Calderdale Hospital and my consultant completes regular blood tests and checks on me to ensure I am OK. This will continue and I have to take only one tablet each day forever.

On a positive note, I was very lucky that I got this type of cancer and this amazing treatment, I feel blessed that I am still here and able to care for my baby. I would like people to know that this is more common than it may seem. Please get your neck checked if you have any swelling or a lump and please request a scan. I shared my story with Catherine and she said this helped her, so I hope this will help others too. "

Huma Akhtar, Deputy Team Manager - Learning Disabilities Team, Kirklees Council



Barnsley Head and Neck Support Group

The group is designed to support Head and Neck patients who are living with cancer or have previously had a Head and Neck cancer and their families.

The focus of the group is to give patients and their families the opportunity to meet other patients who are also living with a Head and Neck cancer and to gain support from each other and staff who specialise in Head and Neck Cancer.

The support group was originally founded many years ago and was successfully run by patients until the end of 2019. Due to different circumstances including the pandemic the group was unable to keep going.

A private Facebook page that has been running since 2017 was used as an interim form of communication for patients.

Coming out of Covid, we asked patients if they would like to attend a face to face group, virtual group or to run on social media.

Patients wanted to restart the face to face support group. A new venue was located and secured, letters were sent with invites and dates to all current patients and meeting agendas plus guest speakers were arranged.

Guest speakers will include dental nurses for dental hygiene talks, speech and language therapists, Head and Neck consultants and pharmaceutical reps.

A Christmas party has been organised at a local venue with support group members and staff.

Over the next 12 months we aim to increase attendance to the group and to arrange group events.

One event was to complete the 10K Mouth Cancer Awareness walk together as a group with staff, patients and relatives. Gillian, Claire and Stephanie are pictured right taking part on the walk.



How to join our group

Contact the Head and Neck team on 01226 432419

The group meets at The Well for Wellbeing (Suite 12, Queens Court, 11 Regent Street, Barnsley S70 2EG) once every two months on the first Thursday of that month 2-4pm.

Facebook – Search Headstrong, Head and Neck Support Group – Click to join, once approved you will be able to see and post in the group.

Taking the Cancer SMART message out and about in West Yorkshire

Now that most Covid restrictions have been lifted, we've been able to get our Cancer SMART information stalls out to more events and organisations.

Cancer SMART is an awareness raising programme which we have been running in partnership with West Yorkshire and Harrogate Cancer Alliance since 2020.

In West Yorkshire 225 people are diagnosed with cancer every week; and 108 people lose their lives each week. Screening uptake is quite low.

More cancers can be diagnosed and potentially lives saved in our community if we can help each other to:

- be aware of unusual, unexplained and persistent body changes
- attend screening
- be better informed about lifestyles choice to reduce your risk
- know where to go for information

If you would like to help us deliver the Cancer SMART message – find out more by contacting jill@yorkshirecancercommunity.co.uk or go to www.yorkshirecancercommunity.co.uk/cancersmart/

Some of the places we visited this autumn



Gul and Zaida run a weekly Carers Trust group at Ravensthorpe Community Centre, which also offers a lovely hot lunch and a variety of speakers: (Pic Zaida (left) and Gul)



The BAME (Black, Asian and Minority Ethnic) Forum, Kirklees have put on a series of events to raise cancer awareness across diverse communities. Above, Nicky (left) and Nicole from Calderdale & Huddersfield Foundation Trust who work in pre-habilitation for cancer patients brought along a Macmillan information stall.

I'm here wearing my Cancer SMART T-shirt at the event which was held at the St John's Resource Centre, Huddersfield. Thanks to Carol from Locorum for organising the evening to mark Black History Month which included lots of interesting speakers and wonderful African Caribbean food.



Cancer Champions Sue and David (who is also a Yorkshire Cancer Community trustee) took the Cancer SMART presentation to a group of Leeds Sea Cadets and Leaders to pilot working with young people. Sue adapted the presentation to make it more engaging, allowing more time for questions and young people fed back their views in a survey. The presentation got a thumbs up and Sue and David will be rolling out the talk to more groups of Sea Cadets in the region.



Cancer Champions Ric, who chairs Cancer SMART online meetings, and James went along to Bradford University Volunteering Day to publicise our Digital Champion opportunity. Volunteers need to be active on social media and be willing to share our positive health messages.



Amina from Carers Count invited me to their chatty group which meets at Batley Community Centre. I met local Councillor Gwen Lowe and staff members from Grove House Surgery who had also popped in. We're all pictured here displaying the Cancer SMART bags -useful for spreading the message and for carrying your leaflets home!

We held two Women's Health Awareness events in September. Here we have Cancer Champion Julie, who is also employed by Pennine Breast Screening Services to raise awareness of screening and how to check your breasts or chest.

There were also stalls from Carers Count, diabetes awareness, Hameedah from Slimming World talking about health and nutrition and Kirklees Wellness Service. Thanks to the Al Hikmah Centre Batley for allowing us to hold the event to coincide with their Macmillan Coffee Morning, and all stallholders for their support.





I'm pictured left with Councillor Mussarat Pervaiz at our second Women's Health Awareness held at the Ravensthorpe Community Centre.

Finally, here is Neil helping to promote Cancer SMART when we visited the International Day of Disabled People Marketplace held at Leeds Museum.

If you would like us to attend an event, please contact Jill or Gemma.



Cancer

Screening saves lives by prevention & early detection

Making cancer an everyday conversation

Awareness of unusual & persistent changes

Reduce risk with a healthy active lifestyle

Take action NOW against cancer

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