

**MACMILLAN CANCER
INFORMATION & SUPPORT SERVICE**

**ANNUAL REPORT
2019**



Report compiled by:

HELEN JONES & MANDY DAVIES

MACMILLAN CANCER INFORMATION CENTRE TEAM

**Covering Calderdale and Kirklees Region. Based from
within Calderdale Royal Hospital and Huddersfield Royal
Infirmary.**

Report to cover period from 2.1.2019 to 31.12.2019

FORWARD BY OUR LEAD CANCER NURSE

The Macmillan Cancer Information Service has established itself as a specialist service over the last 4 years. As Lead Cancer Nurse at Calderdale and Huddersfield NHS Foundation Trust I am immensely proud of what the service has achieved, none more so than in this last year.

The team has offered a listening ear and given expert advice and support with symptoms, work, cancer and finances to more individuals than ever before. In fact, the team offered direct support to nearly 3000 individuals over the last year.

In less than a year, Helen as the new manager of the Macmillan Information Service, has also re-written and delivered a brand new strategy for Health and Wellbeing, this is an integral part of Personalised Care Support. This is delivered by the wider multidisciplinary team and aims to empower patients and their relatives around their own health and wellbeing focussing on emotions, cancer symptoms, physical activity and diet.

Even with the increase in the number of contacts the team dealt with last year, it has been highlighted that this only accounts for around 35% of the Trust's newly diagnosed patients. This alone leaves a significant challenge for the years ahead. One which I believe the team is more than capable of.

One thing that has struck me over the last year is the passion and drive of our volunteers, patient panels and focus groups, which have all supported the co-design of our developing services. It is important that we continue to work alongside our patients to deliver a service that is truly based on their needs.

This report highlights the important work of the Macmillan Cancer Information Service. The work of the team and its impact cuts across all divisions in the trust as well as across primary and social care. It is key that we look to further opportunities both within the Trust and beyond for collaborative approaches to delivering these services in the future.

Christopher Button
Lead Cancer Nurse
Calderdale and Huddersfield NHS Foundation Trust

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EXECUTIVE SUMMARY

This report describes the activity, aims and impact of the Macmillan Cancer Information Service at Calderdale and Huddersfield NHS Trust, in the year 2019. The report highlights the objectives of the service in relation to the trust's delivery of personalised support for cancer patients, as well as Macmillan's strategic, national priorities and quality standards. The report explains the staff and volunteer structure, within the demographic context of Calderdale and Huddersfield; describes promotional and health and wellbeing events; as well as demonstrating the varied practical, emotional and financial support provided to patients, carers and health professionals during the year 2019. The report contains a detailed breakdown of data from 2019, looking at who exactly our service supported and at what stage of the cancer pathway. Patient and professional feedback is featured throughout the report, as well as patient stories. The report concludes with the development objectives of the service for 2020.

"A huge thank you for your listening, understanding, help and advice - you truly were a bright light in a dark room. Just having someone to untangle and put things in place is a huge relief."

Patient, 2019

INTRODUCTION

In 2019, the Macmillan Cancer Information Service provided high quality support for local people affected by cancer, as well as their families, friends and carers. The service began in 2012 and operates out of the Jayne Garforth Macmillan Unit at Calderdale Royal Infirmary and the Resource Room in Greenlea Oncology Unit at Huddersfield Royal Infirmary. The Macmillan Cancer Information Service is managed by two staff members and a team of dedicated volunteers.

The service aims to offer timely and accessible information as well as supporting anyone affected by cancer in terms of addressing their emotional, practical and financial needs. The service aims to support patients from diagnosis, through treatment and provide support to those living with and beyond cancer. As well as being a resource for patients, the service acts as an information and support resource for both hospital and community staff, aiming to complement the clinical team in their delivery of care. A key part of our work is in the delivery of national cancer strategy, in particular supporting Calderdale and Huddersfield NHS Foundation Trust's delivery of the personalised support agenda for cancer patients, identified in the NHS Long Term Plan.

In January 2019 a new manager joined the service, Helen Jones, who had previously managed a Macmillan Information Service in the North West and also worked as a Project Manager for West Yorkshire and Harrogate Cancer Alliance. Mandy Davies, the Assistant Manager, had successfully managed the service single handedly for the previous eight months. 2019 also involved a recruitment drive for new Macmillan Volunteers, with several new volunteers joining the information service team, Headstrong team and newly developed role of patient reps/befrienders.

In 2019, the service showed a huge increase in demand and uptake of patients and family members accessing support. Figures show a significant increase of 48% of contacts between 2018 and 2019 (with 1900 contacts in 2018 and 2820 contacts in 2019). Overall figures show a slight shift in age brackets in 2019, with the service supporting younger people in 2020, with the most common age group accessing the service being 45 – 54 year olds. The team worked hard to promote the service and raise it's profile within the trust and the community in 2019, which resulted in more people accessing the service. Part of our work has been to demonstrate the need for an additional staff member within the service and at the time of writing, a new staff member is currently being recruited to the Macmillan Information Service team on a twelve month secondment. We have also established a new Macmillan information pod in the entrance to HRI, to further promote our service and provide accessible cancer information to staff, patients, family members and visitors.

The service also led on a review of the Health and Wellbeing provision for cancer patients, which is a key part of national cancer strategy, and was instrumental in setting up a new Health and Wellbeing Programme, across the Trust in 2019. This involved the

formation of a new Cancer Patient Focus Group to enable patients to express their views and co-design the Health and Wellbeing programme. Consequently new programmes were set up for people when they were initially diagnosed with cancer (First Steps), as well as for people living with incurable cancer (Thinking Ahead). The Health and Wellbeing Events run for people at the end of treatment were also changed and extended, with the addition of new speakers and a clinical session led by the CNSs. Our Macmillan Volunteers were also instrumental in setting up and delivering three new support groups to support people's health and wellbeing, including a Macmillan Health Walk, Singing Group and generic coffee support group.

The aim of this annual report is to detail the varied support provided to people affected by cancer, by the Macmillan Cancer Information Service in 2019, as well as demonstrating the impact of the service. The report will give a description of the service in 2019 and will detail the emotional, practical and financial support given to people affected by cancer, as well as their families/carers/friends supporting them. The report will include activities, events, signposting and onward referrals and will use a mixture of quantitative and qualitative data, as well as service user and professional feedback. The report will include information on volunteer involvement and the crucial role played by the dedicated volunteer team in the running of the service.

This annual report will attempt to show how the service has offered personalised support and contributed towards improved outcomes and patient experience, for people affected by cancer and has worked in line with Calderdale and Huddersfield NHS Foundation Trust, Calderdale, Greater Huddersfield and North Kirklees CCGs and national NHS priorities.

“Thank you so much for being there and all you do. You have supported me from the start and right through my cancer journey, offering such kindness and diverse help. I appreciate your hard work and I really feel your genuine desire to help and care.”

Patient 2019

OUR 2019 KEY STATISTICS

2818

DIRECT CONTACTS
A HUGE INCREASE OF 48%
ON 2018'S FIGURES

35%

**OF ALL NEWLY
DIAGNOSED PATIENTS
IN CHFT, SUPPORTED
BY THE SERVICE**

£1,145,497.85

**IN ESTIMATED
BENEFIT GAINS
FOR LOCAL PEOPLE
FROM OUR REFERRALS**

321

**ATTENDANCES AT
OUR HEALTH AND
WELLBEING PROGRAMME**

143

**ATTENDANCES AT
OUR SUPPORT GROUPS**

714

**REFERRALS MADE
TO OTHER SERVICES**

£54,984

**IN MACMILLAN GRANTS
AWARDED TO OUR PATIENTS**

**AN INCREASE OF
£34,117.75 ON 2018**

100%

**OF PATIENTS AND CARERS
SAID THEY WOULD RECOMMEND
THE SERVICE**

7403

**BOOKLETS TAKEN FROM
OUR CENTRES & HOSPITAL
INFORMATION PODS**

SERVICE OUTCOME OBJECTIVES

Overall Service Aim

The service aims to provide high quality, personalised information and support for anyone affected by cancer, as well as carers and family members, at each stage of the patient's pathway. Tailored support includes providing practical, emotional and financial support, as well as signposting and onward referrals, within a non clinical, calm and relaxed environment. The aim of the Macmillan Information and Support Service is to complement the clinical support offered by the trust and to meet the diverse and holistic information and support needs of patients and their carers, to ensure they have the best possible patient experience. The service also aims to be a resource and support for Health and Social Care Professionals within both the trust and in the community.

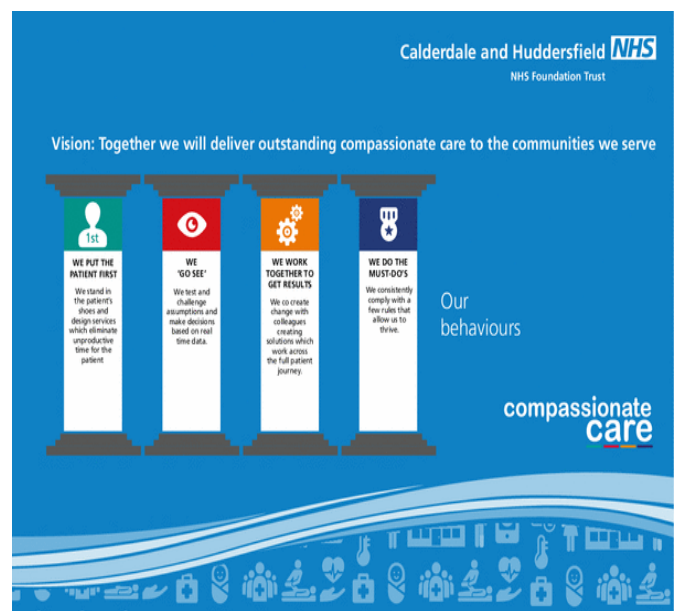
Our service aims and outcome objectives are in line with those of Calderdale and Huddersfield NHS Trust and Macmillan Cancer Support.

CALDERDALE & HUDDERSFIELD NHS TRUST OBJECTIVES

Our service supports Calderdale and Huddersfield NHS Foundation Trust's vision for delivering outstanding compassionate care to the communities we serve, by embracing the four pillars of Trust Values, as well as the NHS National Outcome Framework .The four pillars are:

Pillar One – We Put the Patient first

- Meeting the diverse information and support needs of people affected by cancer, as well as their carers and family member is an absolute priority for our service. We aim to provide a flexible and adaptable service, to tailor and personalise our support in order to give patients the best possible care. We provide information in all appropriate formats for patients, family members and Healthcare Professionals at each stage of the patient's pathway, as well as information points available for public use, to raise cancer awareness.
- We have recruited a Cancer Patient Focus Group to listen and respond to the patient voice and for patients to be at the heart of driving service improvements, both in the



Macmillan Information and Support Service and at a wider level within the Trust.

- We aim to enhance the quality of life for people living with and beyond cancer by helping patients to access emotional, practical and financial advice in a supportive and sensitive environment. Our Health and Wellbeing Events also serve to inform and signpost people to local support, as well as promoting recovery and self-management for people living with cancer.
- We aim to help people recover from episodes of ill health by providing accurate, personalised, timely and accessible information about treatment and care options, as well as referring patients on to other organisations for further support.
- We provide a listening ear and emotional support, giving patients the opportunity to speak to someone outside the patients family and clinical team, if needed.
- We aim to be service user led and encourage regular feedback and suggestions from patients to further improve and develop our service.
- We actively recruit volunteers, many of whom have been patients or carers themselves, allowing them the opportunity to 'give something back' for other patients.
- User and volunteer involvement serves to add to positivity of experience for people accessing the service by influencing improvements.
- We work closely with CNSs to offer personalised support in terms of the delivery of Holistic Needs Assessments and implementing Care Plans for individuals.

Pillar Two – We “go see”

- We are keen to work closely with and learn from, partners and organisations in other areas such as the network of Yorkshire and Humber Macmillan Information and Support Centre Managers, West Yorkshire and Harrogate Cancer Alliance, Mid Yorkshire and Harrogate Macmillan Information and Support Centres and other local hospital trusts.
- Our aim is to constantly evaluate and review our service and learn from good practice in other areas, as well as introducing successful initiatives from other areas. An example of this in 2019, was the introduction of the Thinking Ahead Programme which was successfully introduced in Harrogate Hospital in 2018. Establishing Thinking Ahead in our Trust, involved close liaison with CHFT and Harrogate teams, and visits to observe the programme and discuss with their patients, before implementing it here.
- Similarly, once we had developed 'First Steps', our on diagnosis Health and Wellbeing support session, information was shared with Harrogate and the Cancer Alliance, to benefit patients in other areas.

Pillar Three – We work together to get results

- Our service works closely with cancer teams and different professionals within the Trust, particularly with Clinical Nurse Specialists, chemotherapy nurses and Cancer Care Co-ordinators and consultants and we aim to be a support to clinical teams as well as working together to support our patients. Regular onward referrals and signposting e.g. to onco-psychology are essential, as well as

working with multidisciplinary teams on the wards within the hospitals, to provide information and support for patients.

- We also work alongside and in partnership with other organisations in the community such as GPs, benefit advisors, community nursing teams, local councils, social services, carers organisation and community groups.
- We work in partnership with key local organisations to provide a positive experience for the patient and family members.
- In 2019 we have worked together with our Trust's Lead Cancer Nurse and Macmillan Prehabilitation Project Manager to establish 'First Steps' – our new on diagnosis information and support session for patients and family members who are recently diagnosed with cancer.
- We work together with local support groups, collating their information and distributing this via our Macmillan Information Service newsletter, to an ever growing email contact list of patients and other organisations, in order to make people more aware of the diverse support available locally.

Pillar 4 – We do the must-dos

- We support the delivery of national cancer strategy including the NHS long term plan which aims to deliver personalised, tailored care and support for cancer patients. This includes having meaningful conversations where holistic needs are assessed and built into a personalised care plan – considering what is important *to* the patient as well as *for* the patient - as well offering health and wellbeing support, by 2021.
- We work hard to meet the quality standards, MQuISS, specified by Macmillan for the national delivery of Macmillan Information and Support Centres.
- We promote the availability of the service for all people affected by cancer in the locality, via joint working, patient information packs on diagnosis (which includes information about the service), First Steps sessions, outreach events and networking with organisations.
- We aim to increase the awareness of the symptoms and signs of cancer among Calderdale and Huddersfield residents, by providing information points across the hospitals and posters/leaflets in GP surgeries, as well as attending outreach events, to support the earlier diagnosis of cancer and to prevent people from dying prematurely.
- We aim to treat all of our patients with respect and dignity, and to provide a safe, confidential and pleasant environment in which to meet them.

Supporting Macmillan's National Strategy

As well as the Trust's values, our service supports the delivery of Macmillan's 'Right By You' strategy which provides personalised support to cancer patients and their families:

MACMILLAN'S 'RIGHT BY YOU' STRATEGY

According to Macmillan, right now there are 2.5 million people living with cancer in the UK and this is set to grow to almost 4 million by 2030. Cancer Research UK reports that around 990 people are diagnosed with cancer every day in the UK

https://www.cancerresearchuk.org/sites/default/files/state_of_the_nation_april_2019.pdf

and the Office of National Statistics reports that there were 305,683 new cancer diagnoses in England alone in 2017 (most recent figures available)

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2017>.

The reality is that cancer can affect anyone. Every two minutes someone in the UK is diagnosed with cancer and while it is not always life threatening, it is life changing. Regardless of the diagnosis, life will never be the same again.

Macmillan understands how cancer can affect every aspect of a person's life - so much more than their health - and believes everyone must have the support that's right for them – which is not currently the case. Every day thousands of people are helped by Macmillan, with the physical, financial and emotional impact of cancer on their lives. But millions more will need this support.



Macmillan wants to help everyone with cancer live life as fully as they can. Their five-year strategy sets out how Macmillan will focus their work on six key objectives and what can be done to be right there with people, whatever cancer throws their way. The objectives are:

Objective 1: Everyone with cancer will know that they can turn to Macmillan and how we can help from the moment they are diagnosed.

Objective 2: Everyone with cancer will have a conversation about all their needs and concerns, and get the support that's right for them.

Objective 3: Everyone with cancer will have their vital needs met by high quality services.

Objective 4: Everyone with cancer that is treatable but not curable will be supported to live life as fully as they can.

Objective 5: We'll inspire more people to give to Macmillan so we can continue to be there for people when they need us most.

Objective 6: We'll improve the key activities which support Macmillan to do its work as efficiently and effectively as possible

Our delivery of these objectives is essential to the high quality information and support provided to cancer patients and their families, by our Macmillan Cancer Information Service. The remainder of this report will demonstrate how these objectives are embedded into our work.

ORGANISATIONAL PROFILE

Calderdale and Huddersfield NHS Trust provide care to a population of over 460,000 people and in 2019 the Trust had 3433 patients with a new or secondary cancer diagnosis (41 patients fewer than in 2018). Of these, 3088 were patients with a new primary cancer diagnosis and 345 had a recurrence or secondary diagnosis.

The Macmillan Cancer Information Service at Calderdale and Huddersfield NHS Trust runs between two hospitals and is based within the Macmillan Unit at Calderdale Royal Hospital and on the Greenlea Oncology Unit at Huddersfield Royal Infirmary. The service provides information and support to the local population, as well as to health and social care professionals. As well as the two Macmillan Cancer Information Centres, there are 7 information pods around the two hospitals, and a new large Macmillan Information pod in the entrance to HRI (with a seating area) which is manned by our Macmillan Information Service volunteers at certain points in the week.

OUR STAFF

The service has two full time members of staff – Helen Jones, the Centre Manager being based at HRI and Mandy Davies, Assistance Centre Manager being based at CRH. The Assistant Manager post was funded by Macmillan for 2 years from October 2017, until Autumn 2019, to enable the recruitment and retainment of volunteers to the service. In 2019, this Macmillan funding was extended for a further year until September 2020. Due to the increased demand for the service, we worked with our Trust to secure funding for a third member of staff. Funding has now been obtained through the West Yorkshire and Harrogate Cancer Alliance and a Macmillan Information Support Worker will join the team in 2020, on a twelve month secondment.



Helen Jones
Macmillan Information
Service Manager



Mandy Davies
Assistant Macmillan
Information Service
Manager

Staff roles include a large proportion of direct patient contact face to face and on the phone; patient related admin and onward referrals; strategic planning and development; co-ordination of the Trust's Health and Wellbeing Programme for cancer patients and their families; attendance at meetings and forums, internally and externally; liaison with health and social care professionals both within the hospital and community; managing a Cancer Patient Focus Group to enable the patient voice to influence improvements; evaluation and service development; managing support groups; cancer promotion and awareness raising, by displays and attendance at various events; as well as the recruitment, management, support and training of the volunteer team. The staff have a key role in working alongside clinical colleagues both internally and externally, and to be an information and support resource for patients and staff.

“Contacting the Macmillan Information Service made me feel better, just knowing that people are there to help. The team do a wonderful job - they are understanding and supportive and their help was very informative and useful.”
Patient 2019

OUR VOLUNTEERS

In 2018, the service was supported by an invaluable team of eight volunteers, however by the end of 2019 we had recruited additional volunteers and had 14 people who volunteered either as information service volunteers or patient reps. A few of our volunteers unfortunately had episodes of ill health and needed to take some breaks from



volunteering during the year. Several of our volunteers have had cancer in the past or supported someone through it, as well as one being a retired health professional and others being involved in the wider work of Macmillan, including fundraising.

The Macmillan information and support service could not run without the fantastic support of its dedicated volunteer team and we are truly grateful for the support they provided in 2019. Our team of volunteers provided a total of 1621 hours of donated volunteer time to the service in 2019, saving the trust/Macmillan a huge £13,357.67 (worked out on the basis of £8.21 per hour, minimum wage). The volunteers attend regular meetings and training days and have informal supervision from the staff while they volunteer.

Our volunteers are an essential part of our service and have key roles in supporting patients and family members in face to face meetings and over the phone. The volunteers have faithfully carried out many varied tasks over the year of 2019 such as meeting and greeting people in the information centres and dealing with patient enquiries; answering the phone; contacting patients to ask for feedback about the service and whether they have further support needs; representing the service at various outreach and promotional events; supervising coffee mornings; managing, re-ordering and re-stocking the information centre and hospital pod stock/information leaflets; inputting core data; and other admin tasks. Importantly, the volunteers have covered the new Macmillan Information pod at the entrance of HRI over parts of the week, answering queries and talking to the public about cancer and cancer awareness.

In May 2019 one of our volunteers, Jeff Goodman, who has volunteered with our service for the last four years, won a very prestigious national Macmillan volunteer award – 'The Douglas Macmillan Award' which he won for the North of England. This was for Jeff's dedication both to raising vital funds for Macmillan and being part of the local fundraising team, and also his commitment to providing patient and family support as part of the Macmillan Information Service. Jeff regularly volunteers for 15 hours or more per week on the Greenlea Unit at HRI and was estimated to have given around 750 hours of his own time to the information service in 2019 - not including his hours spent rattling Macmillan buckets outside supermarkets and football grounds across the region in his spare time. Jeff, a very modest man, 'did not want any fuss' about his award, so agreed to a low key cake and drink celebration, as pictured left. Stacey Rhodes, Macmillan Fundraising Manager who nominated Jeff had this to say about him:



“Jeff has volunteered with Macmillan since 2002, and I nominated him due to his ongoing support, commitment, ideas and proactivity. Jeff gives a lot of time, and volunteers for many organisations. His knowledge is vast, he goes above and beyond, by providing emotional support to those who may have received life-changing information at the Centres and on hospital wards. Jeff loves to volunteer on the MISS bus, travelling to destinations across West Yorkshire to offer support – taking public transport, as he doesn’t drive, but this never stops him.



Jeff pictured above with Helen and Mandy and left with Stacey Rhodes, Macmillan Regional Fundraising Manager who nominated him for the award.



Jeff participates in the largest local fundraising event, Holmfirth Artweek, contributing many hours during the event and he has recently been recruited to sit on the North West Volunteer Forum.

His strengths lie in networking and bringing people together for the wider cause through his contacts. Rain or shine Jeff is always ready to put in the hours needed, he is a pleasure to work alongside and is well-known across

West and South Yorkshire by everyone in fundraising and services. He’s a modest man who doesn’t really enjoy being in the limelight but for one time only, he well and truly deserves to be recognised for his contribution.”

In the year 2019, our volunteers had the key role of taking part in and running our support groups. Three volunteers trained as walk leaders with Kirklees council and were then able to run ‘Macmillan Health Walks’ at Greenhead Park, in collaboration with Kirklees Council and the Ramblers association.

Shaz, one of the walk leaders said:

“I’m extremely grateful to have been put forward to train to be a walk leader for a new initiative ‘Macmillan Health Walks.’ The group has continued to grow over the past few months. I love being involved and to be able to give a little back means so very much to me. I’m hoping to help support more patients in Calderdale too, in 2020. To be told by the patients that it ‘gives them a purpose to get out’ and that ‘they are inspired by what we are offering’ and that ‘their expectations had been exceeded’ is truly mind blowing.”



**Margaret, Tricia and Shaz,
Macmillan Volunteers and Walk Leaders**

In 2019 we also developed a new role of patient reps and befrienders, which arose both out of the recommendations of the Cancer Patient Focus Group, and also from one of our consultants, Dr Hoffman, who talked to a patient about offering peer support to other patients. In 2019 we recruited three patient reps and a carer rep, who have been involved in sharing their stories at First Steps and other health and wellbeing events, giving support over the phone or in person, taking part in support groups and leading parts of the Cancer Patient Focus Group sessions – including offering a chance for patients and carers to speak freely to our patient reps without staff being present.

We asked the volunteer team about why they had volunteered in 2019 and what had been the benefits to them. Their responses included:

“I feel proud and privileged to volunteer with the Macmillan information service and also of being part of the wider organisation of Macmillan.”

“I have enjoyed supporting patients and carers who enjoy being part of the Macmillan community. Starting the Macmillan Health Walk has been great and seeing the benefit of this to patients and carers has been the most enjoyable part of my volunteering.”

“The best part of volunteering is being able to help people, though it’s always hard meeting friends or people you know who have been diagnosed with cancer.”

“I have found the volunteer meetings useful as well as support from other Macmillan volunteers and staff. When I have found myself in this position of living with cancer, I have found comfort here in being part of group with a

common theme/ focus. It is like supporting and following a football team in many ways - you have allegiance. "

"The most enjoyable part of volunteering is working with the Macmillan and NHS teams - even though I am happy to have left British Gas after many years... my volunteering does remind me of some of the better aspects of the many roles I previously carried out."

"I may be an unusual case in that my engagement with Macmillan was initially from a volunteering perspective, however my Mum suffers with myeloma. As a result of my interaction from the volunteering perspective, my Mum has also engaged with Macmillan, she has found the service unbelievably efficient and was pleasantly surprised by the availability of help on offer."

OUR HEADSTRONG VOLUNTEERS



As well as a team of Macmillan Information Centre volunteers, the service also manages a team of 10 Headstrong Volunteers, who provide a dedicated hair loss service in the trust.

The Headstrong Hair Loss Service was a national initiative run by Breast Cancer Care which started 16 years ago. Sadly Breast Cancer Care concentrated their services and dropped Headstrong at a national level three years ago. However, our dedicated team of Headstrong volunteers in Calderdale and Huddersfield decided that the service was too invaluable for patients to lose and that they offered to continue to run the service themselves. The Trust then adopted the volunteer team under the umbrella of Macmillan and the service was therefore relaunched in 2016. Headstrong has continued to grow and expand, to run in both hospital sites and with appointments being booked directly from clinic onto the computer system.

Two Headstrong volunteers are available during every session and these run weekly except during Christmas week – alternating between HRI (every other Wednesday) and CRH (every other Friday). An hour is allocated for each appointment with the volunteers giving information on scalp care, different forms of headwear and offering reassuring help and advice about what to anticipate during hair loss due to cancer treatments. Patients are given the opportunity to try on a selection of scarves, headwear and fringes in a relaxed and informal setting, and to purchase these at cost price. The trained volunteers order and manage the Headstrong stock, and the stock has been funded by the Breast Care nurses for the last 3 years.



The volunteers previously had formal training by Cancer Hair Care a charity based in London, which ensures the volunteers are up to date with their training and knowledge and are able to provide the best service to patients. Further volunteer training is planned for 2020.

Chris, would heads up and organises the Headstrong team, including organising rotas, ordering stock, sorting finance and supporting other volunteers, had this to say about her volunteering:

“The most enjoyable bit of Headstrong is always the patients, we’ve had many a laugh and cry with them. They also teach us new things e.g. scarf tying and skin cleansing etc. The least enjoyable part is having to talk over a particularly hard morning session with the volunteers, so they can off load the emotions that have occurred. I would recommend volunteering with this amazing service to family and friends. Volunteering is the best thing I’ve ever done both with Headstrong and working with the Breast Team.”

The Figures

| | Number of appointments available | Number of booked appointments | Number of clients attended | Volunteer Time Donated | Monetary Value (based on national minimum wage 2019) |
|------------|---|--------------------------------------|-----------------------------------|-------------------------------|--|
| CRH | 69 | 60 | 35 | 600 hours | £4,926 |
| HRI | 66 | 54 | 39 | 540 hours | £4,428 |

Here is some of the amazing feedback the Headstrong Service received in 2019:

“Staff volunteers were friendly & made it clear I could come back at any time to look again and reconsider options which was good.”

“I learn a great deal about how I can look so much better and be confident when go out. The two ladies were brilliant I am more confident about going out now if I lose my hair.”

“The ladies have made me feel good about myself - I am so grateful to them”



“Confidence, inspirational information, great ideas, demonstrated well, good fun, thank you.”

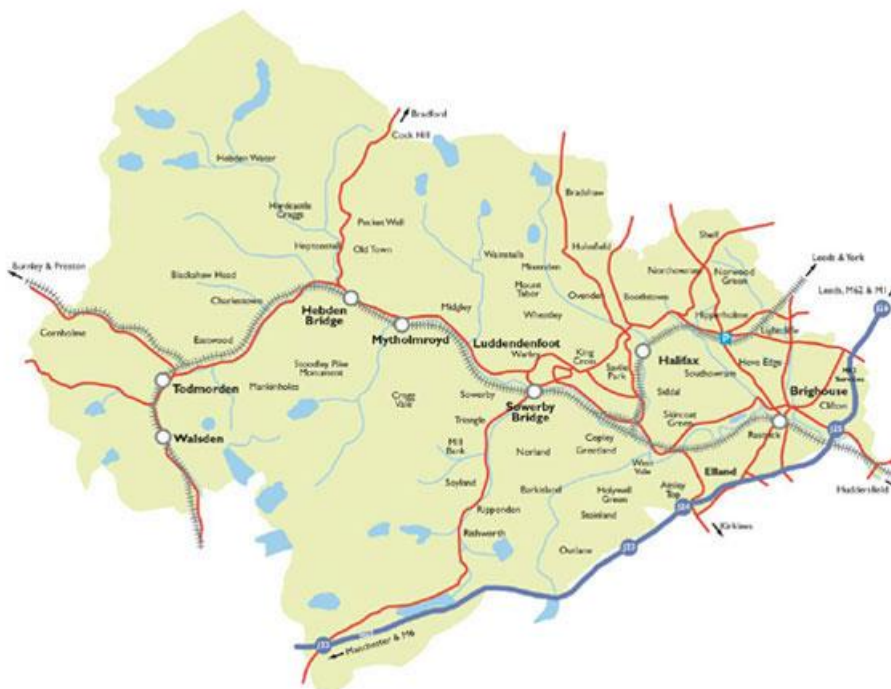
“Lots more confidence in going out into the world - especially with the fringe!!”

DEMOGRAPHIC PROFILE OF THE POPULATION WE SERVE

The Cancer Information Service serves the population of both Calderdale and a large part of Kirklees.

CALDERDALE

Calderdale comprises of the main towns of Brighouse, Elland, Halifax, Hebden Bridge, Sowerby Bridge and Todmorden. Calderdale is one of the smallest districts in England in terms of population, but one of the largest in terms of area as it covers 140 miles. The district is served by NHS Calderdale Clinical Commissioning Group. In June 2019 the Office for National Statistics ONS published its 2018 mid-year population estimates, which indicated that there are 209,500 210,100 people living in Calderdale which is an increase of approximately 6,200 people since the 2011 Census.



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The largest ethnic group in Calderdale is White British (89.7%), as recorded in June 2019. The second largest ethnic group is Asian /Asian British (8.3%) of which the majority (6.8%) are Pakistani.

Source - <https://www.calderdale.gov.uk/v2/residents/health-and-social-care/joint-strategic-needs-assessment/calderdale-demographic-information>

For both males and females in Calderdale, cancer is the biggest contributor to life expectancy, followed by respiratory conditions and circulatory conditions. Over 1,100 cases of cancer are diagnosed each year in Calderdale residents and around 550 residents die each year from cancer. Over half of all cancers could be prevented by changes to lifestyle (e.g. diet, alcohol intake, obesity). Smoking is the single largest preventable risk factor for cancer in Calderdale.

Source - <https://www.calderdale.gov.uk/v2/residents/health-and-social-care/joint-strategic-needs-assessment/health/life-expectancy#expandable-6>

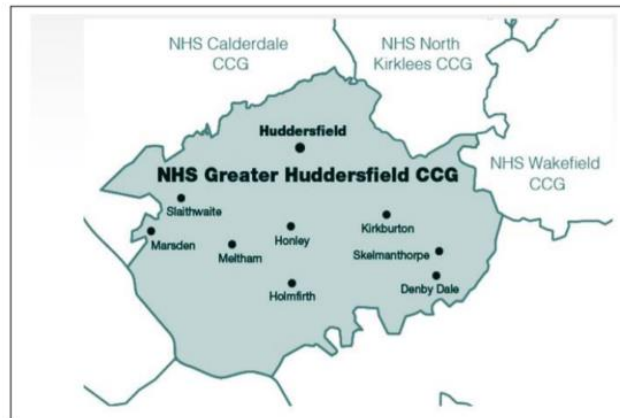
KIRKLEES

Measured in population terms, Kirklees is one of the larger local authority districts in England and Wales, ranking eleventh out of 348 districts and covering 157 square miles. The overall population of Kirklees rose to 438,727 in 2018 (source <https://www.kirklees.gov.uk/beta/information-and-data/pdf/kirklees-factsheets.pdf>). The district contains both high and low areas of deprivation with regions of highest deprivation found in some of the more densely populated areas (Huddersfield, Dewsbury and Batley).



Source - <http://isleworth.blogspot.co.uk/2016/01/districts-of-west-yorkshire.html>

The metropolitan district of Kirklees is served by two Clinical Commissioning Groups – NHS North Kirlees CCG and NHS Greater Huddersfield CCG. Our Calderdale and Huddersfield Trust Macmillan Information and Support Centre serves populations covered by the Greater Huddersfield CCG, which has a population of 247,000 people, approximately 58% of the Kirklees Council area, plus a small representation from North Kirklees CCG. The rest of the North Kirklees CCG area is served by the Macmillan Cancer Information Service at Mid Yorkshire NHS Trust.



Kirklees is an ethnically diverse population, as illustrated in the table below.

| Ethnicity | Count | % |
|---------------|---------|-------|
| White British | 323,890 | 76.7% |
| White other | 10,380 | 2.5% |
| Pakistani | 41,802 | 9.9% |
| Indian | 20,797 | 4.9% |
| Black | 7,905 | 1.9% |
| Mixed | 9,790 | 2.3% |
| Other | 7,894 | 1.9% |

According to the 2011 census, 91.7% of the Kirklees population have English as their first language. Other languages in this area are as follows:

| Main language | Count | % |
|---------------|--------|-------|
| English | 370572 | 91.4% |
| Panjabi | 9706 | 2.4% |
| Urdu | 6685 | 1.6% |
| Gujarati | 5897 | 1.5% |
| Polish | 2912 | 0.7% |
| Other | 9,580 | 2.4% |

Source - <http://observatory.kirklees.gov.uk/jsna/population>

The Cancer Information Service can provide information in other languages and signpost to interpreters via the Macmillan Support Line as well as access 'The Big Word' interpreters via the trust.

Cancer remains the most common cause of death in under 75s in the Greater Huddersfield area and more people die from lung cancer than from any other type of cancer. Rates of new breast, prostate and bowel cancer diagnoses are higher in our area than in the Kirklees average.

Source: <https://www.greaterhuddersfieldccg.nhs.uk/local-health/>

EQUALITY & DIVERSITY ASSESSMENT OF THE SERVICE

Information displayed in the centres is predominantly English, however at each site there is provision for service users who require information in different formats such as alternative languages, Easy Read information for people with learning disabilities, Braille, Audio and children's books.

The service has access to an interpreting service for both sites via the Trust and information can be translated into many languages via this service.

Patients and family members are also signposted to the Macmillan Support line where they can speak to an interpreter in their native language, about their cancer diagnosis and treatment. A translation service is also available for public use on NHS Choices website and printing facilities are available. A hearing loop is available for service users with a hearing impairment. A computer is



available for patients to access and use within the service to enable them to browse and print off any information they require.

The centre staff have continued to be active members of the Kirklees BAME Forum in 2019, within the local community and the service attends Outreach Events within the local 'hard to reach' communities, including health and wellbeing and end of life type events at mosques and a Sikh temple.



"I think your service is invaluable to people with cancer and their families, the holistic care and support you provide is essential to their wellbeing."

Family Member 2019

WHAT SUPPORT DID WE PROVIDE IN 2019?

DELIVERING THE PERSONALISED SUPPORT AGENDA

The Macmillan Cancer Information service is key to the trust's delivery of NHS England's personalised support agenda, detailed in the NHS Long Term Plan, which was launched in January 2019. Section 3.64 of the NHS Long Term Plan states that where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. The plan also specifies that this support needs to be in place by 2021.

NHS
Long Term Plan

[#NHSLongTermPlan](#)

Personalised, tailored conversations, providing holistic support to patients and family members, is an essential part of the delivery of care within the MCISS. All of the volunteer and staff team provide flexible support as highlighted by the patient –

listening to and responding to their unique concerns and needs. This involves working out what matters *to* people as well as *for* them. The whole team believe it to be a privilege to have time to listen and support people from diagnosis, throughout the pathway.

“The Macmillan team are and have been fantastic whenever I’ve visited. They are very friendly, supportive and no matter what you are going through they make you feel special and will offer lots of positivity to keep you feeling that way. Many thanks for all you do.”
Patient 2019

As well as the personalised conversations we have during drop in sessions, we also have a key role to play in implementing the patient Care and Support Plans after the CNS teams have carried out a Holistic Needs Assessment. The HNA identifies very varied and individual needs of a patient at different points in the journey, but particularly on diagnosis and at the end of treatment. The clinical teams throughout the trust can therefore refer to our service to support the recommendations of the Care and Support Plan e.g. in accessing financial/benefits help, work or emotional support etc. As a Trust more HNAs are now being done electronically, which formalises the holistic conversation and Care Plan, providing a useful record for the patient and their GP.



Contains 25 Concerns Checklists
and 25 Care and Support Plans

“The Macmillan cancer information team is like an extension of our specialist team. They have helped us this last year set up a support group for our patients, Mandy was instrumental in this. We know we have a place to refer patients for practical advice and who have time to source this information for our patients. Cancer isn't just about treatment or psychological support - it can be the practical issues such as how to pay bills when you can't work - and the team can provide this and much more. It is very much a two way street, we can refer to them and they can refer back to us. ”
Wendy Markey, Upper GI CNS

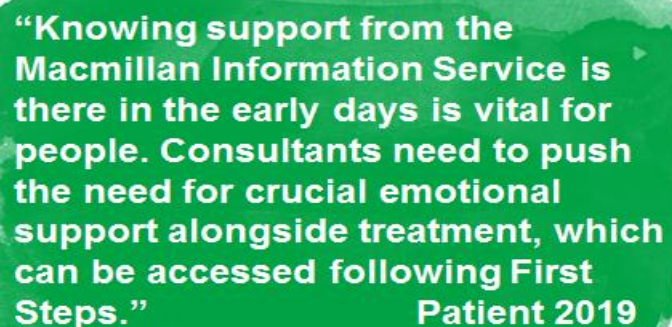
DEVELOPING A NEW HEALTH & WELLBEING PROGRAMME

As well as holistic and personalised conversations with patients and carers, and co-ordination with many teams to deliver the support identified in care plans, the Macmillan Information Service had the important role of reviewing the Health and Wellbeing (HWB) offer across the Trust in 2019. This involved Helen Jones meeting all of the clinical teams with Christopher Button, Lead Cancer Nurse, to see what Health and Wellbeing provision was being offered to patients, and then meeting with other staff including the prehabilitation project manager, Nicky Hill and the service's Mandy Davies, to take the recommendations forward. Plans were discussed at the Cancer Patient Focus Group (CPFG), to crucially ask patients about how the HWB programme should run, and patient recommendations guided the delivery of the programme.

The HWB review indicated an inequitable offer of HWB support for cancer patients in different tumour groups across the trust – some had funded their own programmes at the end of treatment; some referred into the generic HWB Events; some had support groups and others did not. The CPFG told us that the end of treatment Health and Wellbeing Events were useful, empowering and informative, but that they wanted this information much earlier – at the start of their cancer journey, and via face to face discussion rather than being given many leaflets. The CPFG also told us that there needed to be a different and specific HWB provision for people who had incurable cancer as their needs were very different to those under treatment for a curable cancer. They also highlighted the need for a specific support group, as well as patient education, for people living with incurable cancer.

As a result of the HWB review and patient feedback, we developed a HWB programme with three branches:

- First Steps – a new on-diagnosis information and support session for patients and family members
- End of Treatment Health and Wellbeing Event – to help people move forward when treatment had ended
- Thinking Ahead Programme – a new course specifically for people living with incurable cancer



“Knowing support from the Macmillan Information Service is there in the early days is vital for people. Consultants need to push the need for crucial emotional support alongside treatment, which can be accessed following First Steps.”
Patient 2019

HEALTH & WELLBEING SUPPORT FOR CANCER PATIENTS & THEIR FAMILIES IN CHFT

1. FIRST STEPS CANCER PROGRAMME

First Steps was devised as a collaborative venture with the Macmillan Information service, Lead Cancer Nurse and Macmillan Prehabilitation Manager, as well as having input for sessions from our trust’s psychologist and cancer dietician. First Steps was launched in October 2019 and constitutes a monthly information and support session, running for 3 hours at Huddersfield Royal Infirmary, usually on the first Friday of the month. Clinical teams are encouraged to invite anybody recently diagnosed with cancer, as well as a family member/friend.



Cancer Team at the launch of First Steps, October 2019



side effects of treatment and reduce the risk of recurrence; diet; sleep; smoking cessation and managing the emotional impact of cancer.

The main purpose of First Steps is to support patient self-management – to introduce people to the staff they are likely to meet, to introduce treatments and services that can support them during and after their cancer journey, but also, importantly, to educate patients on how they can support themselves. This includes sessions on the importance of keeping physically active to manage the

First Steps starts with one of our patient reps sharing the story of their own cancer journey and experience, which many people find extremely reassuring. Patients are introduced to Holistic Needs assessments and the six personalised support questions – ‘What Matters to you?’ which is then uploaded onto their NHS records for all staff involved in a patient’s care, to see. The staff and Macmillan volunteers are on hand to

answer queries arising from the session and to make onward referrals eg. for benefit advice.

In the three months we ran First Steps in 2019 (Oct/Nov/Dec), 46 patients and carers attended from different tumour groups. Feedback has been extremely positive, as can be seen below, and we are keen to increase sessions in 2020 in order for more patients to access this support as soon as possible after diagnosis.

“The four weeks since my partner’s diagnosis have felt like a real abyss – as if we have been in complete darkness, not knowing what to do or where to turn. What you have done this morning in First Steps is to shine a light on the path ahead – you are all pathfinders – and we are very glad we came.”
Attendee Nov 2019



Rob, one of our Patient Reps, sharing his story at First Steps

“The whole morning was excellent and very informative, especially finding out about what support is available.”
Attendee October 2019

“It was good to meet people in the same situation as yourself and all of the speakers and nurses were excellent. I think a longer session would be good as the speakers seemed a little rushed and more time for discussion would be useful.”
Attendee October 2019

“Hearing Rob’s story was really helpful - he was fantastic and gave me hope that there will be light at the end of the tunnel.”
Attendee December 2019

“As a Cancer Specialist Nurse I find Helen and Mandy’s Service invaluable to the Trust. They have set up the First Steps Programme which I think has been excellent and a lot of my patients have found it useful.”

Miriam Slade, Urology CNS

2. HEALTH & WELLBEING EVENTS

The service also plays a crucial role in organising and co-ordinating generic Health and Wellbeing Events (HWBEs) for the Trust’s cancer patients. These are events for people at the end of their cancer treatment and are run to support patients to live as healthy and active as possible once cancer treatment ends.. All of this



facilitates the national agenda of supported self-management – empowering patients to be in control during their treatment and recovery.

As a result of our review of the HWB provision of the trust in 2019, we changed and extended our end of treatment HWB events, to include an invitation to all tumour groups, the addition of a clinical session where patients could ask questions of their CNS teams and the addition of more sessions making this into a whole day course, with lunch provided (kindly funded by trust charitable funds).



The whole day format ensured a greater positive impact and meant that the clinical teams could support our event, as well as releasing them from organisational pressures and increasing their time to focus on clinical issues.

In 2019 we ran four Health and Wellbeing Events in March, June (both half days), September and December (both full days), at various community locations.

Number of attendees at these events were as follows:

| | March 2019 | June 2019 | September 2019 | December 2019 | Total: |
|-------------------------------|------------|-----------|----------------|---------------|------------|
| Number of Patients Attending: | 56 | 61 | 60 | 63 | 240 |

The numbers attending included patients affected by the following cancer diagnoses – head and neck, colorectal, gynaecological, upper GI, urology, lung and haematology. A staff member from each team was also invited to answer patient queries.



The format of the Health and Wellbeing Events changed slightly during the year. All included generic talks including the Cancer Psychology Service on managing emotions during cancer; talks by the Kirklees Wellness Service and Staying Well (Calderdale) on the benefits and importance of physical

activity and healthy lifestyles; the Macmillan Information & Support service on the practical/financial and emotional support and presentations by the Yorkshire Cancer Community. We also included a session from social prescribing teams which both Calderdale and Kirklees Councils offer. This helps people connect with their community and helps provide support for those who may be suffering from loneliness and social isolation.



Patients were also invited to share their stories at some of the events. After gathering feedback from patients and discussions with the clinical teams, the subsequent Health and Wellbeing Events were made longer, with lunch being provided and patients having an opportunity to meet with their specialist cancer teams in the afternoon, to talk about managing the side effects of

treatment and signs of recurrence.

Feedback about the Health and Wellbeing Events has been extremely positive, from patients, family members and staff:

“The health and wellbeing events, bring together ladies that share their own experiences(both good and bad). Some gain excellent support from other patients and professional support at the same time. Some of our patients have found this helpful in their recovery. We have had ladies that have only just met exchange contact numbers after these events.”

Lesley Walker Gynaecology CNS

“The presentations were perfect, to the point but without terrifying people about cancer. Venue was very good and all speakers were well spoken and clear.”

Attendee March 2019

'The Clinical team discussion is so valuable, almost like being able to have an appointment there and then to be able to talk about specific issues and it was lovely to talk to other people who have been through the same things.'

Attendee September 2019

'The emotional support session was very useful for me personally, especially helping me to know how to manage my thought process, which has been difficult.'

Attendee December 2019

'There is so much more to the Macmillan Information Service than I realised and the session on exercise has inspired me to start and do more. The whole day was very well organised and professionally delivered. Thank you.'

Attendee December 2019

"Very friendly, easily approachable, good chance to chat to other people and touch bases with all the services available. Relaxed atmosphere (no pressure to get up & be involved)."

Attendee June 2019

"Makes me feel normal & capable of making changes, being more positive & fitter. Very calm, soothing, felt welcome. Massive amount of practical advice & information. Very useful."

Attendee June 2019

"The information about Macmillan and social prescribing was helpful. Gained lots of good information and inspiration to be healthier."

Attendee March 2019

When asked about improvements to the sessions patients suggested more time for talking to other patients, booking attendance as an appointment to help those back at work get time off to attend, more meetings like this, better technology and more promotion of the events.

3. THINKING AHEAD PROGRAMME

In November 2019, we launched our new health and wellbeing support programme for people diagnosed with incurable cancer and their families. This was as a result of patient feedback, particularly at our Cancer Patient Focus Group, and the recommendations by the West Yorkshire and Harrogate Cancer Alliance about meeting the unmet support needs of people affected by incurable cancer across the region.

'Thinking Ahead' was devised by Harrogate NHS Trust in 2018, and was developed and extended within our own trust in 2019. We worked in close collaboration with staff from Kirkwood and Overgate Hospices, our specialist palliative care nurses, dieticians, psychologist, trust chaplain and more. Several members of our trust staff attended the

Thinking Ahead course as it was delivered in Harrogate, speaking to patients to get their feedback and to staff about tips for bringing the course to CHFT. We also recruited staff in the community to be involved in Thinking Ahead, including a lecturer in sports science from the University of Huddersfield and a Co-op Estates Planner.

We ran our first 'Thinking Ahead' course over three half days in November and December 2019, with 27 attendances of patients/carers and many professionals leading sessions such as dieticians, palliative nurses, hospice staff, the trust chaplain, exercise professionals, estates planner, Macmillan information team, mindfulness practitioners and even the hospital DJ. Topics were handled sensitively, with time for discussion and questions. Peer support was evident from the outset and there was an atmosphere of understanding and compassion between the group members. One couple told us that attending Thinking Ahead had enabled them to talk about and plan for the future for the first time, when this had previously been too difficult a topic for them to broach.

Helen Harris, Macmillan Advanced Practice Specialist Palliative Care Nurse, who had a key role in developing Thinking Ahead and in delivering sessions wrote the following about the course:

“In the last year I have been really impressed by the range of support offered by the Macmillan Cancer Information Team for our patients. I have directly been involved in the Thinking Ahead programme and have been really impressed by the enthusiasm, teamwork and drive shown by Helen and Mandy. It has been a pleasure to work with them and I have been able to see first hand their kindness, compassion, dedication and their can-do attitude. It has also been fantastic to see the effect this programme had on the participants. The participants being there at all (and attending more than one session) is in no small part due to Helen and Mandy's warm, welcoming style and the care shown to them during the programme. This is a really valuable service and is starting to grow in just the right ways to make tangible differences and benefits to patient's lives. CHFT would be much worse off without this team.”

We asked the patients and family members attending in November and December 2019, to give feedback in order to shape and develop our future Thinking Ahead Courses and this is what they said:

“The Thinking Ahead Course highlighted areas that I was not even aware of such as protecting children via trusts in estate planning, advance care plan options including DNR. There was useful sign posting of how things may evolve medically and what we can put in place regarding how we wish to be treated or not. It was very interesting to learn about the university exercise class and the benefits of keeping active and there were very useful tips on how to manage fatigue and live within your energy means. As a result of

attending the course, I accessed services at Overgate Hospice for the first time."

"Thinking Ahead was very informative and has helped me to see that I still have some control. The facilitators were brilliant and dealt with difficult topics in a sensitive way so as to minimise any distress or upset. I enjoyed the sessions on advance care planning and faith and spirituality, as well as learning useful information about hospice services. Topics were relevant and useful and made me think that I need to allow people to help."

A daughter who attended the course also wrote: **'It was good to meet with people in a similar position to us. The information received will hopefully help me to support my mum. I feel we are talking a bit more but there are still conversations we need to have.'**

In 2020 we plan to run a monthly Thinking Ahead information and support group session, featuring one of the topics from the full course every month, as well as time for a coffee, chat and peer support afterwards.

"I personally have found some of the advice, contact and interaction with your people as being instrumental with me dealing with, and living with cancer."

Patient 2019

INFORMATION AND PROMOTION

In 2019 we were grateful to secure funding from Macmillan for a brand new Macmillan Information seated pod, to go in the entrance of HRI. The purpose of the pod is to promote cancer awareness in the passing public and to provide both cancer specific and generic information (e.g. work/talking to children/physical activity). The pod is manned at certain times during the week by our dedicated volunteers, with space to sit and talk over concerns. We are keen to grow the number of hours our



volunteers provide cover at the pod, to provide a more consistent presence on the pod, to answer people's queries about cancer.



During 2019, 2180 information booklets /leaflets were taken from our Macmillan Information Centres in Calderdale Royal Hospital (975) and Huddersfield Royal Infirmary (1206), which is 857 more than the previous year. An incredible 1183 booklets were also taken from our new Macmillan information pod in the main entrance to HRI, in a six month period from July to December. During 2019, an overall total of **7,403 booklets** were taken from the centres and pods throughout HRI, CRH and Acre Mill. This figure was actually 1,275 booklets fewer than in 2018, which is likely to be due to increased numbers of patients preferring to access the booklets electronically from the Macmillan Cancer Support website or by email.

Booklets/leaflets have included information on many topics including our Macmillan information service, cancer types, treatment information, finance, carer support, hair loss, physical activity and healthy eating – all raising awareness of cancer and the existence of our service within the hospitals. Leaflets from many other services and charities such as Cancer Research, Age UK, Marie Curie, Lymphoma Awareness, are also available for patients to take from the centres and information pods, not only Macmillan materials. Our service also orders a wealth of information booklets for our cancer awareness monthly displays, outreach events and Health and Wellbeing Events, which takes our number of booklets distributed in 2019 to an estimated figure of 8,550 booklets.

The below shows a breakdown of numbers of booklets taken from each of the information pods, showing that more booklets were taken from the pod in the main

entrance of CRH than anywhere else, followed by booklets taken from the main entrance of HRI:

| Location: | No of Booklets Taken: |
|---|------------------------------|
| Main Entrance CRH | 2024 |
| Main Entrance Old pod – 465 New Pod July - 1183 | 1648 |
| HRI Resource Room (info centre) | 1205 |
| The Jayne Garforth Information Centre CRH | 975 |
| A & E CRH | 726 |
| Acre Mill Ground Floor | 355 |
| Acre Mill Second Floor | 235 |
| Acre Mill First Floor | 200 |
| Ambulatory Area HRI | 35 |
| Total: | 7,403 |

The most popular six titles taken from all locations in 2019 are listed below:

1. Are you worried about Prostate Cancer?
2. Are you worried about Bowel Cancer?
3. Recipe Books for People affected by Cancer
4. The Cancer Guide
5. Are you worried about Breast Cancer?
6. Are you worried about Lung Cancer?



This differs from the previous year where our top six most popular booklets included 'Understanding Skin Cancer, Signs and Symptoms of Cancer and Giving up Smoking' – though the top two booklets were the same for 2018 and 2019.



We have cancer awareness stands in the main entrance of the hospitals each month showcasing the signs and symptoms and importance of screening for various cancer sites. We have been able to provide information in other

languages including Punjabi, Urdu and Polish, as well as in audio and video formats.

In 2019 we also launched a bi-monthly **newsletter** in order to keep patients and family members up to date with various events/courses and support groups they can access. The newsletter is circulated to around 350 people each time, mainly by email but with printed copies going out to those who do not have access to email. As well as patients, the newsletter is sent to a wide range of community groups and organisations across Calderdale and Huddersfield, as well as to our own clinical teams. We are also grateful to the Yorkshire Cancer Patient Forum, West Yorkshire and Harrogate Cancer Alliance and CHFT comms teams, for further promoting our events and the contents of the newsletter.

In 2019 we also launched a new **Facebook Page** for the Macmillan Information service which has been a great way to keep in touch with patients and promote the support groups/Health and Wellbeing courses etc.

Outreach Events and Service Promotion

During this year we also attended 24 outreach events at several venues in the community, with the aim of promoting the service and raising cancer awareness throughout the district, as well as awareness stalls in the trust. These included:



Helen with Stacey Rhodes, fundraising manager, Jeff Goodman and Eric Lee from the Holmfirth Macmillan Committee at Holmfirth Art week.

| Date | Event/Meeting | Reason |
|-------------|--|-----------------------------|
| 17.1.19 | BAME Meeting, Dewsbury | Sharing Practice |
| 22.1.19 | Feel More Like You Nurses Session (Boots) | Awareness and support |
| 1.2.19 | Upper GI Support Group | Supporting the team |
| 4.2.19 | Cancer Support Group, Marsden | Providing awareness |
| 4.3.19 | Prostate & Ovarian Cancer Awareness, cross site | Raising awareness |
| 5.3.19 | Health & Wellbeing Event, Elland | Providing support |
| 6.3.19 | Macmillan Regional Managers Meeting, Leeds | Sharing practice regionally |
| 15.3.19 | Moorside Community Event | Raising awareness |
| 26.3.19 | Feel More Like You Patient Session, Boots Huddersfield | Patient support |

| | | |
|----------|---|-------------------------------------|
| 9.4.19 | Upper GI support group | Supporting the team |
| 1.5.19 | Muslim cancer awareness day, Eden Foundation Huddersfield | Raising awareness |
| 13.5.19 | Bladder & Skin Awareness campaign, cross site | Raising awareness |
| 14.5.19 | Upper GI support Group | Supporting the team |
| 14.5.19 | Sikh Temple End of Life Event, Huddersfield | Raising awareness |
| 18.5.19 | Dementia Awareness Day, St. Peters Church, Hebden Bridge | Raising awareness |
| 5.6.19 | Macmillan Information managers Meetings | Sharing practice regionally |
| 6.7.19 | Holmfirth Arts Festival | Promoting the service and Macmillan |
| 24.7.19 | Volunteer Open day | Promoting the service |
| 31.7.19 | Feel More Like you, Boots Halifax | Patient experience |
| 4.9.19 | Macmillan Regional Managers Meeting, Leeds | Sharing practice regionally |
| 24.9.19 | Health & Wellbeing Event, Halifax | Providing support |
| 4.10.19 | Regional benefit advisors meeting | Partnership working |
| 3.12.19 | Health & Wellbeing Event, Halifax | Providing support |
| 10.12.19 | Upper GI Support Group | Supporting the team |

"Thank you for all your help – I couldn't have done it without you. The Blue Badge, grant and all the benefits advice was greatly appreciated. Your support took a little bit of worry out of our everyday living and finances, thank you. Such a caring, well trained and organised service is essential."

Patient 2019

PRACTICAL SUPPORT

During the year 2019, 56% of all the enquiries we received were about practical support. This includes signposting and many onward referrals in order for people to access tailored support for themselves and family members. In 2019 we made 714 referrals to different organisations for people to access practical support as illustrated below:

| | |
|---|------------|
| Benefits – Advice Kirklees | 174 |
| Benefits – Age UK | 230 |
| Halifax Community First | 5 |
| Disability Network Benefits | 12 |
| Bradford CSY Benefit Advisor | 5 |
| PIP Direct Referrals/Appeals | 7 |
| (Total Benefits Referrals: | 433) |
| Halifax Heat Team | 23 |
| CAB - Energy Advice | 4 |
| LEAP Energy Advice | 4 |
| Carers Count Kirklees | 8 |
| Calderdale Carers | 16 |
| Blue Badge Referrals | 150 |
| Feel More Like You Programme | 6 |
| Gateway to Care Kirklees | 27 |
| Gateway to Care Calderdale | 17 |
| Leeds Occupational Health Support | 8 |
| Psychology/Counselling Referrals | 36 |
| Kirklees Wellness Service | 11 |
| Calderdale Better Living Service | 8 |
| Community Rehab Team | 1 |
| Marie Curie Volunteer Helper service | 5 |
| Kirklees Housing Department | 3 |
| Calderdale Housing | 1 |
| Kirkwood Hospice | 2 |
| Overgate Hospice | 1 |
| GP | 4 |
| Wheelchair service | 3 |
| Better in Kirklees – Social Prescribing | 8 |
| Stay Well – Social Prescribing Calderdale | 2 |
| Total Number of Referrals made by our service in 2019: | 714 |

As well as all of the above referrals, many more people were signposted to various organisations such as the carers organisations in Calderdale and Kirklees, hospices (especially support and day therapy/day therapy drop-in), Kirklees Wellness service and social prescribing services – in order for people to opt in if they chose to access this support.

We signpost regularly to the **Macmillan Support Line** which is now open seven days a week, 8am – 8pm. The MSL is a fantastic resource for patients and carers and offers work support/advice, financial advice such as mortgage advice/debt advice, pensions, utility bills/debt advice, as well as access to welfare benefits advice.

Other kinds of practical support offered this year have been:

- **Macmillan Health Walk** – as already mentioned in this report, we launched a new monthly Macmillan Health Walk in Greenhead Park in November 2019, run by our dedicated volunteers who trained as Walk Leaders with Kirklees council. In 2020, we plan to extend this and also run a monthly walk in Caldedale.



- **Travel Insurance Information** – we provide booklets and lists of insurance agencies which patients have informed us about, as well as signposting to travel insurance suppliers on the Macmillan and Cancer Research UK websites. In 2019 we also developed a list of companies offering insurance to people with incurable cancer.
- **Promoting Physical Activity and Healthy Lifestyles**- In 2019 we made new links with a senior lecturer in Sports Science at The University of Huddersfield, Kevin Kipling, who trains exercise professionals nationally in safe exercise for cancer patients. Kevin kindly ran sessions on our Thinking Ahead course and has contributed to our Health and Wellbeing Events. We have also been able to promote his exercise classes for cancer patients at the University.
- **Liaison** – in 2019 we liaised with GPs, consultants, cancer nurse specialists, hospice staff, cancer care co-ordinators, housing teams, benefits advisors and many more health and social care professionals on behalf of patients and in order to get support in place for patients. We also had increased liaison with schools and universities in 2019, as many of our patients had children who needed support.
- We ran two '**Boots Feel More Like You**' sessions in 2019 – one in Huddersfield and one in Halifax. This is due to the national partnership between Boots and Macmillan and Boots staff kindly ran skincare and make up sessions for groups of patients. In 2019, we continued to signpost to 'Look Good Feel Better' in other areas including Leeds, Wakefield and Burnley, for further skin care and make up advice.
- **Transport** – we signposted to Calderdale's community transport service, run by volunteers at minimal cost to the patient, as well as the RVS (Royal Voluntary Services) in Huddersfield who can offer some transport to patients for appointments, support groups and community venues. We also directed patients to the hospital transport service for appointments.

- **Wills** – In 2019 we provided information about will writing services and funeral costs, often directing people to Macmillan’s free will service available at certain times of the year and in 2020, this service will be available all year.
- **Toilet & Restaurant Cards** – We provided Macmillan toilet cards for patients who need access to toilets in shops etc, as well as some radar keys. We also have cards from the oesophageal patients association which patients can show in restaurants/cafes etc.

EMOTIONAL SUPPORT

In 2019, 30% of our service activity was to provide emotional support. Over half of all our contacts - 55%, were with people who simply wanted to talk about their experience (1549 people) and much of our positive feedback is around patients recognising the benefit of just having someone to listen to them. The listening ear that we provide to patients, either through drop in or telephone support, is therefore a key element of the emotional support provided by the centre. This is particularly important when patients may struggle to share their fears and worries with family members or busy clinicians. Of our contacts, 15% asked about counselling and psychological support (an increase of 9% since 2018) and 3.5% of people talked about relationship issues.

Part of our emotional support over 2019 has been to make formal referrals for patients who need more than a listening ear and we have therefore referred to the trust’s psycho-oncology service and signposted patients and family members to local counselling services. We have also met with bereaved families, again being a listening ear and signposting to hospices and other support services such as bereavement support groups.

NEW MACMILLAN SUPPORT GROUPS

In 2019, our service launched three **new support groups** to enhance peer to peer support available for patients and family members. Our Cancer Patient Focus Group in June told us that there was a need for more support groups in our area, as well as there being a need for specific support groups for people living with incurable cancer and secondary breast cancer. We decided to start with generic support groups and hope that site specific support groups may grow out of these. Our volunteers have been an enormous help in terms of attending and helping to run the groups, as well as providing vital emotional support and a listening ear to all who attend.

Macmillan Coffee Support Group



This was the first of our support groups and started in July 2019. The coffee support group meets on the second Wednesday afternoon of the month at 2pm til 3.30pm and alternates between Huddersfield and Halifax venues. The group is small and informal, with a chance to meet and chat with Macmillan

Information staff, volunteers and other patients. There is no agenda – just a chance to get together, share experiences and support one another.

One of our patients said: **“I started attending the monthly Coffee afternoon, where I met Helen (Macmillan Support Manager) and Trish a volunteer. It was an informal event, where I was made very welcome (also my brother and sister-in-law, came to offer their support).”**

Macmillan Singing Group

The wellbeing benefits of singing are well reported and in July 2019, we launched this new support group, which brings together people affected by cancer, family members and friends and staff working in oncology. The group is very informal and light hearted, with the aim of adding some fun, reducing stress and bringing patients and staff together in a different context.



The group meets on the second and fourth Thursday of the month in the chapel at Huddersfield Royal Infirmary, 4pm til 6pm. We have tea and coffee for the first half hour and then the singing

starts at 4.30pm. The group is led by a local musician, Mellow John and some of the hospital staff and patients also play instruments, including our Acute Oncology CNS Anthony Thomas on his guitar. All voices and any song suggestions are welcome.

Here's a quote from one of our specialist palliative nurses about the singing group **"I have benefitted personally from the Macmillan Singing Group which is open to patients, carers and staff who are affected by cancer. This small and very amateur group meets in a really warm, open and supportive environment, facilitated by Helen and Mandy, and is a great source of relaxation, laughter and friendship which is enjoyed by all who attend."**

And another from a patient:

"Next was the Macmillan singing group. I love to sing, what a way to let it all out!! Coffee and a natter first, just fantastic."

Our singing group also did a Christmas video for the local Macmillan fundraising team as a thanks to a supporter for sailing across the Atlantic. The link to the video can be found here on the service's Facebook page:

<https://www.facebook.com/2384220825159295/videos/589959491839944/>

Macmillan Health Walking Group

This group started in November 2019 and not only provides the practical benefits of a monthly health walk and gentle exercise, but also crucially provides peer support to everyone who attends. As well as time to talk to one another and our volunteers during the walk, there is also chance to meet afterwards for a coffee and cake in the park café. Some of the people attending the walks said the following:



"I love going for our monthly walks with Macmillan – it's great to get outside and be in the fresh air. I don't always want to walk by myself so this group is great. I have met some wonderful inspiring people who are great to chat to as you often don't always want to burden your family."

"I attended the monthly walk, were I met more patients and volunteers. Enjoyed a friendly walk at our own level/ speed, followed by coffee... I was hooked, it filled a gap I needed to fill."

We also provide information in our newsletter about local and regional support groups (including spiritual/faith groups) people can access, as well as the Yorkshire Cancer Patient Forum and Cancer Alliance Community Panel. We also support our CNS teams in their delivery of tumour specific support groups, attending where we can and promoting the groups in our newsletter. In 2019, we liaised with and supported the Upper GI team in setting up a new Upper GI support group.

"The Macmillan Information Service have helped us this last year set up a support group for our patient's, Mandy was instrumental in this."

Wendy Markey, Upper GI CNS

BEFRIENDING AND PATIENT REPS

In 2019 we also recruited three patients and a carer to our new role of Patient Reps/Befrienders. These new volunteers have made a significant contribution to our service during 2019 including helping to lead our Cancer Patient Focus Group; attending our support groups to offer peer support; sharing their stories at our First Steps and Health and Wellbeing Events and offering informal befriending to fellow patients and carers over the phone or by meeting for a coffee/breakfast etc.

We are keen to grow and further formalise our patient reps/befriender service over 2020, as this has been recognised by our cancer patient focus group as an improvement in support being made available for patients and family members. Befriending could also be a way to meet the need identified in the national cancer experience survey for our trust, about further emotional support for inpatients.

Our patient reps said the following about their involvement this year:

"Having previously received the excellent support and guidance from Macmillan and never forgetting the effect that this had on me, I wanted 2019 to be a time for me to become a volunteer and help in the bringing of compassionate support and informed guidance in the same considerate manner that I received it."

"I feel there are huge benefits in the First Steps workshop... I would like to look at and explore how do we increase numbers - sadly too many fellow cancer sufferers are missing out... at a time when they need it most. (They just don't know it until much later in their journey)."

“I volunteer to gain new skills and experience to help me to develop my career in a different direction. Having experienced cancer I want to give something back to help others in that situation, my experience has given me lots of tools to help and also a first hand understanding of what it is like.”

FINANCIAL SUPPORT

We know that cancer can cause our patients significant worry about finances, especially if people have to give up work due to their cancer treatment. A key part of our work is to make referrals to benefit advisors, apply for grants and signpost people to the financial advice available on the Macmillan Support Line (0800 808 0000) where people can speak to a professional about concerns over mortgage payments, pensions and other financial concerns.

Welfare Benefits

In 2019 we referred a total of 433 people for benefits advice with 404 of these being referrals to either Eileen Murray, Macmillan Benefits Advisor at Advice Kirklees or to Age UK in both Calderdale and Huddersfield. The remaining 29 people included direct referrals for PIP special rules done by our service, as well as other referrals for under 50s in Calderdale, where there remains a lack in benefits provision. Advice Kirklees and Age UK provide information to Macmillan about benefit gains and one off payments/arrears for patients referred by the trust in 2019, from which we have been able to estimate the benefit gains and arrears for patients referred specifically by our Macmillan Information Service as a huge **£1,145,497.85** – which is an increase of £54,428.37 since 2018. The breakdown of these figures is as follows:

| Macmillan Information Centre Referrals | No of referrals | Confirmed Benefits Total gained in benefit income (regular ongoing payments) | One off Payments Total gained through one off payments (grants, compensation and arrears, etc) | Total for our number of referrals: |
|--|-----------------|---|---|------------------------------------|
| 2019 Advice Kirklees | 174 | £446,559.03 | £24,960.09 | £471,519.12 |
| 2019 Age UK | 230 | £554,665.45 | £42,380.05 | £597,045.50 |
| Estimates for other referrals (PIP special rules and Calderdale under 50s) | 29 | £71,870.07 | £5,063.16 | £76,933.23 |
| Totals | | £1,073,094.55 | £72,403.30 | £1,145,497.85 |

In 2019 the Trust CNSs and Cancer Care Co-ordinators also made benefit referrals to both Advice Kirklees , Age UK and some made direct PIP special rules claims for patients.

We also signposted lots of patients to the Macmillan Support Line for welfare benefits advice, particularly via First Steps, Thinking Ahead and Health and Wellbeing Events.

Grants

In 2019 we were successful in gaining a huge **£54,984 in Macmillan Grants** for 137 patients, which was a significant increase of £34,117.75 compared to 2018 where we were awarded grants of £20,866.25 for 68 patients. Macmillan Grants are means tested and provide a grant of around £300 for those on a low income to help with costs arising from having cancer, such as help with heating costs, clothing and transport.

In 2019 we also applied to other charities for patients in extreme need and were successfully awarded the following:

- Percy Bilton Charity – awarded an electric cooker, 2 x washing machines, 2 x fridge freezers
- EON – washing machine
- British Legion – entire new kitchen installed plus a cooker for a patient with an ex-military background
- Elizabeth Cotman – making memories experience
- Thames Water – negotiated the clearing of debts of £179
- Southern Electric – negotiated the clearing of £489 energy debt
- British Gas – negotiated the clearing of £995.35 in gas arrears
- Mothers Union – caravan holiday awarded to a family in need
- Charles Brooke Convalescent Fund – sofa and carpets awarded
- Mummy’s Star Charity - £500 grant for child care costs and baby items
- Huddersfield Mission – bed/sofa/table and chairs plus Christmas hamper

Being able to apply for additional grants for patients, has benefitted some of those in extreme need, and enhanced and supported their general wellbeing.

“I think the patients really appreciate the time and support that you and your team can give to them. We’re obviously rushed in clinics, and it’s clear that patients don’t always feel they can talk about more practical matters in an appointment they think is more for “medical” matters. The fact that you and your team can give them the time and space is really helpful, and in particular your expert advice re things like travel insurance and benefits, fills a gap which we don’t know a lot about!”

Dr Nick Brown, Medical Oncology Consultant

MACMILLAN QUALITY STANDARDS

As a Macmillan Cancer Information and Support Service, we have to adhere to Macmillan's three quality standards. These are:

Macmillan Quality in Information and Support Services (MQuISS)– a practical tool for information services to improve the quality and sustainability of their service. The aim is to provide a benchmark to assess the development of the service, demonstrate good practice and to provide people with cancer a standard they can trust. This involves completing a biannual thorough review of the service and score all 12 quality areas specified by Macmillan. Macmillan sets the quality standard as 4 for each sub area, and as a centre, we obtained very similar results to 2018, obtaining level 4 or 5 for 71 out of the 72 quality standards. We performed well on areas such as planning, governance, leadership and management, managing people and working with others. MQuISS is due to be reviewed again in 2020.

Macmillan Quality Environmental Standards (MQEM) – this standard is to



ensure service users are treated and supported in high quality environments which provide a space that facilitates information, health, care and support. In 2018 the Macmillan Information Centre at Calderdale Royal Hospital underwent a rigorous assessment for MQEM. The MQEM Quality Standard was successfully awarded and a plaque is now on view in the centre as recognition of Macmillan's cancer environment standards being met. This will need to be reviewed next in 2021. The site at HRI was not included in the environmental assessment as it does not constitute a formal Macmillan Information Centre.

Macmillan Quality Volunteering Standards (MQVS) – this is a tool to assess the quality of the volunteer management to ensure the volunteers get the support and help they require. The centre has a plan to monitor and implement the volunteer standards, led by the Assistant Information Manager, Mandy Davies, as part of her role to recruit and support our volunteer team.

MACMILLAN COFFEE MORNING

Although fundraising is not specifically part of our role, we do receive donations from people either to the national charity of Macmillan Cancer Support (which can be ring fenced for the local area) or for the Trust cancer funds at the Jayne Garforth and Greenlea units.



Our one fundraising events each year though, is to support the national Macmillan Coffee Morning. In 2019, this took place on 27th September at our new pod in the main entrance to HRI, on Macmillan's



national coffee morning day. Each year, we are extremely grateful to our Macmillan Centre and Headstrong volunteers who made so many cakes and helped out on the day, as well as acquiring prizes for a tombola and enthusiastically selling raffle tickets. Thanks to everybody's efforts and staff and public support on the day, we raised £433 for Macmillan Cancer Support.

"The information team are a highly valued extension of the team. Whether that is by patients self-referring or supporting us as a team/working together to achieve the best support for our patients. The support that is given takes a huge workload from the clinic teams, without this team, I'm not sure patients would get as good a quality of service."

Lesley Walker, Gynaecology CNS

2019 DATA

WHO DID WE HELP?

2818 CONTACTS IN 2019

The year 2019 saw a huge increase in our contacts with 920 more contacts than in 2018 (where we had 1900 contacts overall), which constitutes a 48% increase.

Of these – 1259 people accessed the service in Calderdale Royal Hospital and 1561 people accessed the service within Huddersfield Royal Infirmary. Compared to the previous year, the contacts at Calderdale increased by 297 in 2019 and in Huddersfield by 623 contacts. These figures demonstrate a slightly higher accessing of the service at HRI, and clearly demonstrate the ongoing need to deliver the service out of the two hospital sites and maintain permanent staff members in each place.

1630 contacts were from people who had used the service in the past and the remaining 1188 were with people new to the service. In Calderdale and Huddersfield there were 3433 patients diagnosed with cancer for the first time or with a recurrence in 2019. This means that the Macmillan Information Service supported 35% of all newly diagnosed patients in 2019, which is a slight increase of 3% from last year.

WHO DID WE HELP?

The following charts use data taken from our **2818 direct contacts** with people affected by cancer, in the year 2019.

MEN 31% **WOMEN** 69%

These are similar percentages to the last two years.

ETHNIC GROUPS

| | 2018 | 2019 |
|---------------|------|------|
| White British | 91% | 91% |
| Pakistani | 2.4% | 2.3% |

| | | |
|---------------------------------------|-------------|-------------|
| Black African/ Black Caribbean | 1.8% | 1.1% |
| Other White | 0.8% | 0.8% |
| Other Asian | 0.7% | 0.7% |
| Indian | 0.3% | 0.3% |
| Not asked/other | 3% | 3.8% |

Our ethnicity figures are virtually identical for the two years of 2018 and 19 and show that fewer none White British people are accessing the service than are representative in the populations of Calderdale and Huddersfield. Specifically, Black African/Carribbean figures are slightly lower than in the population (1.9% in Kirklees), but Asian communities are much lower (3.3% of our contacts were from Asian communities compared to a population of 8.3% in Calderdale and 14.8% in Kirklees). The service has tried to address this over the last year by attendance at events at Mosques and Sikh temples, as well as membership of the Kirklees BAME network. This will continue to be an area for ongoing development in 2020.

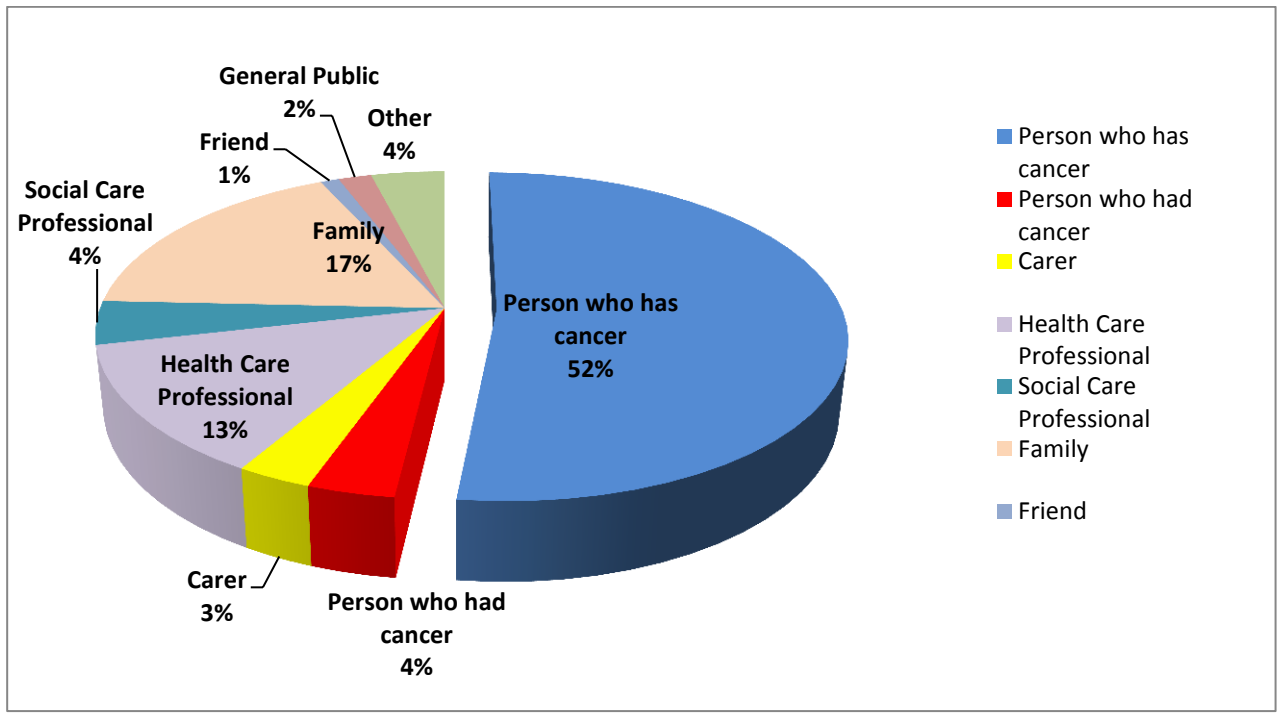
AGE BRACKETS

It was our impression during 2019 that we were supporting more younger people affected by cancer, as well as having many more enquiries about support for children whose parents were affected by cancer. This trend is evidenced in our end of year figures where the age group we most supported throughout the year has lowered from 55 – 64 years in 2018 to 45 – 54 in 2019. Indeed, figures have risen in all of the age groups under 54. In 2018, 40.5% of our contacts were with people under 54 and in 2019, this increased to 47.3%. 2019 also saw a rise of almost double the figures for the age group 75 – 84 making contact with the service.

| Age Brackets: | 2018 | 2019 |
|----------------------|---------------|----------------|
| Under 14 | 0.05% | 0.03% ↓ |
| 15-24 | 0.2% | 0.2% |
| 25-34 | 2% | 3.4% ↑ |
| 35-44 | 10.2% | 11% ↑ |
| 45-54 | 28% | 36.3% ↑ |
| 55-64 | 30% | 27.8% ↓ |
| 65-74 | 12% | 11.7% ↓ |
| 75-84 | 4.2% | 8.2% ↑ |
| 85+ | 0.8% | 0.3% ↑ |
| Unknown | 12.55% | 1.1% |

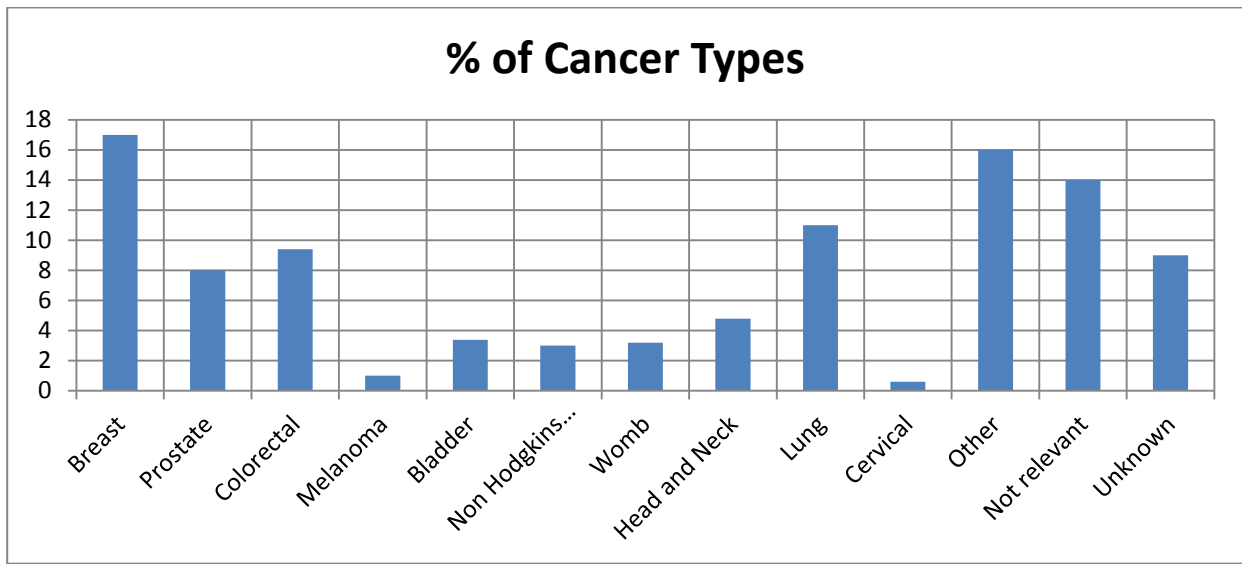
WHO WERE OUR CONTACTS?

56% of our contacts were with people who currently have or previously had, a cancer diagnosis, which is a slight rise of 4% since 2018. The second largest group of contacts was with family members at 17%.



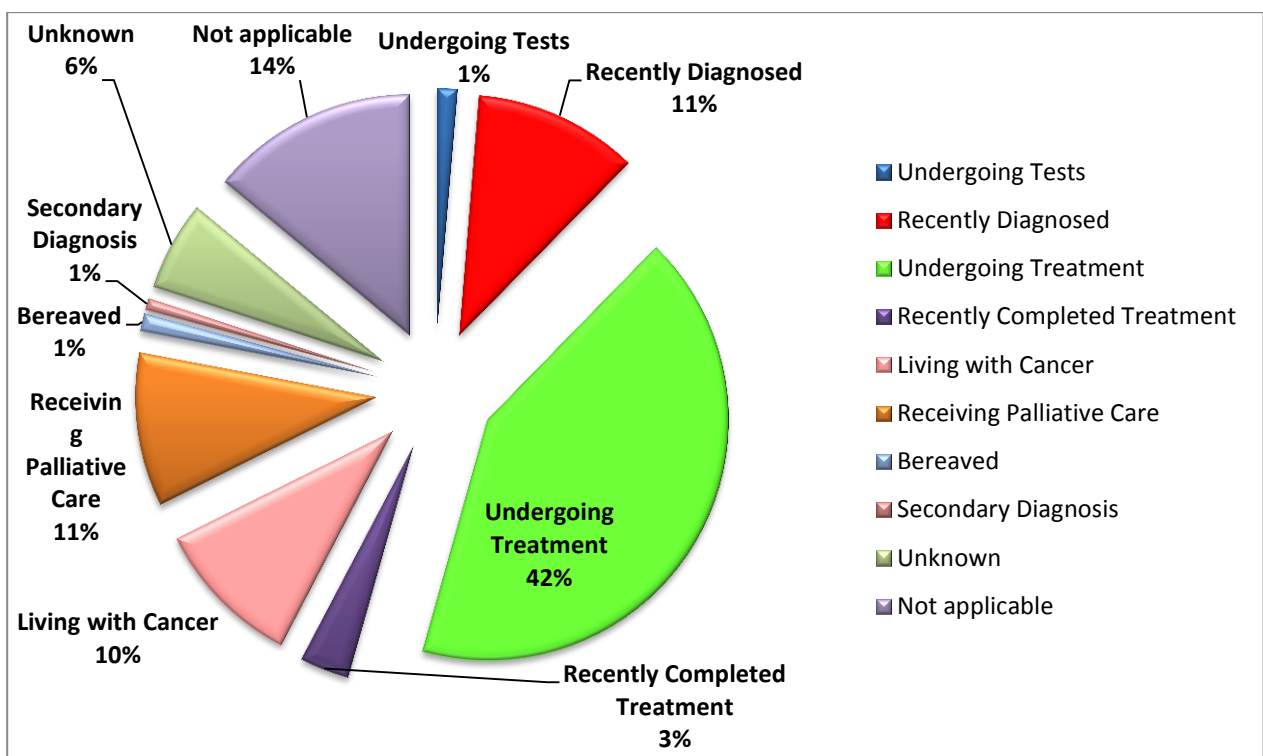
WHAT CANCER DIAGNOSIS DID PEOPLE HAVE?

Breast cancer patients were the most common people who contacted us during the year, and figures increased from 10% of contacts being breast patients in 2018 to 17% in 2019. These figures were followed by lung, then colorectal, then prostate cancer patients. This year we also saw an increase in the percentage of head and neck cancer patients, haematology patients and bladder cancer patients. The relatively high proportion of 'not relevant/not known' figures is felt to be due to some contacts with our volunteer team who potentially felt it inappropriate to ask which kind of cancer patients/carers were affected by.



WHAT WAS THE STAGE OF CANCER PATHWAY?

We were most commonly contacted by people undergoing treatment, which is to be expected in a hospital context, followed by people recently diagnosed, then those receiving palliative care, followed by those living with cancer. It could be that the introduction of First Steps has contributed to people accessing the service at an earlier stage of the pathway, which is very pleasing. We also had more contacts with people receiving palliative care this year, which again could be related to the introduction of Thinking Ahead.



WHAT DID PEOPLE ASK US ABOUT?



During our 2818 direct contacts, we had 6834 queries about emotional, practical and clinical support. Obviously, some people ask us about more than one area, and want different kinds of help and support.

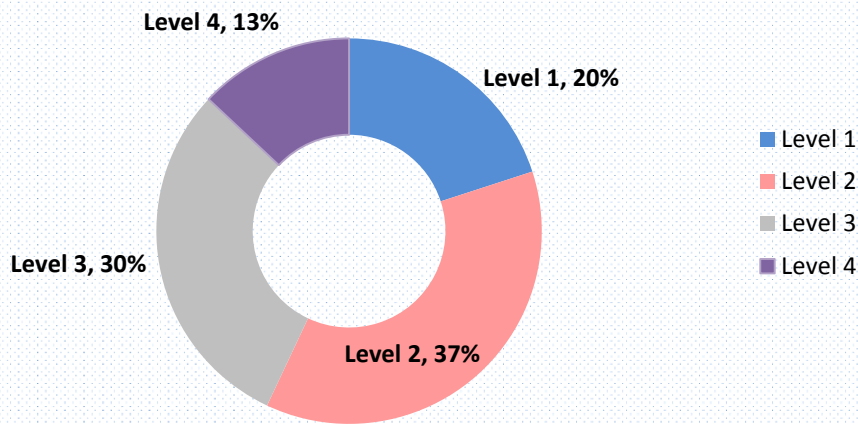
Overall more enquiries were for practical support, then emotional and lastly clinical. Our highest individual statistic in the year was people simply wanting to talk – with a total of this applying to 55% of our contacts. This is particularly important as many people struggle to talk to family members or know where to go to for support and a listening ear. This figure was followed by people having questions about living with cancer (32%); then benefits and welfare advice (31%); wanting local information & support (30% of patients); people wanting information on their cancer treatment (16%); psychological support/counselling (15%), grants and financial support (14%); travel insurance (10%); palliative care and end of life (5%), carers support (5%), and diet and eating (2%).

These figures are similar to the previous year, with a slight increase in the number of enquiries about benefits and financial help.

HOW COMPLEX WERE OUR CONTACTS?

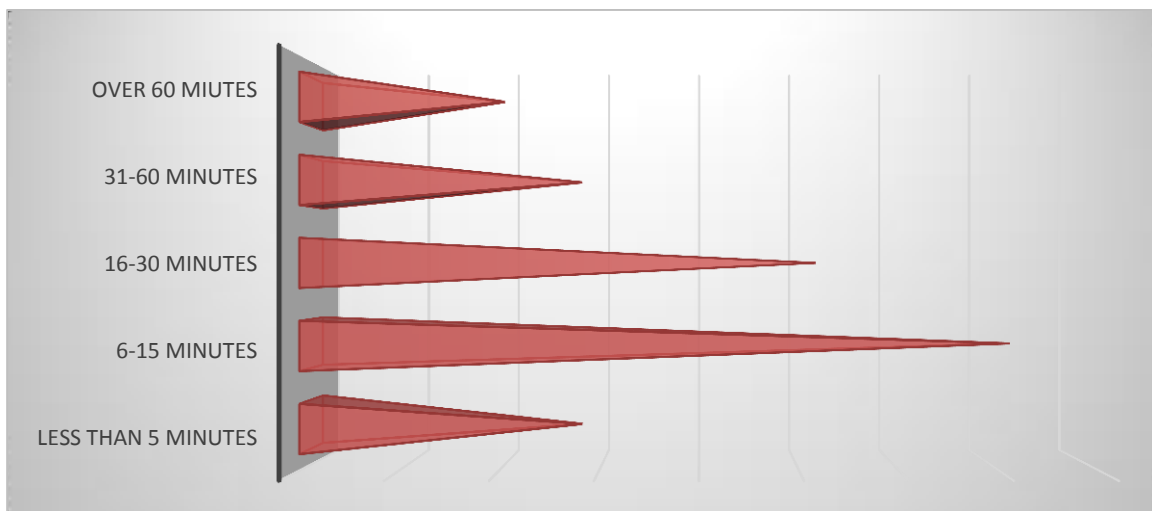
According to Macmillan data collection, our contacts with patients are graded in terms of the level of support required and complexity of each case. Level 1 contacts tend to be those queries easily answered such as paying in a donation; level 2 contacts may require some information and emotional support; level 3 may require onward referral to other organisations, and may return on a regular basis for ongoing support; level 4 are the most complex cases where people need much liaison, various referrals and ongoing, varied support. The majority of our patients were level 2, but the figures for 2019 showed a significant increase in the number of complex patients (level 3 and 4) and a reduction in level 1 contacts.

Complexity of Patients Seen



HOW LONG WERE OUR CONTACTS?

Our most frequent length of time for contacts was between 6 and 15 minutes, followed by contacts of 16 – 30 minutes. Contacts over one hour increased in 2019 compared to 2018 figures and less than 5 minutes was our least common length of contact.



"The Macmillan information service has always been there to provide helpful advice and support to our patients. They are an asset to our multidisciplinary cancer service and always bring warmth and compassion to their work."

**Anthony Thomas, Acute Oncology
CNS**

PATIENT STORIES

The following case study was written by a member of the Macmillan Communication team and includes some patient feedback. The patient's name has been changed:

Graham was diagnosed with bladder cancer in July 2019 and was receiving treatment in Huddersfield Royal Infirmary when he discovered the Macmillan Information Centre at the hospital by accident. Graham met with one of the Macmillan volunteers and took a number of leaflets when he first visited. He then arranged to meet with Helen Jones (Macmillan Information Manager).

Graham explains:

"Helen was a fantastic help to me. At the time I was living in sheltered housing with four other men, we shared a kitchen and a bathroom. This situation was extremely stressful while I was going through chemotherapy, it was unhygienic and I ended up back in hospital with an infection."

Helen spoke to the council and requested that Graham be prioritised for his own home.

"Helen dealt with the council, the supporting letters she sent made all the difference, I had my own home in a few weeks. There was also lots of practical support including hospital transport, a bus pass and a blue badge. I was supported to apply for Personal Independence Payments, that was a massive help."

Graham also received emotional support because the situation with the housing was affecting him emotionally.

"I was supported to get a fridge freezer and carpets for my new place through various grants that the Macmillan Information team applied for, it's been fantastic, I appreciate it all. Helen and Macmillan improved my situation by 110%, without them I wouldn't be in my own home. What the charity have done for me is brilliant and Helen is a diamond. The best thing I could have done was to wander into that Macmillan Centre in my pyjamas – they have provided so much support for me. The next time I see someone shaking a tin for Macmillan, I will make sure I tell them what an amazing job everyone does."

Helen explains:

"Graham came to us extremely stressed about where he was living - this was having an effect on him emotionally - the last thing you need when you're going through cancer treatment."

"At the Macmillan Information Centre we work with lots of local partners, including the council, social care and community organisations. In Graham's case we also worked with Huddersfield Mission, they helped to furnish the new home."

"We offer varied support at the Macmillan Information Centre, from financial, practical and emotional support, whatever the patient needs at any point in their care pathway."

This year we decided to feature a number of patients with shorter stories to illustrate the diversity of support offered by our service.

The names of patients have also been changed in this section, for confidentiality purposes.

| Patient Story: Mark, 39, suspected testicular cancer | How we helped: |
|--|---|
| <p>We received a referral from the national Macmillan Support Line who this man had contacted. He had been told 4 years ago that he had suspected testicular cancer, but had such an intense fear of hospitals that he had been unable to attend any appointments for diagnostic tests and he therefore did not have a confirmed cancer diagnosis. He was now in incredible pain, had swelling, was struggling with mobility, fatigue and dizziness as well as being convinced that the cancer had spread because he had not been brave enough to accept treatment. He also had financial concerns and some debt which added to his anxiety.</p> | <ul style="list-style-type: none"> • Phased entry into HRI – met in Costa • Involvement of psychology and psychiatry • Gave emotional support to stop him cancelling appointments • Supervised him in consultant appointment • Advised that we could apply for benefits and a grant once he had a confirmed cancer • Introduced to acute oncology nurse – took bloods/supervised him for a scan and biopsy • Frequent phone calls for encouragement to attend/access support • Came into HRI acutely – removed testicle – found not to have cancer. |
| <p>Mark's comments: "Thank you, thank you, thank you for all your support which is very much appreciated. Because the Macmillan Support Line got your service involved, means I can now move on with my life."</p> | |

| Patient Story: Bashita, 44, diagnosed with breast cancer | How we helped: |
|--|---|
| <p>Bashita visited the Greenlea ward soon after her breast cancer diagnosis. She was extremely emotional and upset, as well as being fearful of chemotherapy</p> | <ul style="list-style-type: none"> • Encouraged and supported her to complete her benefits forms and send them off • Referral to Headstrong for hair loss |

| | |
|---|---|
| <p>and losing her hair. She had lost her motivation in life, had put on a lot of weight due to being inactive and depressed. Her husband had recently had a medical incident and so was unable to work and her 7 year old son had recently needed surgery in a hospital a 100 miles away. She had registered for PIP but couldn't motivate herself to complete the forms. She was also very worried about her work situation and debt to British Gas.</p> | <p>advice/support and headwear</p> <ul style="list-style-type: none"> • Referral to PALS – Kirklees Physical activity programme for diet and exercise advice • Referral for counselling – Ian Binks – Trust psychology service • Referral to Away From It All – Mother's Union Caravan Holidays in N Yorks • Negotiated with British Gas and applied for grant to clear debt which was unfortunately declined • Signposted to Macmillan Support Line for debt advice • Information given re Occupational Health scheme in Leeds |
|---|---|

| <p>Patient Story: Catherine, 56 diagnosed with cancer of the larynx</p> | <p>How we helped:</p> |
|---|---|
| <p>Catherine was referred into the service by the head and neck Speech Therapist to ask for help with heating costs and finances. Catherine had a laryngectomy in 2018 and had difficulty speaking (used oesophageal speech), so we needed to liaise with her via a neighbour. There was a history of alcoholism and domestic violence against her. When we met Catherine, we learnt that she had £500 arrears on her gas bill which meant her gas was cut off – we learnt that she had lived without heating and hot water for four years. She was also sleeping on a settee and had no carpets in her flat.</p> | <ul style="list-style-type: none"> • Met in Bradford hospital – needed face to face communication as Gas companies etc needed her to give consent over the phone • Negotiated with the energy company to clear the £500 arrears and reconnect the gas on compassionate grounds • Requested that the council visit to inspect all gas appliances and turn gas supply back on • Referred for benefits advice – PIP • Supported friend to apply to Huddersfield Mission for a new bed and wardrobe • Macmillan Grant – used to buy carpets throughout her flat • Emotional support provided and liaison with many other services re her complex needs – district nurse/head and neck team etc |
| <p>Catherine's comments: "The Macmillan Information Service are just bloody brilliant!"</p> | |

| Patient Story: <u>Richard, 57 diagnosed with pancreatic cancer</u> | How we helped: |
|---|--|
| <p>Richard and his second wife came to visit the MCIS to ask about emotional support immediately after his diagnosis. They also asked about financial support, for example Richard had lost five stone over three months and could not afford new clothes. He wanted help moving to another council house to be closer to his older sister so, she could help to support his children, once he passes away. The family situation was rather complex because he had 9 children from his two marriages.</p> | <ul style="list-style-type: none"> • Listening ear • Benefits referral • Blue badge referral • Macmillan grant – clothes due to weight loss. • Signposted to Overgate Hospice – wife in denial – carers support group at Overgate and he needed individual support • Referral to counselling/psychology service – worried about who will care for his children once he dies. • Wrote a letter to the council to support a housing move • Photoshoot – for all children • Referral to Something To Look Forward To, to pay for photoshoot (£350) |

| Patient Story: <u>Matthew, 51, diagnosed with myeloma</u> | How we helped: |
|--|--|
| <p>Matthew visited the service after being signposted by one of the chemotherapy nurses. He was struggling financially due to being unable to work since his diagnosis. He had also had to move out of his house and was living in the house of a deceased relative (which the extended family were keen for him to vacate). This was because he had ripped out the kitchen in his own house, planning to buy a new one and fit it as he worked. However, his diagnosis came just after he had finished ripping out the kitchen and he lacked both the physical capacity and the funds to replace it, as well as kitchen appliances. Matthew had a military background and was feeling extremely frustrated at the</p> | <ul style="list-style-type: none"> • Listening ear/emotional support • Referred him for benefits – PIP claim made • Applied for a Macmillan Grant – bought a cooker • Applied to British Legion – new kitchen was fitted worth £4000, enabling him to move back into his own house • Applied to Eon for a washing machine • Signposted to Blood cancer support group |

| | |
|--|--|
| situation and keen to get back into his own house. | |
|--|--|

| | |
|--|--|
| Patient Story: <u>William, 59, colorectal cancer</u> | How we helped: |
| William came into the centre to ask for help completing a 'Capacity for Work Questionnaire'. He had been to several places (CAB/Civic Centre) to get it completed but had been turned away – needed a medic/nurse to complete part of the form too. Talked about mobility difficulties – had neuropathy (numbness) in his hands and feet from chemotherapy and could not walk far; he had also put on a lot of weight and was feeling breathless. He was struggling to get in and out of the bath and was struggling financially. His wife was also struggling with his diagnosis. | <ul style="list-style-type: none"> • Referral to Gateway to Care for a Bathing Assessment • Referral to physical activity scheme – PALS • Blue Badge Referral • Benefit referral – to see if he was eligible for the higher rate of PIP • William's wife referred to Carers Count for carer support • Macmillan Grant for a day out for him and the family (four children) |

| | |
|--|---|
| Patient Story: <u>Tessa, 32 sarcoma – treated at Leeds</u> | How we helped: |
| Referral from the sarcoma team at Leeds who were quite concerned with a young lady they had been caring for since she was a teenager. Depressed and anxious regarding historic debt – could not see a way through it. Family problems were causing extreme stress and depression. She could not work full time due to the side effects of long term chemotherapy causing fatigue. Her washing machine was also broken. | <ul style="list-style-type: none"> • Macmillan Grant • Benefit referral • Washing machine from Percy Bilton • HEAT - Home Energy Action Team • MSL - debt advice • Counselling support for her daughter who has not spoken to anyone about her mother's diagnosis. • Provided information on the NHS Travel Scheme |

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| Patient Story: <u>Adele, 67, Endometrial Cancer</u> | How we helped: |
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| <p>Referred to the information service by the gynaecology team for a lady who is feeling isolated and is estranged from her daughter. Socially isolated; few friends does not go out has no reason to go out. Telephone conversations are lengthy suggestive of not having a conversation with people for a while suffers from low mood</p> | <ul style="list-style-type: none"> • Benefits Referral – PIP increased • Social prescribing to reduce isolation • Community support worker for their area • Support groups information provided. |
|---|--|

| Patient Story: <u>Louise 59, Cancer of the Kidney</u> | How we helped: |
|--|--|
| <p>Louise was referred via the adult social working team following recent admission to hospital due to historic domestic violence. She was receiving treatment in hospital and while under investigation – was found to have metastatic kidney cancer. Louise had very little access to any money as her husband had frozen her bank account, which he controlled. She also had mobility issues around the home.</p> | <ul style="list-style-type: none"> • Benefits Referral • Macmillan Grant • HEAT referral - energy costs • Signpost to Hospice service • Gateway to care services referral - home adaptations • Away from it all holiday applied for • Something to look forward to charity – making memories • Winston’s Wish / Rip rap information given to support her grandchildren • Blue badge |

PATIENT FEEDBACK

In 2019, our feedback was collected via our volunteers who contacted a number patients by phone each month, to ask if their needs had been met and also whether there was any further support the service could provide. We also have comment books and suggestion boxes in both of our centres, though only a few comments were made via this means in 2019. Our volunteers also supported the palliative team to gather useful feedback on their service.

Of the patients who gave telephone feedback about the Macmillan Information Service to our volunteers, 100% said they would recommend the service to someone else and that they felt listened to and understood; 88% of patients and carers said that contact with our service had specifically helped to reduce their anxiety. Our volunteers also asked patients where else they would have gone for support if our service had not been

available – 40% said they said they did not know where they would have gone for support; 18% said their GP; 12% said hospital staff/CNS; 12% said the CAB.

Various comments were made about the support provided by the service, several of which are already featured in this report. Other comments from patients and family members in 2019 are as follows:

- **As the clinical teams are so pushed for time, it is fantastic to have somebody else to sit and chat with about anything at all, in the hospitals where people are being treated. For my family and I, this has made a huge difference, it has reduced the stress and strain on all of us.**
- **The Macmillan Information Service was absolutely brilliant and put me in touch with the right people and did all the right things.**
- **The staff were helpful and lovely. I really felt listened to and understood.**
- **Macmillan's combined understanding, sympathy and support regarding everything from appointments, transport, prescriptions, operations, treatments and the psychological and emotional needs which may arise from surgery, was a key part of my pre and post-operative recovery. Their booklets have been invaluable in helping me to understand my side effects and how to approach the possible consequences in a positive frame of mind.**
- **The support really helped me and exceeded all my needs. The service triggered everything that was good and definitely met all my needs.**
- **I just wanted to say that the Macmillan Information & Support Service has been a fantastic support to my daughter and myself. In particular your help and support has been invaluable. You have worked really hard to get her some extra financial support at a time when she has been really struggling due to her circumstances. You also organised some counselling for her which she desperately needed and it is helping enormously with her wellbeing. You have also provided lots of information and signposting for both myself and my daughter to access other support and help. The most important thing for me was being able to come and talk everything through with you and you took the time to listen to us both and offer advice and ongoing support, I also felt that we could always contact you at any time if we needed to. Thank you so much.**

- **The service helped me to understand my treatment plan and what support was available – they explained things very clearly.**
- **All very helpful - a very good service and I am extremely grateful for their help and support.**
- **The centre was lovely and very calming. The staff were really patient and answered all my questions.**
- **My Mum has found the Macmillan information service unbelievably efficient and was pleasantly surprised by the availability of help. Furthermore our collective eyes have been opened to the bandwidth of signposting available. We have found the breadth of knowledge offered, quite simply incredible. This has been a major step change as my Mum no longer feels that she is dealing with the condition and the prevailing situation alone. It is difficult to speak for her, but I think this has given her a reassurance and added to her inner strength. Thank you for making a difference.**
- **Very handy that the service is available on the chemotherapy ward.**
- **Helen's professionalism was exemplary. She was very understanding and caring with an appropriate sense of humour.**
- **It was several months after my cancer treatment that I first plucked up the courage to seek help at the Macmillan centre near where we live. I did not know what help or support was available to me. The emotional and practical support you gave me was invaluable. My husband came with me too and he gained so much support from that meeting. It helped me move forward and seek help in different areas, which in turn was a great help to my loving husband. So thank you so much to all the team.**
- **I really appreciate all the support that has been given to me by the service. Myself and my brother are truly grateful - thank you."**
- **I had financial help when it was so needed, and a rant and a cry when that was needed too. I have a stack of useful information which I can refer to when I need it.**
- **I'd thought Macmillan was an end of life care organisation and was most pleased to learn of all the help offered. Your help on getting a Blue Badge was particularly appreciated. Use of it has widened life's opportunities and I feel much more liberated! All the other help is also much appreciated - Occupational therapy, help with Attendance**

Allowance, Fire review and Care Navigator help are all in progress and most welcome. Overall I can't thank you enough for the help given.

- Your help & advice has been massively appreciated. Much gratitude to you all for what you do.**
- Thank you very much for your advice and support. I feel for the first time in a very long time that there are people out there that can support Dad and help us as a family. It can allow us to begin a conversation with Mum and Dad about moving forward with his care.**
- The support I received from Macmillan was super. The information was about things I didn't know existed – the efforts of Eileen Murray were outstanding – totally professional and very helpful.**
- I can't thank you enough for everything you are doing to help my dad. You're truly brilliant at what you do. My dad's words were, I don't know what I would have done without the Macmillan Information service, they've been so good to me.**
- With the help of the Macmillan Cancer Information Service, we were able to obtain a blue badge which now makes getting out and about so much easier, we cannot begin to tell you how much easier this has made my brother's life. He now looks forward to going out, this has reduced his anxiety of not having to walk too far from where he wants to shop/visit, it has made a huge difference to his wellbeing and for that we are truly grateful, so thank you!**
- I'd just like to thank you for everything you've done for my dad. Thanks to you he now has a much needed electric cooker and you have really helped to sort out his debts. Thank you for everything, you've been amazing.**
- I am very impressed with Helen's knowledge and assistance and the prompt and efficient response from Eileen Murray, benefits advisor. Do not hesitate to make enquiries if you have any concerns regarding any subject or regarding your condition, as the service is excellent.**
- I'm so grateful that the Macmillan Cancer support team helped me getting my PIP reinstated. The staff went the extra mile for me and Helen also got me some money to help towards getting some new batteries for my mobility scooter that I have. She was so very helpful, even though she was very busy she took the time to sit down and listen to what I had to say and when I left her I felt a lot better. There are a**

lot of people who need people like Helen Jones to keep their spirits up. She certainly helped me to keep going.

- **Macmillan has helped us in regards to our high heating bills due to my husband suffering from severe anaemia and feeling the cold as a side effect of his chemo. We were also put in touch with hospitality action which helped us with a washer/dryer when ours was on its last legs. We are truly grateful for this support.**
- **Macmillan have been very helpful to me & my husband after my cancer diagnosis & subsequent operations & treatment. In particular the grant we were awarded which enabled us to buy & install a vanity unit for the bathroom. Also the information Macmillan have given us on several occasions has been invaluable. They are brilliant & the help & advice provided is superb.**
- **I cannot praise the Macmillan Information Service enough - thank you for everything you have done for my dad.**
- **I was diagnosed with prostate cancer in December last year. After picking up a Macmillan Leaflet at the Holmfirth Arts and Crafts Fair, I met Helen at her Coffee support group. She arranged an appointment with me at the Greenlea Unit HRI (which I didn't know existed) where she was very professional, caring and understanding. She provided me with a great deal of information, set up my PALS membership for an exercise programme, and also put me in touch with the "Better in Kirklees Social Prescribing service". As I was concerned about my treatment at the time, Helen contacted my Urology Nurse, who got in touch and was able to ease my concerns and anxiety. I was most grateful for this and the knowledge that Helen is there, who I can contact at any time, with any problems or worries. I am sure that many other people have had the same comforting experience with Helen and Mandy and many others will need it. I would recommend their help to anyone going through the same problems that I am.**

PROFESSIONAL'S FEEDBACK

A key part of our work involves liaising and working closely with health professionals across our NHS trust and in the community. Our role is to work in collaboration to provide the best possible care to patients, with our holistic support complementing the clinical support given by our colleagues. We attend specialist forum team meetings, tumour specific health and wellbeing events, steering group meetings and some joint outpatient appointments with other staff. We also answer cancer information and

support queries from staff and volunteers across the hospital sites, as well as externally. We asked our CNS and chemotherapy nursing teams, as well as community staff we work with, about the value of our Macmillan Cancer Information Service to them and their patients and were given the following feedback:

- **A great team can achieve great things, and this sums up our Macmillan information team - their positive contribution to supporting us and our patients should not be overlooked - we have come to rely on them for all the non-clinical details that are so important to our patients, to help them through what can be an arduous journey, smoothing the way, being a friendly ear and developing essential and innovative support services where it's needed most. From sending them claim forms, to financial problems, community care issues and education needs - it saves us so much time, and allows the patients to receive truly holistic care. Without them the Trust's Cancer community would definitely be the poorer.**

Sarah Topen, Cancer Dietitian
On behalf of the Head and Neck Cancer Team

- **The service is always there to support the patients, their families and the staff during some really turbulent emotional and physical times.**

Dr Ashwin Verma, Consultant in Speciality Gastroenterology & General Medicine

- **Thanks to the Macmillan Information service I can now pass a lot of our complex needs patients through to the team, for example:**
 - **I've had patients with housing problems, when the main name on the housing register has terminal cancer & the rest of the household despite being over 18yrs will potentially be without a home on the death of the family member.**
 - **We have had a few cancer patients who are asylum seekers.**
 - **Patients who are living with family members out of their normal area due to cancer -I have passed to Helen & team.**
 - **I pass through lots of patients with financial or employment issues due to cancer.**
 - **I encourage a lot of cancer patients who live alone or are without help & support at home to use the Macmillan information service.**

Allison Ramsden, Oncology Outpatient Sister

- **It's good to know that if we don't know the answer to questions our patient's ask, we can always refer them onto you. It's reassuring for our patients that if you don't know the answers that you will find out or you will sign post them appropriately.**

Michelle Davies, Lung CNS

- **Your service has had a tremendous impact on the service that we deliver to patients and on our workload in general. We know that we can refer to Helen and her team a wide range of queries and that they are always dealt with in a timely manner. It cuts down on the length of time we have to spend referring patients to different organisations and the relatives that attend with our chemotherapy patients can spend time asking about available resources in the Macmillan information office that in normal times is usually always manned by a very capable band of volunteers.**

As a result the patients and their families feel much more supported and it makes their cancer journey more structured. The service has made us as chemotherapy nurses feel more supported and empowered with the information that is available.

In particular when there is a patient who is distressed, especially at the start of their cancer journey, the advice and support that has been given at the time by Helen and her team has been so helpful and beneficial to the patient and their families. We call it the Helen love! The fact that patients can self-refer and the service is at the entrance to both units, makes it so accessible, available and well used.

Bernie Beith, Chemotherapy Sister

- **The Macmillan Information service has been invaluable in the support of the Macmillan Prehabilitation project. Supporting the project manager, being involved with the delivery of the universal element of prehab through First Steps health and wellbeing programme and being there for the patients to support them right from diagnosis. It will be great to continue working alongside the team to support further developments within the prehab project.**

The Macmillan information service, its' staff and volunteers are essential in the support, information and education provided to our patients. Whether it be emotional support, facilitating events, being a listening ear, practical advice and supporting carers and families. They're a team of people who connect with patients and can be there when the health professionals can't, ensuring that our patient's aren't alone at a vulnerable time in their lives.

Nicky Hill, Macmillan Prehabilitation Project Manager

- **As a Cancer Specialist Nurse I find Helen and Mandy's Service invaluable to the Trust. They are always helpful and I use them a lot to sign post my patients regarding numerous support mechanisms for my Cancer Patients.**

They have set up the First Steps Programme which I think has been excellent as a lot of my patients have found it useful. They have also set up the Thinking Ahead Programme which again has been brilliant. The Health and Well Being events they help run are also good for our

patients as they have provided education, psychological support and health promotion.

I think our Trust has an excellent Macmillan Information Centre now due to the hard work of Helen and Mandy.

Miriam Slade, Urology CNS

- **I have nothing but praise for the Macmillan Information Service. You are incredible and the service you provide to local people affected by cancer is just huge. I confidently signpost people to you, for support and help as I know how wonderful you are. For us to be able to work so closely it helps everyone get the support they deserve. You are always willing to support the wider Macmillan team and the Christmas Choir 12 days rendition was just that. You supported me in a request to thank a supporter who had raised a significant amount, without hesitation and even though you are incredibly busy you understood my urgency. I think you and the team of volunteers are remarkable. Thank you so much for being you**

Adele Burrough, Macmillan Fundraising Manager – Yorkshire

- **The information team are a highly valued extension of the team. Whether that is by patients self-referring or supporting us as a team/ working together to achieve the best support for our patients. The support that is given takes a huge workload from the clinic teams, without this team, I'm not sure patients would get as good a quality of service.**

Lesley Walker, Gynaecology CNS

OUR DEVELOPMENT PLANS FOR 2020

We are excited to build on the success of our Macmillan Cancer Information Service in 2020, and will target the following areas in the year to come:

1. **Staff Posts** – due to the increased demand on our service in 2019, we need to ensure the sustainability of current staff posts and secure funding for, and recruit, a third staff member. Our assistant manager, Mandy Davies, is funded until September 2020, when Macmillan's project funding comes to an end. We need to work with our Trust to ensure the pick up of funding for this post and for it to become a permanent post rather than a fixed term post. At the time of writing we have secured funding for a third member of staff from the Trust/Cancer Alliance to join us as a support worker in 2020, on secondment for 12 months. Our aim is also to secure this as a permanent post in the future to

cope with increasing demand and in order to continue to provide a high level of essential patient support across both hospital sites.

2. Growing and Embedding the Health and Wellbeing Programme

It has been a privilege to develop and introduce our First Steps and Thinking Ahead programmes in 2019, as well as extending our Health and Wellbeing Events at the end of treatment. However, not all patients from different tumour groups are accessing the programmes. Our aim in 2020 is to encourage more patients and relatives to access these various programmes and for greater endorsement and invitation to patients particularly on diagnosis, from consultants, CNS teams and chemotherapy nurses. We are also keen to develop a new monthly Thinking Ahead information and support session for people living with incurable cancer, and potentially the HOPE Course for people after cancer treatment has ended. We also aim to continue to work closely with our Macmillan Prehabilitation Project Manager to put health and wellbeing support in place as soon as a patient is diagnosed with cancer.

3. Personalising Support for Cancer Patients – as part of the NHS long term plan, we need to continue to deliver personalised, tailored support based around what matters to patients. We aim to support the implementation of more Care Plans produced by our clinical colleagues following their Holistic Needs Assessments, as well as potentially looking to offer HNAs/Care Plans from the information centre, particularly at the end of treatment. This could be a potential development when our third staff member joins the team. The aim of our service is to be a cancer hub where patients can receive high quality information and support, but then be signposted to ongoing support outside the hospital context.

4. Wider Promotion of the Service and Health & Wellbeing Programme – this year we have worked hard to raise the profile of our service in the trust, which has been helped by our new Macmillan pod in the entrance to HRI, regular newsletter and Facebook page, as well as promoting events via our Trust and Cancer Alliance communications teams and the Yorkshire Cancer Patient Forum. Sadly, only a third of newly diagnosed patients have accessed our support in the last two years and we plan to continue to make people aware of our service both within the trust and community, to encourage more patients and family members to engage with us in the years ahead. We also plan to develop our pages on the Trust website and look at a potential cancer app for patients in our Trust, which would provide key information and also help also to promote our service. We plan to continue to work closely with the clinical teams to encourage more consistent referral.

5. Continued Patient Engagement and Co-design – in 2019, our patient focus groups and patient reps played a key role in shaping our service development. It is essential that the patient voice remains strong in the future in order for us to continue to design services around what patients want and what they feel would be useful. This could include the development of new support groups and courses in 2020.

6. Expand the Volunteer Team – it has been a privilege to grow the volunteer team and recruit more volunteers in 2019, as our service could not run without

the valuable contribution of our dedicated volunteers. We plan to recruit more patient reps and to develop a formalised befriending and buddying scheme with our patient reps and volunteers, in order to provide further peer to peer support for people affected by cancer, and their family members.

- 7. Closer working with GPs across Calderdale and Huddersfield** – we started to promote our service more to GP practices in 2019, by talking at practice manager training in Kirklees, and presenting at the locality group meeting for GP and community leads - however this needs further development in 2020. Increased promotion would support GPs or practice nurses to know where to signpost patients to, after carrying out Cancer Care Reviews and would raise people’s awareness that the service is not only available to patients under active cancer treatment, but to anyone affected by cancer living in Calderdale and Huddersfield.
- 8. Improved Community Links for Patients** – we plan to promote our service more widely in the community in 2020 and to work closely with social prescribing and community services to knit patients and family members, more effectively into support in their communities, which enables better outcomes.
- 9. BAME and Hard to Reach Communities** – we plan to work more closely with the BAME network to promote cancer awareness in hard to reach and ethnically diverse communities across Huddersfield and Calderdale. We plan to increase the visibility of our resources in other languages and formats, as well as linking with groups such as the Deaf community.
- 10. Maintain and develop the high quality service provided** by the Macmillan Information Centre team, as demonstrated in this report.

NOBODY SHOULD FACE CANCER ALONE
WITH OUR HELP, YOU DON'T HAVE TO