

# **MACMILLAN CANCER INFORMATION SERVICE ANNUAL REPORT 2018**

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**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 02/01/2018 to  
31/12/2018**

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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 2018. The report highlights the objectives of the service in relation to the trust's delivery of the Recovery Package and 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 2018. The report contains a detailed breakdown of data from 2018, 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 2019.

# INTRODUCTION

In 2018, 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 with occasional staff cover in the centre by one member of staff (a Centre Manager). A full time member of staff was appointed in 2015 and worked out of the Jayne Garforth Macmillan Unit at Calderdale Royal Infirmary only. Over the last two years, the service has expanded and an additional staff member was funded by Macmillan for two years (an Assistant Manager, funded until October 2019), enabling the service to also run out of the Resource Room in Greenlea Oncology Unit at Huddersfield Royal Infirmary. 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 those living with and beyond cancer and to promote the National Cancer Survivorship agenda, in particular supporting Calderdale and Huddersfield NHS Foundation Trust's delivery of the Recovery Package, designed in partnership between Macmillan Cancer Support and NHS England.

In May 2018 the previous Macmillan Cancer Information Centre Manager, Dinah Coggon, left her position to take up a new Macmillan post in South Yorkshire. The centre manager's post was in vacancy until January 2019, when Helen Jones joined the Trust. During this time, the service was under pressure due to staff vacancy, but continued to offer high level support due to the efforts of Mandy Davies, Assistant Manager and the volunteer team, who offered some cover at both sites. Despite the vacancy, the Macmillan Cancer Information team had 178 more contacts in 2018 than in 2017 (and 1240 more contacts than in 2016), which demonstrates the growing need and demand for the service.

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 2018, as well as demonstrating the impact of the service. The report will give a description of the service in 2018 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 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 work of the service has contributed towards improved outcomes 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 - particularly by promoting health and wellbeing and supporting cancer survivorship.

# OUR 2018 KEY STATISTICS

**1900**

**DIRECT CONTACTS  
— A 9.4% INCREASE  
FROM 2017**

**32%**

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

**£20,866.25**

**IN MACMILLAN GRANTS  
AWARDED TO OUR PATIENTS**

**116**

**PATIENTS ATTENDED  
OUR 3 HEALTH  
& WELLBEING EVENTS**

**8,678**

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

**£1,091,069.48**

**IN ESTIMATED  
BENEFIT GAINS  
FROM OUR REFERRALS  
TO ADVICE KIRKLEES  
& AGE UK**

**100%**

**OF PATIENTS SAID THEY  
WOULD RECOMMEND  
OUR SERVICE**

**87%**

**OF PATIENTS SAID  
CONTACT WITH OUR  
SERVICE DIRECTLY  
HELPED TO REDUCE  
THEIR ANXIETY**

# 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 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 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 Macmillan Information and Support Centre 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.

### **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 and Cancer Care Co-ordinators 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.

## Pillar 4 – We do the must-dos

- We support the delivery of national cancer strategy including the Living With & Beyond Cancer agenda, which states that all cancer patients should have access to the Recovery Package, including health and wellbeing support, by 2020. We are also committed to the NHS long term plan's aim to deliver personalised, tailored care closer to home.
- We meet the quality standards 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), 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.

As well as the Trust's values, our service supports the delivery of Macmillan's 9 Outcomes.

## MACMILLAN'S 9 OUTCOMES:



# ORGANISATIONAL PROFILE

Calderdale and Huddersfield NHS Trust provide care to a population of over 460,000 people and in this year alone the Trust have had 3474 patients with a new or secondary cancer diagnosis. Of these, 3400 were patients with a new primary cancer diagnosis and 74 were 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 8 information pods around the two hospitals.

## OUR STAFF

The service is staffed by two full time members of staff – Dinah Coggon, the Centre Manager being based at HRI and Mandy Davies, Assistance Centre Manager being based at CRH. The Manager post was unfortunately vacant for almost eight months in 2018 (May til December). During this time, both sites were covered to some extent by Mandy Davies and the volunteer team, whose dedication and hard work allowed the service to continue to be offered in both hospitals, despite a vacancy. 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.



Staff roles include a large proportion of direct patient contact, patient related admin and onward referrals, strategic planning and development, co-ordination of the Health and Wellbeing Events offered by the Trust, attendance at meetings and forums, evaluation and service development, 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.



**"I felt a lot less anxious after talking to someone in the Macmillan Centre - it is a fantastic service."**

Patient, 2018

**"The Macmillan Information Service has been invaluable to our skin cancer team in supporting patients to access additional support they may need. Recently, Mandy has helped sign post a skin cancer patient who is terminally ill for financial and carer support. This extra support for patients is often something that cannot be offered at a time restricted hospital appointment. It is important that all our patients have holistic care and the centre's role ensures all patients needs/worries can be addressed."**

**Skin CNS**

## OUR VOLUNTEERS

In 2018, the service was supported by an invaluable team of eight volunteers who helped to keep the service open in both sites during a lengthy manager post vacancy. We lost one volunteer in 2018, who returned to work full time, and other volunteers had their own intermittent periods of absence due to their own health or other issues. 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 volunteers have faithfully carried out many tasks over the year of 2018 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; attending some support groups and other admin tasks. 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 2018. In total our team of volunteers provided a total of 1676 hours of donated volunteer time to the service in 2018, saving the trust/Macmillan a huge £13,123.08 (worked out on the basis of £7.83 per hour, minimum wage).



We asked the volunteer team about why they had volunteered in 2018 and what had been the benefits to them. Responses included:

*"I find chatting to patients and helping them to find solutions very rewarding – and I can see they value being able to talk to someone who has had a similar experience."*

*"It's a privilege to be a Macmillan Information Service volunteer at Calderdale and Huddersfield, and I'm fortunate to be associated with the Charity, as well as fantastic professionals on all sides."*



*"I joined the Macmillan Holmfirth Committee, which helps raise funds and I wanted to see the sharp end of Macmillan to see where the money was spent and to help the general public when they most need it. "*

*"The reason I volunteer is around 'putting something back' - making use of my own cancer patient experience and that of my 'carer'. It's also about bringing my particular (communication) skills with me and being able to use them in a different context."*

*"Working in a cancer service, volunteers need support and guidance from time to time. During 2018 Mandy was essentially the sole person who could be relied upon to provide this support and continuity. It has been a privilege to work with someone who puts the patients at the centre of everything she does. Mandy takes on each new challenge with a huge amount of integrity. There could be no better illustration to show that what we do isn't about branding, it's about people."*

*"Why do I volunteer for Macmillan? Simple, during my recovery period from cancer I became extremely frustrated that I was unable to contact the Macmillan Information Centre at any of the hospitals I attended for treatment - HRI, CRH, and St.James Bexely Wing, despite determined efforts on my part, so I did voluntary work for the trust as my health improved, slowly but surely. Over time I met the Macmillan Manager, Dinah Coggon, who recruited me as a Macmillan Volunteer. From my own cancer experiences, I soon found I had an affinity with some patients undertaking cancer treatment and I could fully appreciate the problems cancer can bring, not only the multiple procedures you become involved with, but also the emotional aspects which effects the 2 F's - Family and Friends. This is where MIC can and does perform a fantastic service to every one effected by cancer. I am devoted to assisting patients and*

*family to the best of my ability and will continue to proffer help whenever and wherever I can. IT IS FANTASTIC."*

## OUR HEADSTRONG VOLUNTEERS

As well as a team of Macmillan Information Centre volunteers, the service also manages a team of 11 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.

Due to increased demand a further two volunteers were recruited to the service in 2018, taking the number of volunteers up to 11. Additional clinics were also set up to accommodate the capacity and recruitment to the service is ongoing due to the demand. In 2018 the Headstrong volunteer team donated a total of 512 hours of their time for patient appointments, saving the trust/Macmillan £4,008.96.

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 2019.

Feedback from the service is gathered on a monthly basis with consistently positive feedback. 100% of all attendees in 2018 agreed or strongly agreed that the service had increased their self confidence by explaining headwear options, had met their needs and made them feel supported by the volunteers. Comments from patients about the service included the following:

*"Thank you for the great service and excellent staff!! Confidence to be myself again and meet the day with positivity. A valuable service!!"*



*"I learned to be positive and learned so much about other choice and change. Staff are great and well prepared to advise and care for patients/patients."*

*"I do feel able to cope with the loss of my hair now. Enjoyed my discussion with the two lovely ladies."*

*"I feel a lot more confident - the two ladies were lovely, helpful & patient with me. I came away satisfied and happy with my purchases."*

*"A great deal of practical information, in a friendly helpful manner."*

## 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 2018 the Office for National Statistics ONS published its 2017 mid-year population estimates, which indicated that there are 209,500 people living in Calderdale which is an increase of approximately 5,600 people since the 2011 Census.



The largest ethnic group in Calderdale is White British (89.7%), as recorded in June 2018. 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 (eg 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

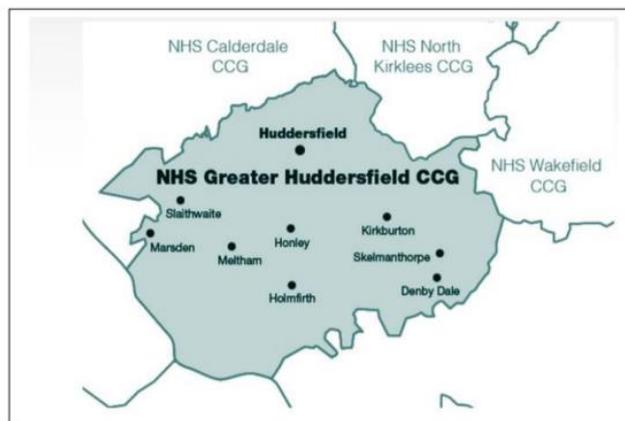
Measured in population terms, Kirklees is one of the larger local authority districts in England and Wales, ranking eleventh out of 348 districts and covering 157 square miles. The overall population of Kirklees rose to 437,000 in 2017 ([source http://www.kirklees.gov.uk/beta/information-and-data/pdf/population-housing.pdf](http://www.kirklees.gov.uk/beta/information-and-data/pdf/population-housing.pdf)) with a population of over 245,000. 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 predominately 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 childrens 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 are also active members of the Kirklees BAME Forum within the local community and the service attends Outreach Events within the local 'hard to reach' communities, including health and wellbeing type events at mosques.

***"This holistic service provides face to face contact when needed, in often very stressful and upsetting circumstances for patients undergoing chemotherapy. For patients to have someone that can sit and talk with them, advise on financial matters re benefits, offer advice re support groups etc. is I feel, vital not a luxury."***

Chemotherapy Day Patient Manager

## WHAT SUPPORT DID WE PROVIDE IN 2018?

### SUPPORTING THE DELIVERY OF THE RECOVERY PACKAGE

The Macmillan Cancer Information service is key to the trust's delivery of the Recovery Package, which according to national cancer strategy, has to be offered to all patients affected by cancer by 2020. Specifically our service provides tailored, personalised and holistic information and support highlighted in a patient's Holistic Needs Assessment and Care Plan (usually carried out by CNSs), allowing clinical teams to concentrate on supporting the physical concerns of the patient and



our team to meet the none clinical needs of a patient/carer. Our service offers a range of holistic support for people affected by cancer which includes:

- Practical support such as work, education, housing, money, pets and transport.
- Emotional support such as coping with fear and anxiety, reducing loneliness and isolation.
- Family or relationship support including support for carers, intimacy and body image support.
- Spiritual concerns such as challenges to faith and sense of purpose.
- Information and lifestyle support on exercise, diet and nutrition, smoking cessation, planning ahead, making a will, complementary therapies.

The service worked closely with the Living With and Beyond Cancer team in West Yorkshire and Harrogate Cancer Alliance in 2018 and supported a patient focus group to determine patient views of what personalised support should look like for people affected by cancer living in Calderdale and Huddersfield. The focus group recommended the need for a named support worker to be an anchor throughout a person’s cancer journey and to signpost to all kinds of support in the acute and community sector. This report and recommendations can be found in the appendix.

The Macmillan Cancer Information Service also aims to support GPs in their delivery of Cancer Care Reviews (CCRs), which again forms part of national recommendations in the Recovery Package. A CCR should be offered within six months of diagnosis and when concerns are discussed as part of the review, GPs/primary care staff can refer or signpost into our service to help meet the identified needs. By promoting the service in GP practices, word can be spread about the service being available to all people affected by cancer living locally, not just those under active treatment. Developing closer links with GP practices is a priority for 2019.

## HEALTH AND 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,

another key part of the Recovery Package, to encourage people to live as healthy and active a lifestyle as



possible once cancer treatment ends. The service also supports cancer teams with the delivery of site specific Health and Wellbeing Events across the trust, and promotes and supports site specific support groups. All of this facilitates the national agenda of supported self-management – empowering patients to be in control during their treatment and recovery.

In 2018 we ran three Health and Wellbeing Events in March, June and November, at various locations. Number of attendees at these events were as follows:

	March 2018	June 2018	November 2018	TOTAL:
Number of Patients Attending:	25	50	41	116



The numbers 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 and on average, 16 staff members/volunteers

attended each event. Breast cancer patients have their own health and wellbeing programme called 'Moving Forward; which is delivered by 'Breast Cancer Now' and so were not invited to the generic Health and Wellbeing Events. Patients were invited to bring a 'plus one' if they wished and various information stalls were also set up at the events.

The format of the Health and Wellbeing Events changed slightly during the year. All included some generic talks by Dr Hannah Gormley, Clinical Psychologist, on managing the emotional effects of cancer; a talk on the benefits and importance of physical activity and healthy lifestyle with some exercise taster sessions; a session on the Macmillan Information and Support Service and presentations by the West Yorkshire Community Panel/Yorkshire Cancer Patient Forum. Patients were also invited to share their stories at some of the events. The initial two Health



and Wellbeing Events were longer in duration, 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. The format changed in November due to budget constraints, with a generic HWBE being provided and clinical teams asked to organise and deliver their own separate tumour specific events/meetings with patients.



Feedback about the Health and Wellbeing Events has been extremely positive, with the events being highlighted by a West Yorkshire & Harrogate Cancer Alliance Event (Recovery Package Implementation Day, 11.10.18) as an example of good practice in the region. Indeed, Christopher Button, Lead Cancer Nurse and a Huddersfield patient, Gill, were invited to share their experiences and talk about the HWBEs to over 50 professionals and patients from across West Yorkshire and Harrogate. Gill talked about how attending a HWBE in 2018 had made her feel 'empowered' to get on with life after her cancer diagnosis and that she felt 'like super woman.'

Other feedback about the HWBEs included:

- *"Very well organised, excellent speakers and a great opportunity to talk with other cancer patients."*
- *"Friendly and welcoming, very informative in a relaxed atmosphere."*
- *"The Psychology Session and site specific sessions were excellent. There was also lots of information and other resources available."*
- *"The topics presented were all good, with barriers being broken down. There was good signposting for physical activities too."*
- *"All stands were well stocked and covered a variety of topics. Everyone was very approachable."*
- *"Brilliant presentations, very helpful info and understanding of patient's journey of cancer and effects. Really appreciate the info."*
- *"Very reassuring as to what other people are experiencing/what is normal!"*
- *"Very interesting and helpful especially as your partner is there to hear these things from someone other than yourself."*
- *"Excellent, supportive and*



*useful – the speaker who described his own experience was amazing, really heartfelt and honest description of his journey – outstanding.”*

- *“The November Health & Wellbeing event was the first time haematology patients were invited to attend. It was great that there was now consistent access to services for all cancer patients and to be able offer this as part of our patients’ end of treatment plan. Mandy was a key part in co-ordinating this event.”*Rebekah Ramsden, Macmillan Haematology Clinical Nurse Specialist

Any negative comments made were essentially about people wishing they had had the information or event sooner in their cancer journey:

- *“Could have done with emotional support/warning straight after my operation.”*
- *“Was unaware there was an Oncology dietician service available whilst I was going through treatment.”*
- *“Session was very helpful. It would have been better had I had access to this day/information closer to my diagnosis and initial treatment.”*

In 2019 we will be reviewing our health and wellbeing support for patients and carers, and looking to develop a wider health and wellbeing programme, as well as events/sessions for people living with incurable cancer.

## INFORMATION AND PROMOTION

During 2018, 1,323 information leaflets were taken from our Macmillan Information Centres in Calderdale Royal Hospital (743) and Huddersfield Royal Infirmary (743), as well as 7,355 leaflets from the information pods in the main entrances and across the hospital departments. This makes an overall total of **8,678 booklets** or leaflets taken. 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, PALS (physical activity programme), 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 2018 to an estimated figure of 9,728 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:

A & E CRH	1239
Main Entrance CRH	2820
Main Entrance HRI	1466
Ambulatory Area HRI	100
Acre Mill Ground Floor	416
Acre Mill First Floor	239
Acre Mill Second Floor	559

The most popular six titles taken from all locations in 2018 are listed below:

- Are you worried about Prostate Cancer?
- Are you worried about Bowel Cancer?
- Understanding Skin Cancer
- Signs and Symptoms of Cancer
- The Cancer Guide
- Giving up Smoking

We have 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.

During this year we also attended 21 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:

Date	Event/Meeting	Reason
16.1.18	Macmillan Bus, Halifax	Sharing local information
18.1.18	BAME Meeting, Dewsbury	
22.1.18	Cervical Cancer Awareness Week	Cross site raising awareness
24.1.18	steering group meeting info service	
13.2.18	Crossley Heath Health Fair, Halifax	Raising the profile of the information service
15.2.18	BAME Meeting Hudds	Raising the profile of the information service
7.2.18	Moving Forward Breast Support Group Elland	Sharing local information
15.2.18	BAME Meeting Dewsbury	

9.3.18	Health & Wellebing event St Johns Stadium	
15.3.10	BAME Meeting Dewsbury	
26.3.18	ovarian/prostate/kidney awareness week cross site	Raising the profile of the information service
21.3.18	Event BAME Dewsbury	Raising the profile of the information service
23.4.18	Bowel & Testicular awareness	Cross site raising awareness
9.5.18	Cancer Education Course	
10.5.18	Cancer Education Course	
21.5.18	Skin Cancer Awareness	Cross site raising awareness
21.6.18	Health & Wellebing Event, Cedar Court	
25.6.18	Male Cancer Awareness	Cross site raising awareness
12.7.17	BAME Meeting Clear, Huddersfield	
18.9.17	Mosque Riza	Ladies health awareness event
21.9.18	Health Awareness, Plain Trees GP Practice	
24.9.18	Leukemia & Lymphoma Awareness	
4.10.18	BAME Meeting Clear Huddersfield	
15.10.18	Breast Cancer Awareness	Cross site raising awareness
	Huddersfield University Event	Cancer awareness and raising the profile of the service
26.10.18	Norland Scarecrow committee	Donation collection
13.11.18	Colorectal Open Day, Briar Court	Raising the profile of the information service
26.11.18	Lung Cancer Awareness	Cross site raising awareness
30.11.18	Coffee Morning MEQM	
3.12.18	Bring your Neighbour Event Halifax High School	Raising the profile of the information service
11.12.18	Insight Health Care	Raising the profile of the information service



*"The Macmillan information service plays a very big role for our patients, in terms of helping with benefits/ heating/ grants/ insurance. Mandy will normally go through the different types of benefits with the patients and will do the referrals to the necessary departments. This is so much appreciated and I have her number on speed dial! Mandy will go that extra mile for you, if she is not sure of something, she will find out and let us know. She is a credit to the Macmillan Unit and does a brilliant job!"*

**Upper GI Cancer Care Co-ordinator**

## PRACTICAL SUPPORT

During the year 2018, 48% of all the enquiries we received were about practical support. The following highlights some of the ways this practical support was given to people affected by cancer, as well as their families and carers.



1. **Headstrong Service** - the Headstrong Hair Loss Service has been an outstanding service offered to local cancer patients by a dedicated volunteer team, as featured earlier on in this report. A total of 94 ladies were seen by the Headstrong team in 2018 – 42 In Calderdale (76 appointments were offered by the volunteer team) and 52 ladies in Huddersfield (87 appointments were available). These figures indicate that unfortunately 42% of the Headstrong sessions made available by the volunteer team were either cancelled due to patients not feeling well enough to attend, not booked or not attended. Further promotion is needed in 2019 to make best use of the fantastic service that is available to patients. The service is available for men also, though in 2018 only ladies were seen.
2. **Blue Badges** – we referred an estimated 78 people for Blue Badges in 2018.
3. **Promoting Physical Activity and Healthy Lifetsyles-** We made referrals to PALS exercise sessions, Restart Fitness, Calderdale Better Living team, smoking cessation and signposted to community health walking groups, dance halls etc.
4. **Onward Referrals** During 2018 we made onward referrals to a variety of organisations, for practical support. This included support such Gateway to Care for home access assessments and adaptations; Occupational Therapy; Onco-Psychology; Advice Kirklees; Age UK; Social Services; Community Mental Health Team, hospices, posture and mobility(wheelchair) services and the Community

Palliative Team. These organisations were then able to provide further emotional and practical support for our patients.

5. **Work Support** – we refer regularly to the Occupational Health Advisory Service in Leeds, funded by Macmillan until Autumn 2019.
6. **Macmillan Support Line** – we regularly signpost people to the national Macmillan helpline, which is now open seven days a week, 8am – 8pm. Anyone affected by cancer is able to access benefits advice, financial advice regarding mortgages, pensions, utility bills and debt advice.
7. **Travel Insurance Information** – we provide booklets and a list of insurance agencies patients have informed us about, as well as signposting to travel insurance suppliers on the Macmillan and Cancer Research UK websites.
8. **Signposting to community groups** – a key part of supported self management is in our signposting to many organisations to reduce social isolation and improve mental health – including specific groups which are for men’s mental health. Organisations we have signposted to in 2018, include Huddersfield Man Shed, Calderdale Phoenix Project, Andy’s Man Club across both districts, Staying Well (Calderdale’s community wellbeing project), and Kirklees Community Directory ([www.kirklees.gov.uk](http://www.kirklees.gov.uk)) for social events.
9. **Carers Support** - in 2018 we signposted and referred to Carers Count in Kirklees and to Calderdale Carers, as well as giving information about carers support at local hospices. Free courses for carers are run by these organisations, so we encourage attendance from the carers of our cancer patients. We are also looking to develop further support for cancer carers in 2019.
10. **Liaison** – 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.
11. **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.
12. Unfortunately the Look Good Feel Better service was withdrawn locally in 2018, though as a service we have been in discussion with Boots due to Macmillan’s national partnership, and plan to set up regular ‘**Boots Feel More Like You**’ sessions in 2019. In 2018, we continued to signpost to ‘Look Good Feel Better’ in other areas including Leeds, Wakefield and Burnley.

13. **Wills** – In 2018 we have provided information about will writing services and funeral costs.

13. **Toilet & Restaurant Cards** – We provide 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

*“The Macmillan Information service is absolutely wonderful and I would definitely recommend them to other patients.”*

Patient, 2018

In 2018, 36% of our service activity was to provide emotional support. A huge 65% of all our contacts with patients, were with people who simply wanted to talk about their experience (1234 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, 6% asked about counselling and psychological support and 0.6% people talked about relationship issues.

Part of our emotional support over 2018 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 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.

Lastly we encourage peer to peer support and provide information on local and regional support groups (including spiritual/faith groups), as well as the Yorkshire cancer patient forum and Cancer Alliance Community Panel. Feedback from our Health and Wellbeing Events has also included information on the benefits of patients supporting one another and sharing tips around treatment and managing symptoms. We also support our CNS teams in their delivery of tumour specific support groups, attending where we can and promoting the groups. In 2018, we have liaised with and supported the Upper GI team who are planning to start a new Upper GI support group in 2019. In 2019 we are keen to consult with patients to find out what new support groups they wish to see developed, as well as potentially starting a new patient buddying service, all to further improve the emotional support provided to our patients.

*“Having a Macmillan Information staff member in the office daily is invaluable to the running of the Oncology clinics. As we usually run on only one qualified member of nursing staff in the Oncology clinics and have up to six Oncology clinics running at a time, I refer a lot of our complex patients to the staff for support and advice.”*

Oncology Outpatient Sister/CNS

# 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.

In 2018 we referred a total of 235 people for benefits advice to either Eileen Murray, Macmillan Benefits Advisor at Advice Kirklees or Age UK in both Calderdale and Huddersfield. Both organisations have provided information about benefit gains and one off payments/arrears for patients referred by the trust in 2018, from which we have been able to estimate the benefit gains and arrears for patients referred by our Macmillan Information Service as a huge **£1,091,069.48**. 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)
2018 Advice Kirklees	115	£475,043.54	£26,841.80
2018 Age UK	120	£464,687.52	£124,496.62
Totals	235	£939,731.06	£151,338.42
Combined regular payments and arrears			<b>£1,091,069.48</b>

The trust CNS and Cancer Care Co-ordinators also make benefit referrals to both Advice Kirklees and Age UK and the overall figures for the region, including our Macmillan Information Centre figures, are as follows (information provided by Age UK and Advice Kirklees, February 2019):

	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)
Age UK (across Calderdale and Huddersfield)	386	£1,498,992	£401,602.00
Advice Kirklees	502	£2,065,406.72	£26,841.80
Total Figures:	888	£3,564,398.72	£428,443.80
Overall Total benefits income gained for patients:			<b>£3,992,842.52</b>

We were able to apply for Macmillan Grants for 61 people facing cancer on a low income, which included requests for help with heating costs, travel expenses and clothing due to changes in weight. We were successful in being awarded a total of **£20,866.25** which was a significant increase of £12,196.25 on the previous year when we secured £8,670.00 for 26 patients.

In 2019, we plan to apply to Macmillan and other charities for grants to support our patients where necessary.

## 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 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 April 2019.

**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, under Dinah Coggon's leadership. 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 and will need to be reviewed under MQEM over the next year.

**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, 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 Jackie Garforth and Greenlea units. Our one fundraising event each year though, is to support the national Macmillan Coffee Morning. In 2018, this was deferred to 30<sup>th</sup> November rather than being held at the usual end of September, as a celebration of achieving the Macmillan Quality Environment Mark, when the plaque was also placed on the wall at Calderdale Royal Infirmary. 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.



# 2018 DATA

## WHO DID WE HELP?

### 1900 CONTACTS IN 2018

This is an increase of 165 contacts from 2017, despite an eight month staff vacancy.

Of these - 962 people accessed the service in Calderdale Royal Hospital and 938 people accessed the service within Huddersfield Royal Infirmary. Compared to the previous year, the contacts at Calderdale increased by 317 in 2018 and in Huddersfield reduced by 152, due to the vacancy at HRI. These figures demonstrate a fairly even split in contacts across the two sites, indicating the ongoing need to deliver the service out of the two hospital sites and maintain at least one permanent staff member in each place.

785 contacts were from people who had used the service in the past and the remaining 1115 were with people new to the service. In Calderdale and Huddersfield there were 3474 patients diagnosed with cancer for the first time or with a recurrence in 2018. This means that the Macmillan Information Service supported 32% of all diagnosed patients in 2018.

## WHO DID WE HELP?

The following charts use data taken from our **1900 direct contacts** with people affected by cancer, in the year 2018.

**MEN** 35% **WOMEN** 65%

(the same percentages as 2017)

## ETHNIC GROUPS

White British	91%
Pakistani	2.4%
Black African/ Black Caribbean	1.8%

<b>Other White</b>	<b>0.8%</b>
<b>Other Asian</b>	<b>0.7%</b>
<b>Indian</b>	<b>0.3%</b>
<b>Not asked/other</b>	<b>3%</b>

The figures above demonstrate 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 in proportion with the population (1.9% in Kirklees), but Asian communities are not (3.1% 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 by attendance at Health and Wellbeing events at Mosques and Sikh temples, as well as membership of the Kirklees BAME network in 2018. This will continue to be an area for development in 2019.

## AGE BRACKETS

The most common age group we supported in 2018 were those people between 55 and 64, followed by people aged 45-54. These figures indicate that we supported slightly younger people in 2018 than in 2017, when our top two categories were people between the ages of 55-64 and 65-74.

<b>Under 14</b>	<b>0.05%</b>
<b>15-24</b>	<b>0.2%</b>
<b>25-34</b>	<b>2%</b>
<b>35-44</b>	<b>10.2%</b>
<b>45-54</b>	<b>28%</b>
<b>55-64</b>	<b>30%</b>
<b>65-74</b>	<b>12%</b>
<b>75-84</b>	<b>4.2%</b>
<b>85+</b>	<b>0.8%</b>
<b>Unknown</b>	<b>12.55%</b>

*“Without a doubt, I felt listened to and supported - the staff were very helpful.”*

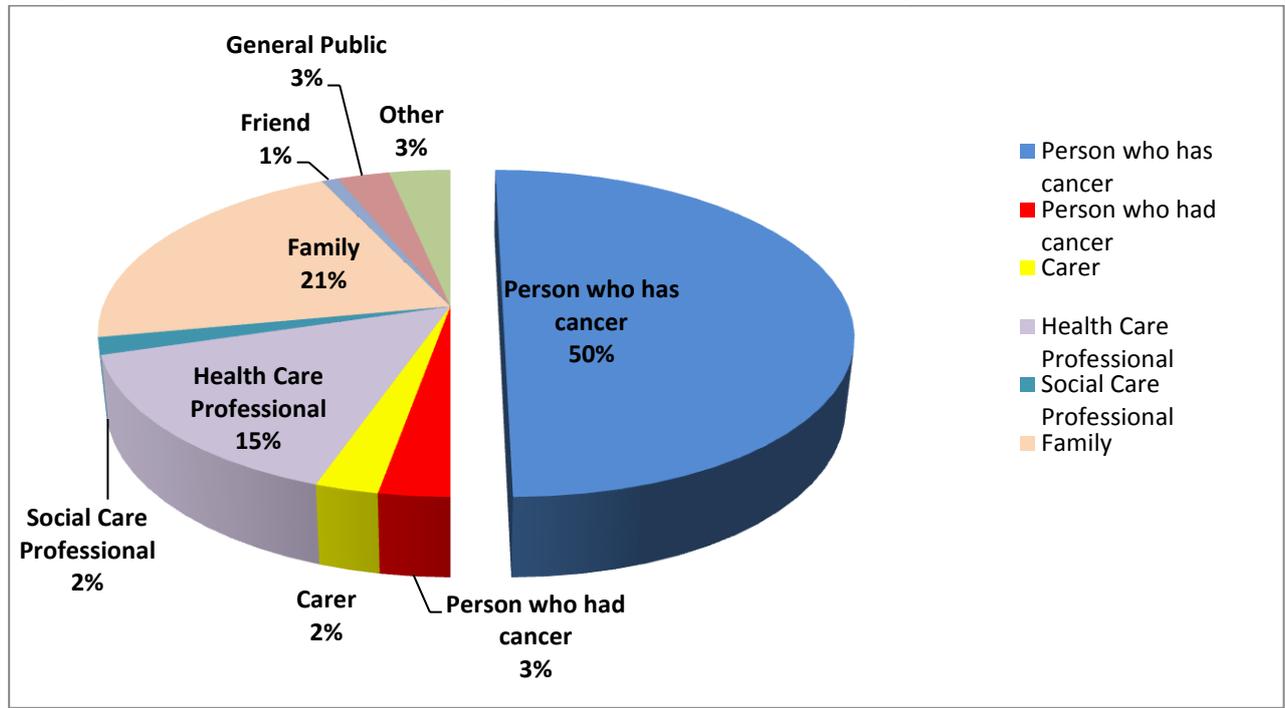
Patient, 2018

***“Mandy has been and continues to be an asset to the team and the patients. Having Mandy on site has made such a big difference and addition to the service that we can offer .”***

Chemotherapy Day Unit  
Manager/Clinical Nurse Specialist

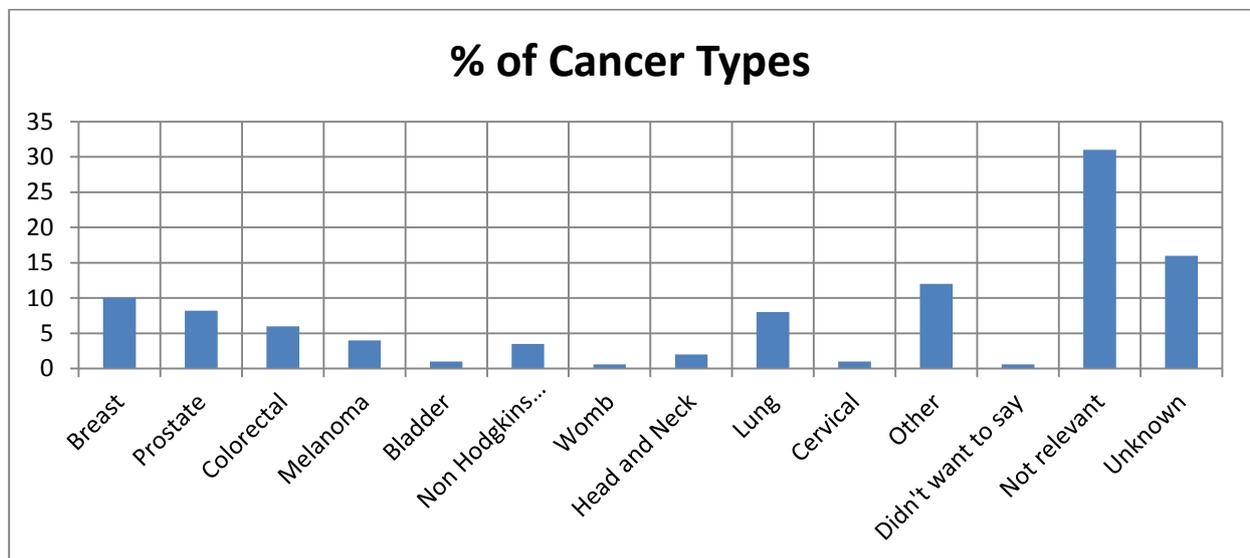
# WHO WERE OUR CONTACTS?

53% of our contacts were with people who currently have or previously had, a cancer diagnosis. The second largest group of contacts was with family members at 21%.



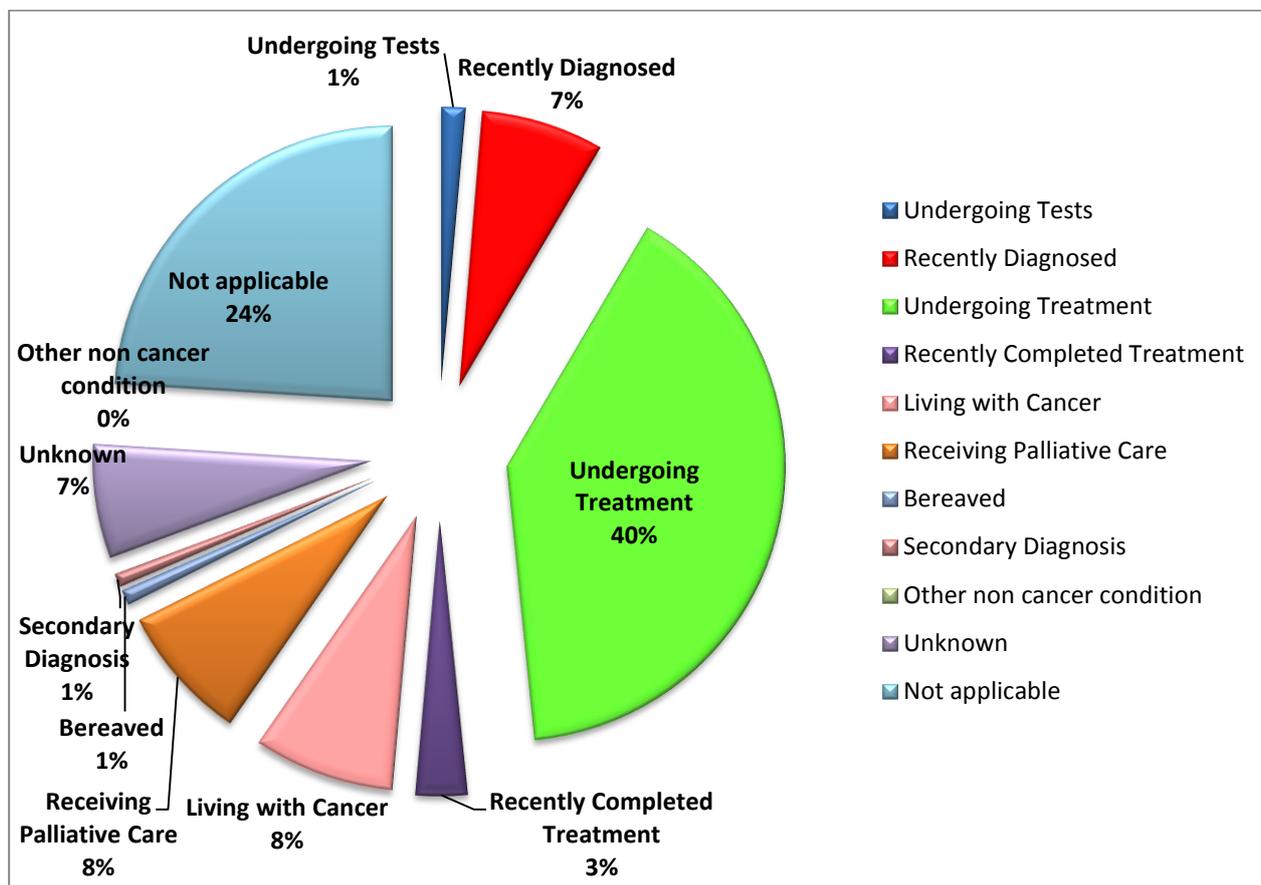
# WHAT CANCER DIAGNOSIS DID PEOPLE HAVE?

Breast cancer patients were the most common people who contacted us during the year, followed by prostate then lung cancer patients. The 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, as well as a number of health professional contacts.



# 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 those living with cancer and those receiving palliative care.



# WHAT DID PEOPLE ASK US ABOUT?



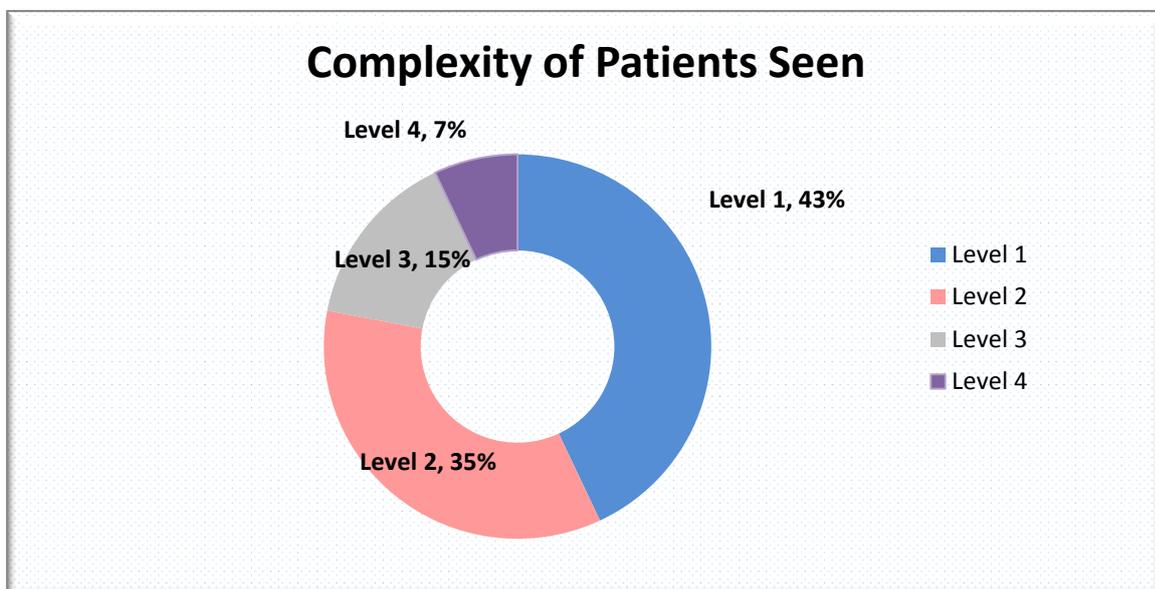
During our 1900 direct contacts, we had 3833 queries about emotional, practical and clinical support. Obviously, some people ask us about more than one area, and want different kinds of help and support.

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 65% of patients. 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 wanting local information & support (28% of patients); then benefits and welfare advice (27%); people wanting information on their cancer treatment (16%); travel insurance (11%); grants and financial support (11%); support for issues around living with cancer (8%); psychological support/counselling (6%) palliative care and end of life (4%) and carers support (4%).

This is slight shift from 2017 figures, where our highest number of enquiries were about local information and support, followed by benefits and welfare advice, then wanting to talk and financial/grant support.

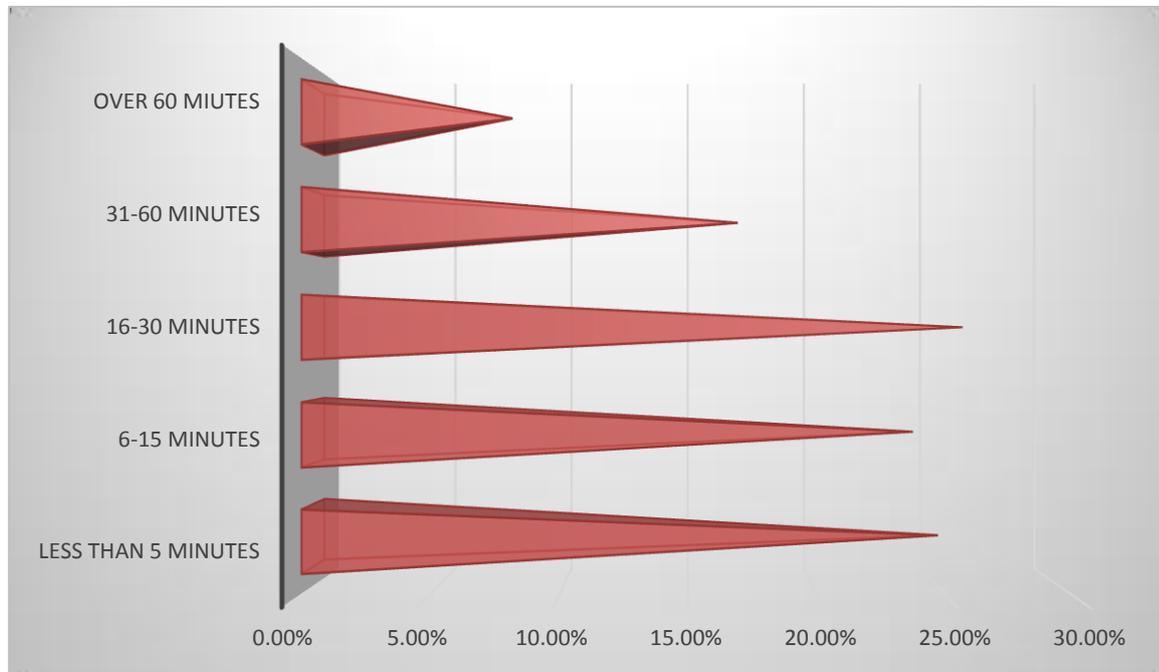
## HOW COMPLEX WERE OUR CONTACTS?

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 fell in the first two categories in 2018.



# HOW LONG WERE OUR CONTACTS?

Our most frequent length of time for contacts was between 15 and 30 minutes, followed by contacts up to five minutes. Contacts over one hour were our least common length of contact.



## PATIENT STORIES

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

### Jackie, 56, diagnosed with endometrial cancer

Jackie was diagnosed in February 2018 with endometrial cancer. She was initially told her cancer was stage one, then when she had had her surgery it was reclassified as stage three, which created a whole mix of emotions. Jackie struggled to process her diagnosis and was initially concentrating on the practical side of transport from Huddersfield to Halifax for treatment, which seemed to be her main focus and which became a distraction. Shock, disbelief and anger all presented themselves and Jackie became distressed. As well as support from the Macmillan Information Centre team, Jackie was supported by the CNS, clinical psychologist and chemotherapy team, all helping her to access varied and appropriate services.

The role of the Macmillan Information Centre was to provide crucial emotional support at Jackie's time of crisis and beyond. Mandy was able to provide a listening ear, mainly

being there when the need to share was strong, offering tea and hugs where necessary. Mandy reported that providing this care, and seeing how much Jackie's confidence grew, restoring her into the remarkable lady she had always been, has been a privilege and honour to be part of.

*"I first met Mandy Davies at the Macmillan Centre in Calderdale when I was first diagnosed with cancer. I was dazed and confused and had no idea what to do or where to turn, or how to tell my family. Mandy was wonderful, helpful and supportive, she helped me make sense of what was happening as well as helping me with practical things such as getting transport to bring me for my treatment, pointing out leaflets which might give me more information and contacts who could help me personally. I can honestly say that I didn't take my diagnosis or treatment well, in fact I was suicidal. Mandy helped me get to the right people to get the psychiatric care I urgently needed. Now, twelve months down the line, Mandy is still there for me. My mental health is still fragile and she is still pointing me in the right direction to find a way through. We have found hypnotherapists and now a Life Coach, which was Mandy's idea and has proved to be incredibly useful to me. I can now say that I feel like my life is worth something. I am proud to be able to say that Mandy has been an absolute godsend to me and she continues to help me tirelessly. If I hadn't met her all those months ago I honestly don't know what I would have done.*

*So, the help and advice from the Macmillan Centre for me was crucial but without Mandy, I wouldn't be here now. Thank you Mandy from the bottom of my heart."*

#### Daniel, 63, diagnosed with prostate cancer

Daniel visited the Jayne Garforth Macmillan unit for guidance and support in 2018. He was anxious, scared and fearful of the future and reluctant to access medical treatment and investigations. The unknown was creating a huge strain on his relationship with his wife. Centre staff worked with Daniel to develop his confidence and strength, in order to enable him to attend for appointments to have investigations, discuss treatment options, and then receive a course of treatment.

Over the course of the year, and by regular contact with the centre, Daniel transitioned from the gentleman who refused to believe he had any issues, to one who faced each issue with courage and huge dignity. Mandy Davies reported that it had been a pleasure to support Daniel and his wife, and a privilege to have been part of his care.

*"The service I received from the Macmillan Information Centre was great. Mandy was so supportive to both myself and my wife and helped by applying for a grant and allowing us to talk, which was so helpful and we were always made to feel so welcome. Mandy and the rest of the oncology team have been very helpful, especially Mandy, when I was first diagnosed with prostate cancer. We always feel very welcome and I do not know what I would have done without Mandy to help us."*

# PATIENT FEEDBACK

In 2018, our feedback was collected via our volunteers who contacted a number of 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/suggestion boxes in the centres, though no comments were made via this means in 2018. Our service also supported the palliative team to gather useful feedback on their innovative project seeing patients in MAU and A&E, which helped to then provide evidence for an award nomination for the team in the Nursing Times.

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; 87% of patients and carers said that contact with our service had specifically helped to reduce their anxiety.

Various comments were made about the support provided by the service, several of which are already featured in this report. Others are as follows:

*"Very supportive and helpful."*

*"Macmillan came up trumps, thank you."*

*"I absolutely felt listened to."*

*"Eileen Murray at Advice Kirklees was amazing - I was grateful that the team referred me to her for benefits advice."*

*"A really good service, thank you."*

*"Would definitely recommend to others."*

*"The lady I spoke to was lovely and she helped my understanding of the information in every way."*

*"I absolutely felt listened to and understood - the staff were lovely."*

*"I would definitely recommend this service and can't think of anything that could have been done to make my experience better."*

*"I don't think there is anything you could do better - the service is very good."*

*"Would definitely recommend - all very good."*

*"A brilliant service, thank you."*

*"My anxiety didn't lessen, mainly due to my circumstances, but the team were still helpful."*

*"The staff were really lovely and I would definitely recommend the service. It was useful to be told about the Macmillan website who had an online community for travel insurance discussions."*

# 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 about the value of our Macmillan Cancer Information Service to them and their patients and were given the following feedback:

*"The Macmillan Information service is an integral part of the support offered to patients/families of those on chemotherapy. It is vitally important that the units on both sites are staffed daily for both patients and staff alike to access information and support as part of the patient treatment/pathway."*

Sarah Zeimer, Chemotherapy Day Unit manager/Clinical Nurse Specialist

*"I have to say from a personal and professional experience I have always found Mandy very helpful, amenable and supportive to me. The support she offers our service and patients has helped our work load tremendously. I have received positive feedback from patients I have referred to Mandy; the support and advice she has given them in a very timely manner has reduced their anxiety and worries."*

Ann Binns, Colorectal CNS

*"I often refer into the Macmillan Information service from clinic, especially the complex patients who require a lot of input. This support ranges from patients requiring help at home; help in the community – especially when patients are living out of their usual area because relatives are caring for them; help with housing, especially when a dying patient is going to be leaving a family member who doesn't necessarily qualify for housing; complex emotional & family needs – either due to mental health issues or when our patients are the main carers for others. I also refer a lot of patients into the service for support with their cancer diagnosis which often includes benefits advice, hospice day care and travel insurance advice."*

Sister Allison Ramsden, Oncology Outpatient Sister

*"I was running a Macmillan Project in ED/MAU for 16 months up to Dec 2018 and Mandy co-ordinated gathering patient and carer feedback for us, using volunteers or doing it herself. This was a massive help to us as a Project and enabled accurate data to be produced to support the Project aims, and it's not possible to gather feedback myself. I've really valued not only Mandy's willingness and flexibility (plus sunny*

*disposition) and also the service they were able to provide as a whole team, which led to us being able to evaluate that part of our work."*

Helen Harris, Macmillan Advanced Practice Specialist Palliative Care Nurse

*"Mandy is a great help to our service. She has lots of knowledge that helps our patients and lots have reported back that she has been of great support."*

Lisa Diamond-Haigh, Colorectal CNS

*"The most vital aspect of Mandy's role has been a presence on the CRH site as much as possible so patients feel they can 'drop in' to the service for additional information, advice and support whilst they are attending the unit for clinic or chemo (or ad hoc if needed). This is obviously a great support for patients, but also myself, as this helps my role as haematology CNS, for example by completing referrals for benefits, blue badges etc."*

Rebekah Ramsden, Macmillan Haematology Clinical Nurse Specialist

*"The Macmillan volunteer really listened to me, which was great. I'm quite happy with the service I received!"*

Carer, 2018

## OUR DEVELOPMENT PLANS FOR 2019

We are excited to build on the success of our Macmillan Cancer Information Service in 2019, and will target the following areas in the year to come:

- 1. Staff Posts** – our assistant manager, Mandy Davies, is funded until September 2020, when Macmillan's project funding comes to an end. It is imperative that we secure funding to make her post permanent in order to have at least one member of staff on each hospital site. Ideally, we would also like to extend the staff team in order to further offer the support highlighted in the aims below.
- 2. Personalising Support for Cancer Patients** – as part of the NHS long term plan, we need 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. 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.

- 3. Wider Promotion of the Service** – our presence at HRI is far less visible than at CRH, and we plan to work with Macmillan and the communications team in the trust to promote the service on a much larger scale. As part of this we plan to introduce a Macmillan information pod with seating, in the main entrance/ground floor of HRI and to review signage around the hospital. We will also devise a regular information centre newsletter for patients and staff, and look to develop our own facebook page, twitter account and website page on the trust's website. We also plan to explore the development of an online information portal/app for patients. We plan to work more closely with the clinical teams to encourage more consistent referral to our Macmillan Cancer Information Service, so that more than 32% of newly diagnosed patients in Calderdale and Huddersfield know they can access our support.
- 4. Expand the Volunteer Team** – our service could not run without the valuable contribution of our dedicated volunteer team. We plan to recruit more volunteers, working with clinical teams to potentially recruit patients who have finished treatment, or carers, who may want to give something back to support others. We are also looking to develop a new patient advocate/befriending team, to provide peer to peer support for people affected by cancer.
- 5. More Patient Engagement and Co-design** – we plan to work more closely with patients to ask what support is needed, which may not be currently available to them. Part of this work will look at developing new support groups for patients across Calderdale and Huddersfield and to look to introduce courses such as the HOPE Course, with patients co-facilitating.
- 6.** We also plan to recruit a patient focus group who can help to design a **new Health and Wellbeing Programme** – looking to establish more regular patient education days/health and wellbeing events after treatment ends and also to introduce wellbeing days/courses for patients with incurable cancer who have ongoing, maintenance treatment, or no treatment. We also aim to more actively promote physical activity as an essential factor which reduces the symptoms of cancer during treatment (such as fatigue), and significantly reduces the likelihood of cancer recurrence in several tumour groups. We plan to work collaboratively with the pre-habilitation post holder due to join the trust in April 2019, to also look at support before treatment commences, including physical activity and education. Introducing such wellbeing/education days would support the trust in the delivery of Risk Stratified Follow Up, enabling supported self management.
- 7. Closer working with GPs across Calderdale and Huddersfield** – we aim to publicise the existence of our Macmillan Cancer Information Service more widely in GP practices and to GPs directly, by attending meeting and GP training events. Awareness of the existence of our Macmillan Information and Support Service should support GPs or practice nurses to know where to signpost patients to, after carrying out Cancer Care Reviews. We also aim to promote the service via

GP practices to 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 work closely with social prescribing and community services to knit patients more effectively into support in their communities, which enables better outcomes. We also plan to work in closer partnership with local Carers agencies and more actively refer to the services and courses provided by these organisations.
- 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**

**MACMILLAN  
CANCER SUPPORT**

Calderdale and Huddersfield   
NHS Foundation Trust