



news

Yorkshire Cancer Patient Forum News February 2018

Welcome to this edition of the Yorkshire Cancer Patient Forum News. Newsletters are produced quarterly. If you have any ideas for articles or you have a feature you would like to submit, please contact jill@yorkshirecancerpatientforum.co.uk

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Macmillan Cancer Support Chief Executive Officer, Lynda Thomas, meeting members of the Yorkshire Cancer Patient Forum



From left: Barbara, Phil Kelly (YCPF Chair), Paul (YCPF Treasurer), Sara, Lynda Thomas, John, and Jill (YCPF Engagement and Communications Officer)

Head of Macmillan Cancer Support's stamp of approval for Yorkshire Cancer Patient Forum

Lynda Thomas, CEO of Macmillan Cancer Support met with members of Yorkshire Cancer Patient Forum when she visited St James Hospital, Leeds, in early February.

She hadn't come across another structure like the Forum, which is supported by a Macmillan funded Engagement and Communications Officer, Jill Long, who is based with Healthwatch Wakefield.

She felt there were not enough roles like this within Macmillan, or groups like the Forum which bring together people affected by cancer with healthcare professionals.

She was interested in how the Forum's independent structure allows it to work in partnership with Cancer Alliances across Yorkshire and Humber. She was also pleased to hear of the success of Healthwatch Wakefield's bid to support a community panel commissioned by West Yorkshire and Harrogate Cancer Alliance.

Lynda was in Leeds to see the award winning specialist Macmillan speech and language therapy team working with head and neck cancer patients at Leeds Cancer Centre. Through their work, team members identify

patients who are at risk of swallowing difficulties before radiotherapy begins.

They help to reduce hospital admissions by offering education, therapy and exercises to patients in order to improve their outcomes and avoid them reaching crisis point. This means patients can stay at home longer, with advice available at the end of the phone.

Lynda also met with Prof Sean Duffy, who is Clinical Lead with the West Yorkshire and Harrogate Cancer Alliance, to talk about the progress being made to transform cancer care, treatment and support across the region.

Lynda said "It's been great to spend time in Leeds and to see and hear about the good work that is clearly going on around the delivery of cancer care and support across this region. Macmillan is delighted to be involved.

"I'm always inspired to meet with people affected by cancer alongside the health and care professionals who support them, as we have so much to learn from each other if we are to deliver the best possible outcomes and experiences – and that's an ambition we all share."

Healthwatch Wakefield successful bid to create a Community Panel

Healthwatch Wakefield, who host the post to support the Yorkshire Cancer Patient Forum have won the contract to set up a Community Panel for West Yorkshire and Harrogate. The Panel of volunteers, to include cancer patients, carers, and members of the public has been commissioned by the West Yorkshire and Harrogate Cancer Alliance.

The proposal has been developed jointly with all six Healthwatch organisations across West Yorkshire and Harrogate, including Healthwatch Kirklees, Healthwatch Leeds, Healthwatch Bradford (also covering Craven), Healthwatch Calderdale, and Healthwatch North Yorkshire (for Harrogate and Rural), along with the Yorkshire Cancer Patient Forum.

Healthwatch has been representing patient and service user voice in health and social care for nearly five years and has excellent skills and experience in this area, not to mention extensive contacts and networks with local community groups and individuals. In 2017, Healthwatch Wakefield, who will act as the lead provider for this project, secured funding from Macmillan to host a post to support the Yorkshire Cancer Patient Forum (YCPF). YCPF is a long standing forum of involved and engaged patients, carers, and support workers who are already working with the Cancer Alliance as it develops.

Nichola Esmond, Healthwatch Wakefield Chief Executive Officer, said: "We propose to build on this strong basis to develop and sustain a vibrant and engaged Cancer Alliance Community Panel of individuals who have been affected by, or have an interest in, cancer services in our area."

Reaching cancer patients from Black, Asian and Minority Ethnic Communities



Reaching cancer patients in the Black, Asian and Minority Ethnic communities is notoriously difficult. Without their voice, myths about why these communities do not engage continue to circulate.

The Yorkshire Cancer Patient Forum was asked to find representatives from BAME communities to take part in a research project, but struggled to get responses.

Kursh Siddique knows from first hand experience, the issues which arise from people within his community not talking about cancer. His mother died of breast cancer in 2013, but for many months, she kept her diagnosis to herself, even though she was living under the same roof.

As a family, all they knew was that Mum needed regular appointments at Bradford Royal Infirmary and assumed they were for matters of a sensitive nature. She allowed them to drop her off, but not to go inside. Tragically, having experienced his father dying of lung cancer in 1997, Kursh feared the worse.

He discussed his concerns with his siblings and it was agreed his sister in law would attend future appointments, and eventually his mother opened up and the family were allowed to accompany her. However, she still did not want to talk about her experiences, and sadly despite chemo and radiotherapy, the cancer returned and she died.

Kursh explained his Mum was modest and independent. It was not the culturally accepted thing to

disclose an illness which she would have felt was very intimate.

Now with his not for profit company, BAME Voices Yorkshire Ltd, he is attempting to reach out to those hard to reach communities, to capture their voice. He said: "There're some excellent organisations working to help people with cancer, all we would like to do is help them to reach some of the perceived harder to reach communities and to create awareness within the communities of the support that is available to them. We want to give people from minority groups in West Yorkshire a voice and a chance to make their lives better".

Currently BAME Voices are working with Yorkshire Cancer Research, Cancer Research UK, Pennine Breast Imaging and Bradford Clinical Commissioning Group, to help develop strategies to increase the awareness and uptake of Cancer screening within the South Asian communities.

There isn't a one size fits all solution. In some communities, women's groups would be willing to visit a breast screening clinic as a group. They would not want the screening offered within their own community because of compromise to their modesty and privacy from the rest of the community.

South Asian men in Kursh's experience would be more inclined to present for lung cancer screening, blood tests or BMI checks, if the screening was offered within the community setting using established community groups and masjids. He felt that publicity needed to target community groups and community centres, not just GPs and health centres.

In the long term Kursh feels that stigma and sensitivity surrounding talking about cancer will disappear through education and awareness of help and support available. Younger generations already understand the importance of screening and early diagnosis.

BAME Voices are also working with Clinical Commissioning Groups and local councils throughout Yorkshire. They also represent BAME voices on the Equality Delivery System panel for the NHS which is in support of the WRES (Workforce Race Equality Standards) report. Projects BAME Voices have been involved in other than cancer; include future care home provisions for the South Asian community, diabetes, obesity and heart disease.

● For further information about BAME Voices see www.bamevoices.org.uk

Boyz2men Health Project

Men have a poor record when it comes to health – men in Leeds are more likely to die at a younger age than women. This finding came out of a joint project between the Centre for Men’s Health at Leeds Beckett University and Leeds City Council. The majority of men’s health problems are preventable and are related to their lifestyle or their social conditions.

The project which resulted in a report in 2016: *The State of Men’s Health in Leeds*, did not however have sufficient numbers of men from Black, Minority Ethnic communities to get an understanding of what the picture is like for them. As a result, the Boyz2Men health project was established to target boys and men from BME communities who have the least access to health information and services in the Chapeltown and Harehills areas of Leeds. The project is led by Leeds West Indian Centre Charitable Trust in partnership with Leeds Men’s Health and Wellbeing Network, the Leeds Islamic/Al Khidmat Centre and the Sikh Centre. Funding has come from North Leeds Clinical Commissioning Group Third Sector Grants, administered by Leeds Community Foundation. The project aims to raise awareness around heart disease, cancer, diabetes and obesity and help increase life expectancy.

Project Manager Claude Hendrickson says men in general are ostriches when it comes to their health, but it would seem that BME men are worse. He is concerned that boys and men from BME communities are unlikely to visit their GPs. Claude has his own health reasons for wanting to raise greater awareness. As a black man he knows that his risk of getting prostate cancer is 1:4 compared to a 1:8 risk for other ethnicities. He also knows that the risks increase for over 45 year olds and for anyone with a father or brother who has had the disease. He went to his GP who carried out a PSA test, which helps to predict the likelihood of developing prostate cancer. He was referred to the hospital, and because his PSA level was high, he opted for treatment. He said: “I feel more confident about speaking to other men about their health and early detection, as a result of what I have been through.”

He doesn’t want to focus only on prostate cancer and miss the opportunity to raise awareness of all the other cancers. He wants boys and men to be more aware of their own bodies so they present earlier with worrying symptoms. Boyz2Men are trying to get a better picture of boys and men’s health in the area by circulating health surveys to find out whether participants are registered with their GP, and do lead healthy lifestyles.



Claude wants every young man to get himself registered and make an annual appointment to see his GP. He says that statistically, men aged between 18 32 are missing from health networks. They attend GPs with their mothers as a child, but when they leave home, start college or work, they do not prioritise their own health needs.

The project is running health and wellbeing events at a variety of locations around the Harehills and Chapeltown area often in conjunction with sporting activities. The project is only funded until April, but Claude hopes that its legacy will be health ambassadors who will still have health conversations within their communities. Getting men to open up to talk about health problems is a long term challenge. Claude added: “We see low life expectancy in Chapeltown and Harehills, especially among the many men under 50 dying of unnecessary illnesses. We want to challenge this and make men more responsible for their own health.”

For further information contact Claude at Leeds West Indian Centre Charitable Trust on 0113 262 2270 or email claudio@lwicct.co.uk

● See next page for cancer statistics and an extract from: ‘*The State of Men’s Health in Leeds*’, published in 2016 by Leeds Beckett University and Leeds City Council.

Men's Health Cancer Statistics

An extract from: 'The State of Men's Health in Leeds', published in 2016 by Leeds Beckett University and Leeds City Council:

- For men aged under 75 years old in Leeds, cancer is the leading cause of death and the second highest cause of death for all ages.
- A similar proportion of males and females in Leeds are diagnosed with cancer, however men are more likely to die from cancer.
- Lung cancer results in the most cancer deaths for men in Leeds.
- The rate of lung cancer deaths is 40% higher for men than women and 23% higher for men aged under 75 years compared to women.

The male death rate for bowel cancer is almost double the female rate.

Men's greater cancer risk is largely due to lifestyle factors and health behaviours – men generally have higher smoking rates, alcohol consumption and poorer diets compared to women.

Healthier lifestyles and early detection can reduce the risk from cancer.

It is important men are aware of the symptoms of prostate cancer to ensure early diagnosis and effective treatment.

This is particularly important for men from black ethnic groups as they have a higher risk of developing prostate cancer.

Everyone in Leeds between the ages of 60 and 75 receives a free bowel cancer screening test through the post.

While 55% of women completed their tests, only 45% of men completed theirs. Of those who completed their tests, 2.4% of men and 1.2% of women tested positive for bowel cancer. This means that men are less likely to be screened for bowel cancer, yet more likely to benefit from it.

Authors:

Prof Alan White, Men's Health, Leeds Beckett University

Dr Amanda Seims, Research Officer, Leeds Beckett University

Rob Newton, Health and Wellbeing Policy Officer, Leeds Beckett University and Leeds City Council



'THE ENEMY WITHIN' FILM NIGHT – 50 YEARS OF FIGHTING CANCER

Wednesday 21st March - Free Event but booking essential

'The Enemy Within' documentary tells the incredible story of the fight against cancer over the last 50 years. Join Yorkshire Cancer Research for a free screening followed by a question and answer session with leading cancer clinicians and researchers.

Tickets are free but need to be booked in advance at: www.ycr.org.uk/theenemywithin

Venue: The Allam Medical Building, University of Hull

Time: 6.15pm for sandwiches, cake and drinks with researchers and the film starts at 7pm.

For further information or to book your place over the phone, contact Andy Wilson on 01423 501269 or andy@ycr.org.uk

www.ycr.org.uk

Spenningsham Cancer Support Group – it's a beauty

When breast care nurse Lorraine Newton wanted to set up a new cancer support group – she didn't have any difficulty finding a place to meet.

She decided to base the group at the beauty salon she owns in the village of Roberttown in North Kirklees.

Lorraine, who has been a nurse for 39 years and a Macmillan cancer support nurse for 21, understands the value of a support group.

During her years spent as a breast care nurse at Dewsbury District Hospital, she helped to set up and run a number of support groups located at leisure centres, hotels and community centres all over the area. Now those groups have either disbanded or have turned into friendship groups.

Lorraine, who now works part time for Bradford Teaching Hospitals, felt that Bradford patients had a wider choice of facilities. She wanted to offer something in her home area of Spenningsham, and thought her salon would be a welcoming venue.

"When people are diagnosed with cancer, they go through a lot of physical and psychological turmoil. Many of the local services have been diluted, and I felt I would like to offer my years of experiences and contacts, in providing a drop in facility, with support

from Macmillan and linking into other organisations for people who are living with cancer," she said.

Cancer patients and families meet on the last Friday of every month for coffee and cakes. The group are friendly, informal and share lots of fun and laughter.

One member, arriving for the first time, was apprehensive about joining the group. "I needn't have worried. I found lots of smiling faces and I've made new friends," she said at the January meeting.

When she was concerned about a new lump in her breast, Lorraine, who is her breast care nurse, was able to refer her for an urgent hospital appointment.

Talking things over with a group of people who have gone through the same worries, is what makes this group tick.

Money raised from the monthly meeting funds free pamper treatments for cancer patients living in the Spenningsham area.

The cancer support group runs from 12 noon to 2pm, the last Friday of each month.

● For further information contact Lorraine on 01924 400093 or email info@bebebeauty.co.uk



**WE ARE
MACMILLAN.
CANCER SUPPORT**

IN YOUR AREA

What's going on near you? Find out about support groups, where to get information and how to get involved with Macmillan where you live.

Go to www.macmillan.org.uk and search 'In Your Area'

Meet the Forum Members: Jonathan Tobutt

Life is tough when you are caring for a loved one. Carers UK tell us carers are twice as likely to be in bad health as non care givers. We also know that the value of care, given by unpaid carers in the UK amounts to a massive £132 billion a year. Contrast this with total health spending in the UK of £134 billion a year. If carers feel they are not valued or recognised, imagine how much harder it is, if you are not seen as a 'traditional' carer.



YCPF member, Jonathan Tobutt, is raising the profile for carers from an LGBT (Lesbian, Gay, Bisexual, Trans) and single person perspective. He feels that within discussions about carers, there is little acknowledgement of the diversity of caring, with an expectation that caring is provided within the family.

Jonathan, a former teacher, cared for his partner Barry, who was a bowel cancer patient, until his death in 2015 at Kirkwood Hospice, near Huddersfield. He gave up his work to become a full time carer, for Barry, a no nonsense ex salesman, twenty years his senior.

The experience of having to negotiate for care and the medical equipment needed to make life tolerable, has toughened Jonathan up. The healthcare profession working at the coalface were supportive, but it was the bureaucracy to simply order essential medical supplies, which frustrated Jonathan.

On one occasion, Barry was discharged from hospital with a newly fitted stoma, but Jonathan had been given no instructions on how to care for Barry following this surgery. "I learned to be assertive, on behalf of Barry." This still didn't prepare Jonathan when he was asked by

healthcare professions about care for 'his father'. An assumption had been made, that Jonathan was Barry's son.

Jonathan contributed to the 2016 Marie Curie report: 'Hiding Who I am' – the reality of end of life care for LGBT people which was published in partnership with King's College, London and the University of Nottingham. The report found that nearly three quarters (74%) of LGBT people are not confident that health and social care services provide sensitive end of life care for their needs. As a result, they often delay accessing the care they need and are more likely to experience unmanaged symptoms and pain at the end of their lives.

Jonathan acknowledges that he was not well supported as a carer, and that his views echoed those of the Marie Curie report. For three years, as a carer he was ignored at worst and tolerated at best. However, things changed when Barry progressed to palliative care. For the first time, Jonathan felt that he was part of the team looking after Barry. Jonathan learned how to care for Barry, from watching the district nurses who came out to attend to Barry's needs. "I acquired certain skills purely by accident and often when district nurses and doctors were not immediately available to help. Basic caring/nursing skills generate confidence for both carer and their 'patient'". However there seemed a reluctance on behalf of the medical profession to offer support of good nursing practice as well as practical aspects to caring – the need for a yellow bin for soiled materials and for wearing rubber gloves – for example.

Jonathan believes carers need training which is appropriate for their needs at that time. He believes it should not be a tick box exercise but should empower carers to confidently care for their loved one. Ultimately this means carer and patient can be more independent, and enjoy a more fulfilling life.

Jonathan's advice to new carers is simple: Make sure you are claiming the benefits and respite care that you are entitled to. Contact your local Carers Support organisation, and they will be able to advise you. A directory of information for carers can be found at: www.carersuk.org.

Jonathan has been actively involved in raising awareness of carers from the LGBT community by working with Macmillan nationally on reference groups and task forces. He is also involved at a local level with the West Yorkshire and Harrogate Health and Care Partnership.

Meet the Forum Members: Yvonne Conner, Advice and Support Worker



As an experienced advice and support worker, Yvonne Conner was used to knowing where to go to seek help.

But following diagnosis and treatment for Stage 2 breast cancer in 2014, she felt she didn't have any contacts or places she could turn to.

Friends and family had been great, but she felt that unless someone had been through a cancer journey themselves, they couldn't really understand what she was going through.

She had worked for 15 years in the voluntary sector at the Mixenden Resource Centre, but could find nothing in her locality.

Breast Cancer Haven offered some respite, and she had five sessions at their Leeds centre, but she found combining travel with work and family commitments very difficult.

In the end she decided to form her own group, Breastfriends Halifax and Huddersfield, with some initial funding from Macmillan Cancer Support, and support from her own breast care nurse, Julie.

The group which attracts members from both Huddersfield and Calderdale meets every two weeks at Cartwheel Centre, Temperance Buildings, Huddersfield Road, Elland.

Macmillan funding has allowed Yvonne to run free taster sessions from January to May. Sessions so far have included a demonstration of chemical free skincare products and a visit from the Knitted Knockers charity – an alternative to uncomfortable prosthetics.

Each 'knitted knocker' is hand made, and free of charge from www.kkukciowix.com. The charity even supply aqua knockers, which allow ladies to swim in confidence.

For one of the new support group members, the discovery of this service catering especially for her needs, was absolutely overwhelming.

She told the group she had got so much out of coming along and listening and talking to other members, and finding a place where she could be open and honest.

The rest of the group's programme is below.

As a result of the success of Breast Friends, Yvonne has also set up GEMS – General Emotional and Mental Support which she hopes will offer support to men, women and children. With her background in advice and support she hopes GEMS will be able to offer a listening ear and signpost to other helpful therapies and services.

Little Gems is a service designed to help those who are battling illness and may need a helping hand. A bit of housework, weekly shopping or the dog walking, or maybe just someone to come and keep you company and provide a listening ear.

● For more information about Breastfriends or Gems contact Yvonne on 07957112557 or email gem.shine803@gmail.com

Breastfriends Halifax & Huddersfield

Free taster sessions for ladies who have or are experiencing life with cancer

Thursday 1 March 2018 7pm
Tai Chi

Wednesday 14 March 2018 7pm
Yoga

Wednesday 4 April 2018 7pm
Mindfulness

Thursday 3 May – 14 June 2018 7pm
Guided Meditation

For more information and to book your place contact Yvonne on 07957112557 or email gem.shine803@gmail.com

Meet Dawn Gulliford: Cancer Patient Service Manager



A can do attitude sums up Dawn Gulliford, Cancer Patient Service Manager at Airedale General Hospital, which is based on the edge of Keighley, catering for a population of 200,000 people much of it widespread covering West and North Yorkshire and East Lancashire.

As Hospital Trusts go, Airedale is quite small, which allows them the flexibility to be innovative in their care for patients. Dawn's role, which is slightly different to the larger teaching hospitals, means that she knows and regularly meets up with all of the Clinical Nurse Specialists (CNS) which aids communication and good practice.

Having recently experienced cancer services herself, in the role of a carer, she has seen first hand some of the practices which are not as patient centred as she would hope to find within her own hospital.

Dawn is always keen to learn more about how to improve patient experience, but isn't up for a tick box

approach to patient engagement. It has to be meaningful, and she is always willing to listen to new ideas.

Airedale was one of the first hospitals within West Yorkshire to commission Breast Cancer Now to carry out a 'Service Pledge'. This involves the charity and their patient ambassadors working with breast care nurses and breast cancer patients to look at what is good about the breast cancer service, and what could be improved. Together they draw up an action plan, which is agreed by all, and launched at a public event.

Dawn thinks there is scope to use the same model to work with rare and less common cancers where there is a need for greater awareness.

She is also keen to improve their reach into Black, Asian and Minority Ethnic communities where recent work she commissioned showed that Asian women were not attending screening, as they did not understand its importance.

Now working with community leaders, Dawn's plan is to organize gynaecology, breast and colorectal clinical nurse specialists to visit Asian women in their own community groups. They will talk about screening and why it is so important; and give the women the opportunity to ask questions in a setting where they are comfortable.

She also recognizes that some hospital policies – such as using a paid interpreter – are another barrier to good patient engagement. Her patient focus group told her, that within the Asian community, they would prefer to use their own translator as they are fearful about confidentiality. There is still stigma surrounding cancer and its treatment.

Make Money One Less Worry



The financial impact of cancer can affect people from any background, with any type of cancer. Macmillan's specialist finance team are available to people across the UK. Calls are free on 0808 808 00 00 Monday to Friday 9am–8pm.

They can help answer questions and provide guidance about:

- Benefits
- Insurance, taxes and banking
- Dealing with household costs
- Managing money, budgeting and planning ahead

Or visit www.macmillan.org.uk/moneyworries

If you pay Council Tax to Leeds City Council you can use their Macmillan Welfare Rights and Benefits service. Contact Tracy Parsons or Jane Tidd on 0113 3760452 or email welfarerights@leeds.gcsx.gov.uk

Together – facing cancer

Keighley and Airedale Cancer Support Group was born out of the friendship of two young women who met at Airedale Hospital, Keighley, while receiving treatment for breast cancer. Rachael and Adele were both diagnosed in 2011, and both had young families. They embarked on a journey of surgery, chemotherapy and radiotherapy together. During their life changing journey they found great comfort and support in each other. Along the way they met other people in similar situations who did not have the support that their new found friendship had provided. It became clear this type of support was not available in their area and so they decided to form a support group to help other cancer sufferers and their families.



“Cancer can be the loneliest journey” said Rachael, “I was lucky to have Adele to share my journey with. We cried together, were sick together, we moaned together, but most of all we could laugh together.

“We could laugh at ourselves too, which isn't always easy when you are feeling so ill. We also found that we could share experiences and feelings in a way that we wouldn't have done with our families or friends just because we both GOT IT!”

Adele returned to work two years after the group was formed. Rachael decided to continue offering this valuable service and now works alongside a dedicated team of people who have all been affected by cancer in some way. The group became a Cancer Support Centre gaining charitable status in 2016. Although being a charity creates more administration, Rachael feels it gives funders, clients and volunteers extra reassurance about the service.

Late last year they moved to larger premises at Aire Valley Business Centre in Keighley, in order to grow with the increasing demand, and now provide a large range of services for people affected by cancer in the local area, including their families and carers. The Centre offers a weekly drop in, and a range of therapies and services including hypnotherapy, reiki, reflexology, counselling and meditation. Therapists all attend the drop in, and short appointments can be made on the day. The new premises have two well equipped therapy rooms which are calm and restful places and an airy meeting room equipped with comfortable chairs and cosy throws.

All the spaces are a credit to the charity's team of hard working volunteers, who decorated and furnished the premises in time for Christmas celebrations. Funding for comfortable new furnishings and various therapeutic sessions came from Macmillan.

Rachael wants to be able to offer the people of Keighley and Airedale, the sort of services they would usually have to travel outside of the area, to access. It's clear that Rachael is passionate about KACS, and there is a whole team who are just as committed. There is a Board of Trustees, a fundraising committee as well as other hands on volunteers. “We involve people in everything we do,” said Rachael. “There is an openness and honesty about the place and I think that's why it works.”

● To find out more see their website www.keighleyairedalecancersupport.co.uk or call Rachael on 07940 291937

Making More Lung Cancers Curable

Lung Cancer is the most common cancer in West Yorkshire – and our biggest killer.

Yet because the incidence of lung cancer is directly related to smoking – limiting tobacco use is the most important way to prevent the cause of lung cancer.

In West Yorkshire and Harrogate Cancer Alliance area, it's estimated that tobacco addiction has caused over 2,300 cancers in 2010.

Smoking rates in West Yorkshire and Harrogate are 18.6%. The national average is 15.5%. It's estimated there are 350,982 smokers within the Alliance patch.

In late January, health and care services across Wakefield joined forces to tackle lung cancer.

Members of Wakefield's Health and Wellbeing Board agreed proposals put forward by Professor Sean Duffy, Clinical Lead for the West Yorkshire and Harrogate Cancer Alliance, for a wide-ranging programme of work to tackle lung cancer across the District.

There are four work programmes:

- 1. Support people to stop smoking**, including those already receiving treatment in the NHS for smoking-related illnesses, by using every patient contact to offer help to quit.

Earlier this month, Professor Duffy and Scott Crosby of Public Health England, also the Alliance's Tobacco Control Manager, were involved in the launch of the NHS Smokefree Pledge in Westminster.

The Alliance is backing the pledge, which asks NHS organisations to commit to help smokers in their care to quit and to creating smokefree environments that support them to do so.

- 2. Raise awareness of early signs and symptoms**; so people seek information and advice earlier than is often the case, making more cancers curable.
- 3. Develop a pilot 'lung health check' scheme** to invite those most at risk of cancer, for screening using low dose CT scanning in community venues, such as supermarket or community centre car parks.
- 4. Improve the experience for those affected by lung cancer** by ensuring care and treatment pathways are as speedy and efficient as possible.

For lung cancer the one year survival rates across the region are broadly as good as the England average (38%). The Alliance ambition is for all patients across the area to have the best possible outcomes, but at present some places have worse survival rates than others. Wakefield and Bradford have been highlighted as two key areas for the initial phase of the Alliance backed programme. They offer the greatest potential for change in patient health due to current higher levels of smoking.

The proposal creates a local health and care partnership between the local council, providers of NHS services (hospitals, mental health, GPs and community services) and commissioning organisations to be established in order to drive the four-pronged programme.

Regional funding of £12.4million has already been secured by the Cancer Alliance through the National Cancer Transformation Fund, which will support early diagnosis across West Yorkshire and Harrogate. The Curing Lung Cancer programme will be an integral part of that work.



Handy Hints Guide for Running Support Groups

We love our support groups

It's really clear from visiting groups and working alongside cancer patients, that you all value your support groups. Often it's when treatment has finished that you can feel isolated. This is where the peer support and information of a support group is so valuable. Many of you have made strong friendships and will describe these friendships as a real positive during your cancer journey. Many of the ideas for this Handy Hints Guide came from a day spent with members of Breast Cancer Support Groups from Yorkshire and Lincolnshire. This day was jointly organized by Lynda Duff Macmillan Engagement Lead, Zoe Bounds, chair of Breast Friends York and a member of the YCPF steering group, and Jill Long, Macmillan Engagement and Communications Officer, YCPF.

Thank you so much to everyone who participated for their generosity in sharing ideas.

● Organisation

Decide who is best placed to deal with inquiries from patients and families wishing to attend the group – the contact person must be available – and like dealing with people. A possible new member may be nervous or low in mood, and can easily be put off. If the contact person doesn't get back to them, or isn't friendly and approachable, it would take a resilient person to persevere. Perhaps the tasks can be shared with a small group, so all the work isn't left to one person. As organisers, take responsibility to ensure your group is warm and welcoming and not seen as cliquy.



The Hub Cancer Support Drop In Crossgates Leeds

● Referrals/publicity

How will patients and their carers hear about your group? You will need to liaise with healthcare professionals to publicise the group to new patients. Can you advertise your group within your local hospital or via your Macmillan Information Centre (if you have one)? Some groups publicise their meetings via their local Voluntary Action. You can also have your group information on the Macmillan website. If your group is part of a specific cancer charity – such as Myeloma UK or Prostate Cancer UK – they will advertise your group meetings on their website. Many groups use Facebook to advertise meetings and events. Breast cancer support groups often make heart-shaped cushions with their own personalized message to newly diagnosed patients, which are distributed to local hospitals. This can attract new members.

● Venue

Venues are incredibly important. Holding a meeting in a formal setting, may make your group feel starchy and reserved. Ideally you want a room where people feel comfortable. Go and check rooms and halls out with another person, and see what they think too. Some groups choose to meet on hospital premises because it's easy to get clinical staff to support the group, and patients know the venue well. However, it doesn't work for all groups, and some choose to be based elsewhere – somewhere with easier transport links and cheaper parking – and away from a clinical setting. A warm and cosy room can help participants to feel relaxed and comfortable enough to share their thoughts and feelings. It may not be the right sort of room for a fundraising event – so move locations for events. A community hall might suit a group who want an inclusive setting, where members may for example, share a meal together. A city based group may choose a local coffee shop for being sociable and central. It's also easy for a newcomer to visit.

• Welcome

A warm welcome is so important– it can make or break a new group member’s experience. Someone should stay near the door to welcome visitors. If possible, newcomers could be introduced to a couple of regular members, so they have someone to talk to, until they start to feel comfortable enough to join in.



York Haematology Group



Wakefield Urology Group

• Signing up

You might want your new group members to sign up to the group – be clear about why they are signing and what they will receive. Is this membership, and will they receive a newsletter? Is the group open to patients and/or family and carers – it’s best to be clear from the outset.

• Providing free refreshments

One group based in a coffee shop pay for all their visitors’ refreshments – so no one will feel excluded if they can’t afford a drink. Some groups have a Macmillan Support Grant which cover the cost of refreshments. Contact your local Macmillan Engagement Lead for details of this new grant. Some groups make a small charge and use this to help pay for room hire. Advertising if there is a small charge is helpful, so no one is put on the spot

• Fun

What keeps people going back is not only the emotional comfort and moral support, but also having some fun. Popular fun activities can include pampering, singing, walking, flower arranging, arts and crafts, mystery tours, going out for a meal, or even a holiday.

• Activities

- Some groups are relaxed places for conversation – with no planned activities
- Others have a programme of activities and speakers – but allow some time for informal chat.
- You need to work with your group to see what feels right for them
- A group could have small sub groups which take responsibility for events and fundraising

• Moving up a gear

- Many groups have decided to become a charitable incorporated organization. This helps the group to apply for grants, can increase their credibility and raises their profile. However, smaller groups could find it too bureaucratic. Information is available at www.gov.uk and local branches of Voluntary Action may be able to help.
- Some groups offer their members the opportunity to apply for small grants. They hold a funding pot and a small committee offers financial help to patients for transport costs, or wigs. Breast Cancer Nurses can also make referrals.
- A North Lincolnshire group runs a group for children whose parents or carers are affected by cancer. This has proved so popular they now run residential breaks through the school holidays.

It’s important that your group meets the needs of its members, so there is no ‘one size fits all’ and you can change things too. If you have any questions, please contact Lynda at lyduff@macmillan.org.uk or Jill at jill@yorkshirecancerpatientforum.co.uk