Yorkshire Cancer Community

Winter Edition 2021

VOICE

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

www.yorkshirecancercommunity.co.uk

Welcome to our winter newsletter. We are a support and information network for people affected by cancer and those who support cancer patients and carers in Yorkshire and the Humber area.

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 have recently returned from spending three weeks in the USA with my American relatives. Because of Covid, this was the first time I had seen my American grandson in more than two years, although my daughter came over by herself twice in 2021.

After an emotional reunion at the airport, we had an amazing time. We went into New York to see the Christmas lights, shop fronts and the giant Christmas tree outside the Rockerfeller Center.

For the first time we celebrated Thanksgiving in America and went to Vermont for the occasion and some family members enjoyed the first skiing opportunity of the winter.

Travelling during Covid is complicated and expensive. The rules for the UK changed the day we arrived home and so we had to book a different Covid test and stay home until we received a negative result.

48 hours before returning to the UK, I had to fill in Passenger Locator Forms (PLF) and they are very difficult so I suggest anyone going abroad allows adequate time for this.

While I was away, I managed to join a Yorkshire Cancer Community Board meeting via Zoom!

We are all very excited about our work with the charity for the year ahead. I send you all festive greetings and best wishes for the New Year.

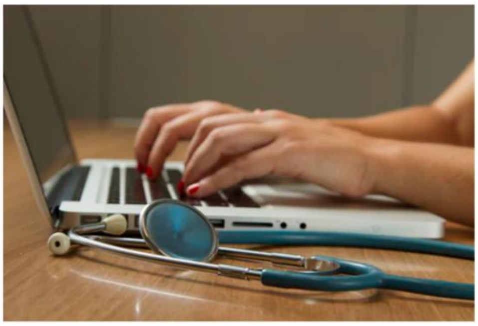
Dr Stewart Manning
Chair

Yorkshire Cancer Community Membership Survey

Thank you to everyone who completed our survey.

We will bring you the findings in the New Year.

Congratulations to Samantha McAnena who was the lucky recipient of the prize draw for a £25 Amazon voucher.



Could you volunteer to help first year medical students?

Leeds University has asked if we can find volunteers to talk to first year medical students about their experience of living with cancer or caring for someone with cancer.

Each year, the Long Term Health Condition Project, offers students an opportunity to learn by experience about what it is like to have, or to care for someone who has a long-term health condition or disability.

The University donate £10 per volunteer to the Yorkshire Cancer Community as a thank you. You may have been involved in previous years, but due to data protection regulations, the University cannot retain your contact details. Volunteers who have been involved in previous years have enjoyed the experience and the satisfaction of giving back.

Each volunteer is matched with two or three students who will meet via Zoom, or an alternative online platform. The meeting will take place in February or early March 2022, and last for about an hour.

Volunteers might talk about:

- How you managed with your health condition (or someone you care for)
- What you think about your health condition
- How things might have changed since your diagnosis
- The impact the health condition has had on your life and others close to you
- Your experience of medical and support services

All this information will be treated in confidence, but if you feel there is anything you would rather not talk about, please do not feel under pressure to do so.

If you would like to help with this project, contact **E**: iandpY1@leeds.ac.uk with the following information:

- Name
- Phone number
- Email address
- Brief details of the condition, you or the person you care for, experiences
- The support organisation you were contacted through

Are you looking for speakers for your group?

We have volunteers who can talk to your group about raising cancer awareness and the importance of screening.

This is our Cancer SMART project, which is a partnership between West Yorkshire & Harrogate Cancer Alliance and ourselves.

The talk includes a power point presentation and should last around 30 minutes. Talks will be given by zoom or face to face, depending upon location.

Your local volunteers are:

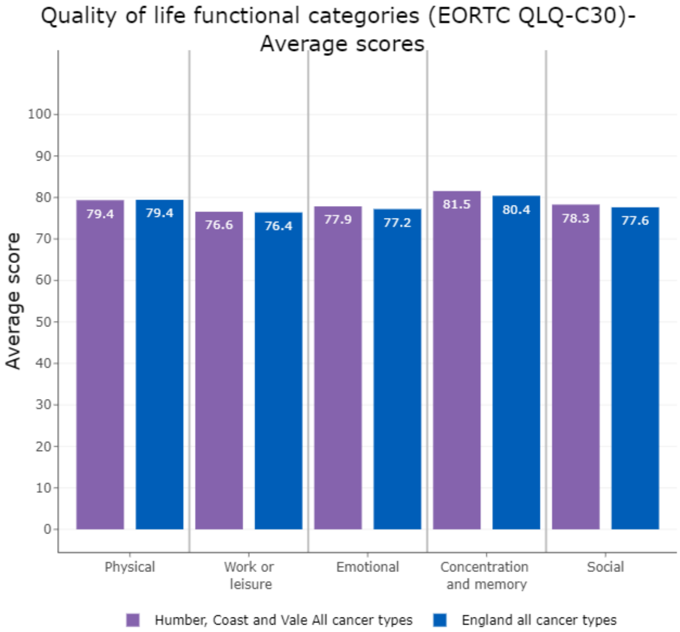
Deborah Adams – **E:** deborahadams1952@hotmail.com
Dr Stewart Manning – **E:** stewart@rsdf.org.uk

Dr Stewart Manning presents to a group organised by the Leeds Jewish Welfare Board

Cancer Quality of Life Survey results released

The first set of results for NHS England and NHS Improvement and NHS Digital's Cancer Quality of Life Survey have been released via an online dashboard.

The results show that quality of life for people affected by cancer in Humber, Coast and Vale was higher than for those with a cancer diagnosis living in the rest of England.



Cancer patients scored 75.2/100, whereas the general population scored 81.8. Respondents 18 months post-cancer diagnosis rated their quality of life below the general population.

As well as measuring quality of life, the survey asks a series of questions to determine an overall health score. While quality of life was rated highly, overall health for those 18 months post-cancer diagnosis was lower than for the general population. Overall health was also slightly lower for the cancer population in HCV than for those with a cancer diagnosis living in the rest of England.

The survey, which aims to find out how quality of life may have changed for different groups of people diagnosed with cancer, helps to identify where care is working well or not so well, and whether any new services are required.

From 2020, people around 18 months past a breast, prostate, or colorectal (bowel) cancer diagnosis were asked to complete the survey. Those 18 months past any other type of cancer diagnosis began being asked in July 2021.

2,216 patients in Humber, Coast and Vale (HCV) were sent the survey. Of this sample, 1,241 people responded, achieving a 56% response rate from September 2020 to July 2021.

Overall, feedback demonstrated a large amount of variation in cancer quality of life, and this was dependent on factors such as cancer type, age at diagnosis, and location.

Information from the survey, which will be updated on the dashboard approximately every six months, is one of a range of resources that will be used to work out where changes should be made to care, with the goal of improving services and quality of life for people diagnosed with cancer.

For more information on the survey and an in-depth look at the results, please click here.

Cancer Patient?

Please fill in the Cancer Quality of Life Survey if you're asked

Tell us, how are you doing?

BLESS Community Services - a warm welcome for those affected by cancer

The BLESS team and Jill: From left: Founder Julie with Geraldine, Brad and Jill. Missing from the picture are regular volunteers Nicola and Elaine who couldn't be there.

Storm Arwen was doing its worst but inside there was a warm welcome to the Upton Cancer Support Group for anyone affected by cancer. The group is run by BLESS Community Services, a Community Interest Company, who operate from the High Street Library.

Founder Julie Green, a former school cook, started BLESS to offer these services:
B connected
Learning
Environment
Support
Socialise

During lockdown she realized how isolated and lonely people living in the former mining community were, with few amenities provided for young or the old.
The Cancer Support Group which runs every Thursday from 2-4pm (booking essential) came about because there were so many families and individuals touched by cancer in the local community.
Many of them lacked transport, so found it difficult to attend support offered in nearby towns.

Lovely ladies: From left: June, Mary, Betty, Elaine, Sandra, Linda and Edna now the best of friends

The lovely ladies on my table had all lost family members and some of them felt very alone until they started attending BLESS. They told me that Upton was the ‘lost triangle’ situated around 10 miles from Doncaster, Barnsley and Wakefield, with poor public transport.

Now they look forward to the weekly get togethers, which offer afternoon tea, games of bingo and quizzes plus a chance to catch up with their new friends.
Julie and her volunteers, Carly and Geraldine are on the go non-stop to cater for everyone’s needs. Refreshments are free and visitors donate what they can afford. Macmillan Cancer Support also donated £1,000 to kickstart the venture.

Social media guru Brad, who lives locally, currently studies Graphic Design at Lincoln University and is an essential part of the BLESS team creating social media posts and lending a hand.

Thinking caps: Sandra, Linda and Edna get their thinking caps on for the challenging weekly quiz

To find out what other services are on offer search Bless Community Services on Facebook or go to www.blesscommunityservices.co.uk or
T: 07907 106360

Cavendish Care Sheffield

Many cancer support services, closed their doors during Covid-19, with some services still not open today.

Cavendish Cancer Care, a Sheffield charity, who were founded 29 years ago, also had to close their Wilkinson Street premises, but found a way to continue their support.

Cancer Buddies, which offers peer to peer telephone calls, went from strength to strength during the pandemic. Kim Scott, Community and Peer Support Manager said the scheme had provided a boost not only for the person receiving the call, but for the buddy offering the support.

Cancer Buddies are a group of trained volunteers who have either had cancer themselves or have cared for someone with cancer. Because they have been in a similar situation, they can understand what it is like to deal with a cancer diagnosis as a patient, or as partner or family member. People can self refer to the scheme, or be referred by a health care professional. The service is flexible to offer support from a couple of weeks to six months. Kim added: "It was particularly valuable when people were so isolated because of lockdown." Therapeutic staff, who oversee the matching up of volunteers, are mindful when the client may need to be moved onto other Cavendish services such as counselling, wellbeing courses or a selected range of therapies.

Cavendish Cancer Care are available on 0114 2784600

Kim also manages Sheffield Cancer Information Hub, funded by Sheffield Clinical Commissioning Group.
The Hub, now in its fourth year, is based at the city's Moor Market and is open Monday – Friday 10 am – 4pm.

The Hub's purpose is to promote the widest access to local and national support services to anyone affected by cancer. Its market location, makes it more acceptable to diverse communities and provides information on prevention, symptoms, treatment, support and living with and beyond cancer.

Kim is also keen to take information out into communities – bus fares can be the deciding factor in whether someone seeks out support or not. She is therefore working with communities that can sometimes find it difficult to access services or information to take the message to them.

To find out more about any of the services provided by Cavendish Cancer Care see **W**: https://cavcare.og.uk. There is also information about how to volunteer to become a buddy.

Macmillan Charity Ball – Holiday Inn, Barnsley

Strictly's Flavia Cacace Mistry and Jimi Mistry were star guests at the Macmillan Charity Ball, Barnsley held this autumn.

The professional dancer and former Eastenders actor first got together on the 2010 show and married in 2013.

Julie Ann Bathie joined Macmillan Barnsley as a volunteer just over seven years ago. She mentioned to Regional Fundraising Manager Amy Hebdon that she would love to organize a Ball for Macmillan to celebrate her 60th birthday. Unfortunately due to the announcement of Covid-19, the Ball was put on hold.

Despite working 14 hour shifts as a Neonatal Nurse at Jessops Hospital, Sheffield, Julie managed to organize the Ball with help from Macmillan Corporate Ambassador Volunteer Eileen Jones ably assisted by Julie's husband, Steve, who helped with administration. The team worked throughout the pandemic to organize the Ball and after a year with very little socializing, wanted to offer an event which would give people a lot of fun.

The Ball, which so far has raised in excess of £11,000 was also to raise awareness of Macmillan and cancer. Everyone who attended the glittering event, also received a goodie bag.

Flavia and Jimi Mistry auctioned dances to raise extra funds

Eileen pictured with Richard Bond, Macmillan Corporate Ambassador and Julie Ann and Steve Bathie.

I knew I had been born into the wrong body

Growing up in fifties Doncaster, Rob always knew he was different. He didn't want to play outside with his older brother. He preferred to sit and read.
It was only when he was nine years old, sitting chatting to his Auntie as she bathed his female cousin, he realized she had the body, he thought he should have had. He had been born into the wrong gender.
"I had a body map in my head and knew I should have been a girl. But I also knew the sort of backlash that would happen if I said anything."

Even at that early age, he was convinced it was not a 'phase' but he was also realistic enough to know that there was nothing he could do about his situation.

Over the years a saying 'If you can't change it, don't worry about it' summed up his behaviour and he 'got on with life'.

His parents had split up when he was very young, and with no one to talk to about his emotions, he got used to suppressing anything difficult or upsetting.

Now retired and living in Leeds, he says he had a good life with a lovely wife, children and grandchildren; and a satisfying career initially working as an engineer before studying as a mature student and moving into IT at a Leeds Cancer Hospital, and then to a financial services organization.

Over the years, Katie only occasionally got the chance to come out and Rob chose to bury the side of his personality that he knew was Katie.

A lump the size of a melon

In 2004, looking in the mirror one day, he decided he had overindulged on sweets and biscuits as he scrutinized his stomach. But while prodding his abdomen he felt a distinct lump. Having worked in a cancer hospital, he was well aware of the potential danger.

"I knew the sooner I was checked and diagnosed, the better the chance of having a good outcome."
At hospital, they found a large mass, but couldn't tell which organ it was growing on, and said they would write to his GP. When he was told it could take six weeks for the consultant to review the scan, he decided to use his work's private insurance to get the lump removed.

The lump was 14 cm large and was in his abdominal cavity, close to his stomach, pancreas and liver, but not attached to any of these organs.
He was diagnosed with a gastrointestinal stromal tumour (GIST), a rare cancer that develops in the digestive system that affect around 900 people in the UK each year.

He had experienced no symptoms and did not need chemotherapy or radiotherapy.

Other than routine follow ups, there was no further treatment needed and now the only outcome is a slight intolerance of fat.

Very sadly his older brother was diagnosed one year later with a cancer which affected his digestive system. He only survived six months.
"It was the luck of the draw. I was in the right place at the right time, with the knowledge that I needed to get treated, "

A pathway to transition

By 2009, Rob began to understand there was a pathway to transitioning, and that he could become a trans woman. But after years of 'hiding' his inner turmoil, he feared the emotional effect on his family and decided to maintain the status quo.
It was only due to a change of circumstances at work that meant Rob needed to bring home a bag of clothes he wore as Katie. He stashed them in the garage. His wife found them and asked why they were there.

Rob knew he could make up an excuse about them being for the skip, but he chose to admit they were his clothes which he liked to dress in. His wife could see how passionate he felt about being allowed to be Katie but struggled with the idea of it happening while they were living together. So, she suggested that he go away for a weekend to be Katie, but Rob knew that he wanted to be Katie full time, not just for an occasional weekend.

He and his wife separated, with Rob renting a flat where he lived as Katie but remained Rob at work until in 2018 when he felt he could no longer carry on living two lives. Over a period of a few weeks, he'd adjusted his dress until he was no longer wearing smart menswear but wearing the female equivalent and made the decision to transition while living full time in role.
His employers were supportive, creating policies and procedures and cascaded the information through the company so that everyone would be aware that Rob would now be known as Katie.

Friends of Dorothy Leeds

During counselling for gender reassignment, Katie was referred to TransLeeds who helped her to tell her story and come to terms with everything she had been through. The group were helpful and supportive but were much younger than Katie and facing different issues and circumstances.

A chance invite to a Friends of Dorothy Fundraising Ball, allowed Katie to go to a public event for the first time with her family and their friends.

Friends of Dorothy, Leeds, is a charity that brings together older LGBT+ people to make friends and share meals and outings. Katie found a group of people of her own age group with whom she had lots in common.

"We all had different stories but could relate to elements in each of them and this was a great comfort knowing we weren't on our own."

Now Katie has become a Friends of Dorothy trustee and helps to raise awareness of gender issues and of cancer and screening benefits.

Know your own body

Katie is passionate about people knowing their own body and supports our #CancerSMART message:

Cancer

S

creening saves lives by prevention and early detection

Making cancer an everyday conversation

Awareness of unusual and persistant changes

Reduce risk with a healthy active lifestyle

Take action now against cancer

"Be aware of what's usual for you and follow up with your GP if something doesn't feel right," she maintains.

She knows that many people are afraid of cancer, and afraid to be screened.
"Screening is preventative. It doesn't cause cancer. Screening can be a bit uncomfortable, or painful but it only takes a few minutes. If you don't catch cancer early, you may be dealing with the consequences for the rest of your life," she added.
Katie works with the Rainbow Alliance, part of the NHS, to raise transgender issues to ensure that Trans men and Trans women don't miss out on screening checks because of their changed gender status.

Katie continues to enjoy spending time with her loving and supportive family and volunteering as a Friends of Dorothy trustee. Taking part in a local weekly parkrun and competing in four races each year keeps her fit and well. A side effect of her cancer treatment has been a slight intolerance to fat which means eating chocolate can make her nauseous.

But in her own words: "I can live with that! I've been incredibly fortunate."

To find out about Friends of Dorothy, Leeds: W: www.friendsofdorothy.org.uk
E: hello@friendsofDorothy.org.uk or T: 03333 449 017

Women's Cancer Awareness Workshops – at the Al Hikmah Centre, Batley

Women attending the Cancer Awareness Workshops at the Al Hikmah Centre, Batley, got the opportunity to see inside a mobile breast screening unit.

The unit, which is run by Pennine Breast Screening, has been offering mammograms during the Autumn months, and saves Batley women having to make the journey to hospital premises.

The workshops were the idea of the Women's Committee of the IMWS (Indian Muslim Welfare Society) and featured informal presentations and question and answer sessions led by Julie and Sadie from Pennine Breast Screening. Yorkshire Cancer Community also got on board and talked about Cancer SMART, our awareness and screening promotion project, which is run in partnership with the West Yorkshire & Harrogate Cancer Alliance.

Julie demonstrating breast checks

Pennine Breast Screening serves a population of around 202,000 registered females from Bradford, Airedale, Calderdale and Kirklees. They are invited automatically for a breast X-ray every three years, from the ages 50 – 70. A first invite will be received within three years of turning 50. This means you will receive your invite before you turn 53-years -of - age. Appointments can be offered at one of their mobile breast screening units travelling across the region, or at St Luke's Hospital, Bradford. Trans people should proactively discuss Well Person checks with their GP, as they may not get an automatic invite for appropriate screening when their gender marker has been changed on their NHS record.

Julie and Sadie, pictured below, urged the women attending – most of whom were too young for a mammogram – to know their own bodies and what is normal for them. "Know your body like you know your face," explained Julie, who demonstrated the correct technique for checking breasts, under arms and up into the neck. She also advised against ignoring early potential signs – and hoping the problem would go away. She used the analogy of turning a blind eye to a leaking roof with disastrous results.

One young Mum who attended the workshop said: "The presentation was inspirational. We have to reach out to our community and help make them more aware. Fear tends to hold you back. I have female relatives who had breast cancer, so I'm going to talk to my GP about it now."

To find out more contact Pennine Breast Screening on **T**: 01274 365521 or look on NHS Choices to find breast screening in your area.

Two participants from the Cancer Awareness Session visit the mobile screening unit parked at the Al Hikmah Centre

Use MY data

Use MY data is the only independent UK movement of patients, relatives and carers focussed on the use of patient data to save lives and improve outcomes. Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

We are patient-led and through a policy of positive engagement, work to bring the voices of our Members to discussions about patient data and build confidence in the use of patient data.

Our Membership comprises:

- **Members** - patient advocates who are either patients, relatives or carers and who all want patient data to be used to save lives and improve outcomes.
- **Associate Members** – who are clinicians, researchers, charity workers, academics, public and commercial sector workers. They support our work and are united by an interest in sharing healthcare data to improve patient outcomes under appropriate levels of consent, security and privacy.

The more Members and Associate Members we have, the stronger our voice becomes in campaigning for patient data to be used to save lives and improve outcomes.

The benefits of joining use MY data:

- Being part of a community, which works to build confidence in the use of patient data, to save lives and improve outcomes.
- Receiving regular updates about patient data matters including engagement opportunities, event information, patient data developments, opportunity to input into consultations.
- Receiving guidance/support on patient data information and queries.
- Direct invitations to use MY data events.

There is no charge to join use MY data.

To join or obtain further information (all enquiries are welcome) please email join@usemydata.org.uk.

W: **www.useMYdata.org.uk @useMYdata #usemydata**

Christine Allmark

A cancer patient from Wakefield
Member of Yorkshire Cancer Community
Former research assistant, Leeds University
Patient Advocate, use MY data

Data is important to research because it is the experience of the patient's pathway, the patient's journey, what happens to them during their diagnosis, treatment and post treatment and their subsequent progress through life for however long or short that may be.

This information is vital to researchers because they will know what the real experience is of the patients. So, this information should be known to the researchers and all those involved, in order to properly shape treatments and policy which is accurate and matches the experience of the patients on the actual side of the treatment pathway itself.

One problem is that the primary care may use one data system, secondary care may use another. That incompatibility can be a cause of concern. So, there is no direct communication sometimes between the GP and the patient's specialist in the hospital. So, if this was a seamless transfer process, the patient's journey through care from the initial diagnosis, treatment and subsequently, would be much smoother.

We are building an online library, where the patient voice is heard direct, talking about the rewards of using their data. **W:** www.usemydata.org.uk **E:** getinvolved@usemydata.org.uk

Hug on a Tray

Providing tea, snacks and TV to benefit haematology patients and their families in St James' Hospital, Leeds

Could there be anything more welcoming than a hot cuppa and a snack when visiting loved ones at a blood cancer ward in hospital?

What started as a simple idea to make life more comfortable for patients and families snowballed until the friends involved had raised around £100,000 in just five years.
In 2016, Lesley Noble, 72, a Chaplaincy volunteer for 15 years, noticed on regular visits to patients on J88 that all the TVs had been removed from the individual rooms on the ward. Patients were expected to pay up to £7.50 to watch TV. Lesley, who had just formed a social group for women in Otley called Chevin Socialites, asked her group if they would help to fund free television over the Christmas period.

Fundraising took off and not only were they able to fund televisions on wards J88 but also to adjoining ward J89 over both Christmas and New Year.

Leeds Friends of Leukemia donated kettles to patients in these isolated rooms and as Lesley puts it: "This was a lightbulb moment. With the thought…if there's a kettle in the rooms, well maybe we could donate, not just for the patients but their visiting families and friends, free teabags, coffee, milk, biscuits, cups and a tray"

The Hug on a Tray team

So Hug on a Tray was born and Lesley, helped by the 'Girls' Jane, Teresa, Edie, Trish, Christine, Linda and Elaine have continued to fundraise ever since. Companies big and small have stepped forward to offer support and even during lockdown, they were able to continue.

Each year, they hand over £26,400 on January 1 to cover the costs of TV for two wards for the following year. It would cost a patient £10 a day, without this help. They also provide every patient on those wards with a tray with all they need to make a drink and snack.

Lesley points out that all monies raised goes straight into the charitable pot, as volunteers do not claim any expenses. This year, to aid their regular raffles and stalls, the Girls opened the Hug on a Tray Hub at 15 Manor Square, Otley, thanks to another benefactor. This will help them to continue to offer events and stalls even during inclement weather.

If you would like to support Hug on a Tray, or volunteer for this worthwhile venture see
W: www.hugonatray.org

Shop opening times are Tuesday, Thursday, Friday and Saturday from 10 am until 3.30 pm.

Opening of the Hug on a Tray shop by YEP Bruce Rollinson

Helpforce Award Champions 2021
West Yorkshire & Harrogate Cancer Alliance - Community Panel

The West Yorkshire and Harrogate (WYH) Cancer Alliance Community/Patient Panel aims to support cancer patients, carers and anyone affected by cancer, by getting them involved in the work of the WYH Cancer Alliance. This can include helping to design a new cancer service, sharing patient experience and influencing the delivery of improvements in cancer patient care across our local areas.

Covid 19 has brought a huge range of challenges over the past 18 months and like so many other groups, the panel has had to adapt its way of working and in response to national restrictions, the panel switched from meeting face to face to virtual engagement via Zoom. This enabled panel members to continue to work in partnership with the Cancer Alliance in order to make tangible differences based on what matters to them

In August 2021, the panel's coordinator Fraser Corry took stock of the panel's work and the impact this has had on a wide variety of cancer projects. This included:

- Co-working with Calderdale and Huddersfield Foundation Trust to create a new cancer online web resource.
- Sharing patient experience to help the design of three local cancer screening campaigns, designed to improve uptake
- Supporting a funding bid for two Macmillan funded Community Personalised Care Leads, with individual panel members being involved in the recruitment process.
- Advising on how to build patient confidence and overcoming barriers to accessing health services during Covid 19.
- Working with the Innovations Programme to look at how the process for the new Pin Point blood test could be administered on a practical basis within the community and advising on associated patient information

To recognise these achievements as well as the high levels of commitment demonstrated by the panel's members, Fraser submitted a nomination to the national Helpforce Awards Champions Awards 2021 - Partnership and Systems Working In Volunteering' category. Fraser works for Healthwatch Wakefield, which hosts the panel on behalf of the Cancer Alliance.

At the end of September, it was announced that the panel had been shortlisted as a finalist and Fraser asked to submit a video to showcase its nomination link here.

The video features several panel members who each talked about on what the panel means to them personally. Ovarian patient Val Balding confirms *"Cancer diagnosis shatters your confidence and being a part of the community panel has helped me build my confidence, it's helped me feel useful, productive and to really be a part of something important. I represent the panel on the non-surgical oncology steering group, sharing all of our experience with professionals and putting the patient at the centre of influencing cancer services, across West Yorkshire and Harrogate."*

At the end of October, Helpforce Chief Executive Mark Lever, pictured below, announced that the panel had won this year's 'Partnership and Systems Working In Volunteering' award.

Welcoming the news, Jason Pawluk, WYH Cancer Alliance Programme Director, said: *"We are delighted that our hardworking, dedicated and inspirational patient panel have been collectively recognised through winning this prestigious award. Their success is richly deserved. Everyone involved in the Alliance views our panel members as essential partners in our mission to close the gap in care and outcomes for all people affected by cancer in West Yorkshire and Harrogate."*

Lots of other supportive messages have been shared online, including local MP Andrea Jenkins who tweeted *"I'm delighted to hear that West Yorkshire and Harrogate Cancer Alliance Community Panel (hosted by @healthwakey) has won this year's Partnership and Systems Working in Volunteering award. A huge well done goes to the whole team."*

The panel has since been celebrating the award win amongst the group and would welcome new patient and carer members who are keen to volunteer and ensure that patient voices are heard loud and clear in the development and improvement of care and services across our region.

Learn more about the community/patient panel on the Healthwatch Wakefield website and the Cancer Alliance website

If you are interested in joining the panel, please contact the panel Coordinator, Fraser Corry, by E: fraser.corry@healthwatchwakefield.co.uk or T: 07597 801623

Cancer Advocacy Service, Citizens Advice Rotherham and District

Being diagnosed with cancer can be a confusing and overwhelming time – and when Covid-19 gets factored in – people can feel much more isolated than usual. Many services and support groups are still paused which can leave a newly diagnosed patient feeling bewildered.

The Cancer Advocacy Service, offered in partnership with Rotherham Clinical Commissioning Group and Macmillan Cancer Support, was launched in 2018, to complement existing services in the borough. However this service has come into its own at a time when patient's support options have been limited.

Faye McDool, who started at the Service this Autumn following Julie Cox's retirement, says they have been able to continue by simply switching from face to face contact to telephone support.

People affected by cancer, can be referred by their Cancer Nurse Specialist (CNS) or make a self referral themselves.

Volunteer advocates can:
Listen and give a client time to talk about their worries and concerns
Support a client to find and access the services or information they need easily and quickly
Empower a client in expressing their views, what they want and need.

A volunteer advocate will call the client and discuss the sort of support they would like. The Service will then work with the client to find a way forward, resolving difficulties, cancer related or not, and improve the quality of life for that client.

Some of the things they can help with:

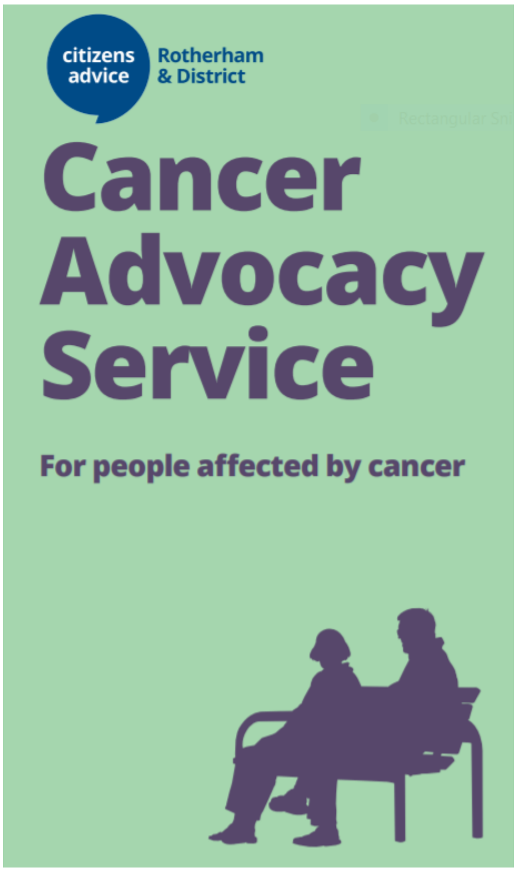
- Provide information on diagnosis and treatment, support dealing with the effects of treatment
- Support dealing with emotions and stress
- Support and provide information on managing day to day tasks
- Discuss money worries or find out about benefits
- Employment issues
- Family and relationship issues
- Signpost to other cancer services

citizens advice Rotherham & District

Advocates are there to support and empower their clients, and do not offer advice or their own opinions.
Volunteers to the Service are always welcomed. The work is rewarding and a chance to give back. Volunteers can access both CAB and Macmillan training.
Volunteering hours can be flexible with some advocates choosing to give a full day or part of a day.
Faye, who joined CAB from Doncaster Council's Public Health team, said she hopes in time, volunteer advocates can help to shape the Service.

The Cancer Advocacy Service is free, confidential and open to anyone affected by cancer.
If you would like to self refer, or if you would like to volunteer, here are the contact details:

T: 01709 515680 ext. 171 Monday – Friday 9 am – 5pm **E**: advocacy@citizensadvicerotherham.org.uk
W: www.citizensadvicerotherham.org.uk



citizens advice Rotherham & District

Cancer Advocacy Service

For people affected by cancer

From left to right : Jamie Ashton (Citizens Advice Project Manager) Faye McDool (Macmillan Cancer Advocacy Manager) Linda Evan (Volunteer) Sue Rowley (Citizens Advice Interim Advocacy Officer) Julie Smith (Volunteer)

The Capture Study

Improving pain control for people living with cancer

Hi, we are Olivia and Matt, researchers from University of Leeds.
We are running a research project about how to improve the management of chronic pain for people living with advanced cancer and who are cared for at busy cancer centres.

We are looking for people who have experienced cancer pain or have supported someone with cancer pain to join our patient and public involvement group. The group will help to shape the project by providing their advice and experience about what it's like living with and managing cancer pain. This will help us to improve pain assessment in oncology services for people with advanced cancer.

How can you be involved?
You can join our patient and public involvement group and provide feedback on our pain assessment tool we will be creating. We will ask for your feedback on how we plan to carry out the study and how we will share the results. We will meet every 3 months on Microsoft Teams or at the University of Leeds. We will reimburse group members for their time in taking part, and travel costs. If meetings are held in-person catering will be provided.

Want to hear more about the project?
If you are interested in taking part, please contact us on the below information. We will be able to tell you more information about the study.

Please contact us on:
E: M.R.Mulvey@leeds.ac.uk or o.c.robinson@leeds.ac.uk
Thank you for your help!
Matt Mulvey and Olivia Robinson

Females: Can

Sheena Hussain, the Bradford poet, set up Females:Can a network for women who have recovered from cancer. When she was diagnosed with thyroid cancer, she says she missed out on the benefits of sharing with a peer group, what she was going through.

She founded the network to allow women to shape their own wellbeing through a holistic approach. A safe, non judgemental and caring ethos to help transform women's life beyond cancer.

Females:Can recognized Breast Cancer Awareness month with a Pink Tea Party and invited speaker Samina Hussain, founder of Sakoon Through Cancer, a South Asian charity in Berkshire supporting women through their cancer journeys and beyond.

Sheena, pictured left, also leads Cancer Care in Communities in association with Better Communities Bradford funded by Sovereign Health Care. This is a six month holistic programme for women on living well post-cancer and includes creative writing, post cancer cookery, managing fatigue and networking. The programme is delivered at 40 Lidget Place, Bradford, BD7 2DJ and the venue is disabled access friendly.

To find out more about Females:Can or Cancer Care in Communities contact Sheena:
T: 07935 177 562 or **E**: sheena4076@live.com

Females:CAN

Cancer care closer to home - a new mobile medical cancer care unit for Airedale

A state of the art mobile cancer unit was launched last month by Airedale NHS Foundation Trust taking care and treatments to patients in Airedale, Wharfedale and Craven.

The Next Generation unit provided by charity Hope for Tomorrow, is a ‘world first’ in healthcare innovation, designed to change the way cancer care is given.
It will visit communities to provide accessible clinics as well as cancer treatments including chemotherapy. Staffed by specialist oncology nursing teams and pharmacists, the unit will allow cancer services to be delivered in the heart of the community.

Manufactured in the UK, the mobile unit includes two hydraulic powered consultation rooms, which expand from its side. Each room is fully connected with digital facilities so that patients and staff on board are able to connect remotely to the main hospital. The unit has been named ‘Christine’ in memory of the charity’s founder Christine Mills MBE who died in 2018 from cancer.

The hospital trust received their first mobile unit from Hope for Tomorrow in 2018, and also made use of a second unit during the peak of the pandemic, so that patients didn’t need to visit the hospital.

Moving cancer care closer to patients has proven health and wellbeing benefits. In some cases, once initial consultations and first treatments have taken place, mobile cancer care units allow for the removal of hospital visits for all of a patient’s treatments.

Rachel is one such patient. She was 40 when she was diagnosed with breast cancer in July 2016 and underwent surgery soon after. Rachel had a PICC line inserted and was treated on board one of the mobile units, weekly at first.

“I think the service is amazing,” she says. “Everyone should know about it – especially that you can get treatments like line flushing as well as chemotherapy on board. I love the staff – they’re always happy and smiling, and they make me feel so welcome. I get coffee, biscuits and a friendly reception every time.
"For people who have to rely on public transport, the mobile units are invaluable. When you’ve spent most of the day at the hospital having a gruelling chemotherapy treatment, imagine what it must feel like to face a 45 minute bus journey home when you can only shuffle rather than walk, and you’re feeling so incredibly sick that you just can’t get home fast enough.”

Mobile Cancer Care Unit now launched in Airedale

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