

MACMILLAN CANCER INFORMATION & SUPPORT SERVICE ANNUAL REPORT 2020



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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 2.1.2020 to 31.12.2020

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EXECUTIVE SUMMARY

This report describes the activity, aims and impact of the Macmillan Cancer Information and Support Service at Calderdale and Huddersfield NHS Trust, in the year 2020. This was an unprecedented year, heavily impacted by the Coronavirus pandemic, but the service competently adapted its delivery in order to continue to provide high quality personalised support and information for cancer patients and their families.

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. As well as demonstrating the varied practical, emotional and financial support provided to patients, carers and health professionals during the year 2020, the report describes the health and wellbeing/patient education programme co-ordinated by the service. The report contains a detailed breakdown of data from 2020, 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 being included in the appendix. The report concludes with the development objectives of the service for 2021.

"An absolutely fantastic service – friendly, efficient, caring and helpful. They go above and beyond in all they do and the help I was given has been a lifeline to me."

Patient 2020

Your team made me feel like an individual that someone cared about, and not just an NHS number. A big thank you - I now feel I am in a better place and facing the future with positivity.

Patient 2020

INTRODUCTION

In 2020, the Macmillan Cancer Information Service continued to provide personalised, high quality support for local people affected by cancer, as well as their families, friends and carers, both before and during the Covid pandemic. The service began in 2012 and operates out of the Jayne Garforth Macmillan Information Centre in the Macmillan Unit at Calderdale Royal Infirmary and the Resource Room in Greenlea Oncology Unit at Huddersfield Royal Infirmary. The service provides cancer 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 large Macmillan Information pod in the entrance to HRI.

The service was grateful to appoint a third staff member in June 2020, Holly Smith, who joined the service as a Macmillan Information Support Worker, on a twelve-month secondment. Sadly, since March 2020, the dedicated volunteer team for the service

have been unable to be physically present in the hospitals due to the Coronavirus pandemic, though some volunteers have been involved in virtual and telephone support for patients.

The Macmillan Information and Support 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, right 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.

2020 was an incredibly busy year for the service, which had more contacts than any previous year of its existence. The service maintained a high quality and beneficial standard of care throughout the Covid pandemic, consulting with patients and family members at various points about how to implement delivery of virtual support and education sessions. Though face to face delivery was not offered for 10 weeks of the year (end of March – mid June), telephone and virtual support via Microsoft Teams, was offered throughout the year, as well as the service running a Cancer Support Line for the Trust. Staff have been available since June for face to face support also.

The service also led on delivery and implementation of the Health and Wellbeing/ Patient Education Programme for cancer patients, across the Trust in 2020. The first three months of 2020 involved delivery in person, and this then shifted to virtual delivery via Microsoft teams. This transition involved engaging with patients and family members via the Cancer Patient Focus Group, to shape the virtual adaptations of the Health and Wellbeing programme. In addition to the First Steps Cancer Programme, Thinking Ahead and end of treatment Health and Wellbeing Events, the service also offered a new online course – iHOPE – Macmillan's health and wellbeing course to help manage the stress of a cancer diagnosis. The service also continued to provide support groups throughout 2020 to offer key peer support – in person prior to the pandemic and then virtually via Microsoft Teams. The service manager was also invited to present at two national NHSE webinars, one of which in November 2020, was delivered with a patient rep, to showcase patient co-design of the education programme and virtual delivery.

This annual report will attempt to demonstrate the impact of the Macmillan Information and Support Service, showing how it has offered personalised support at the point of need and that it has contributed towards improved outcomes and patient experience, for people affected by cancer in CHFT.

OUR 2020 KEY STATISTICS

3166

DIRECT CONTACTS

12% INCREASE FROM 2019

29%

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

£1,195,978.68

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

356

**ATTENDANCES AT
OUR HEALTH AND
WELLBEING PROGRAMME**

288

**ATTENDANCES AT
OUR SUPPORT GROUPS**

731

**REFERRALS MADE
TO OTHER SERVICES**

£44,685

**IN MACMILLAN GRANTS
AWARDED TO OUR PATIENTS**

100%

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

2338

**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 in terms of delivering the four pillars of compassionate care (putting the patient first, 'go see', working together to get results and doing the must do's). We also adhere to Macmillan Cancer Support's strategy around personalised support for cancer patients from diagnosis and right throughout the cancer journey. This includes adherence to MQUISS – Macmillan's Quality Standards for Information and Support Services and MQEM – Macmillan's Quality Environment Mark.



The service also crucially delivers national cancer strategy around supported self-management and the personalised support agenda identified in the NHS Long Term plan by:

- Providing high quality information, emotional, practical and financial support, as well as onward referrals, to address a patient's diverse needs.
- Offering holistic, personalised care for patients from the point of diagnosis and throughout the cancer journey, to help to manage the impact of cancer on a person's life. This holistic assessment and support saves clinical teams time in meeting the social and psychological needs identified by patients, through signposting and referral to community and appropriate services.
- Implementing the Health and Wellbeing/Patient Education Programme (PEP) strategy for cancer patients to promote supported self-management and reduce pressures on clinical teams. PEPs at the end of treatment for cancer patients who are on risk stratified/patient initiated follow up, keep patients from requiring numerous hospital visits as they self-manage. The Thinking Ahead Programme for patients with incurable cancer, supports the national end of life targets

around advanced care planning and may prevent some unplanned end of life hospital admissions.

- Running support groups, the Cancer Patient Focus Group and recruiting patient reps to provide peer support and highlight the importance of the patient's voice in service improvement within the trust.
- Further integrating services and support with the community, such as greater links with GPs and social prescribing link workers, for equitable and sustainable services.
- Further supporting of vulnerable and hard to reach communities, to start to address health inequalities.

ORGANISATIONAL PROFILE

Calderdale and Huddersfield NHS Trust provide care to a population of over 460,000 people and in 2020 the Trust had 3,171 patients with a new or secondary cancer diagnosis (262 patients fewer than in 2019). Of these, 2,765 were patients with a new primary cancer diagnosis and 406 had a recurrence or secondary diagnosis.

In the year 2020, the service had contact with 920 newly diagnosed patients, equating to 29% of those newly diagnosed within the trust. This is a slightly lower figure than the previous year and the service is committed to continued promotion in order that more patients across the trust and region, can benefit from contact with and support from, the Macmillan Information team.

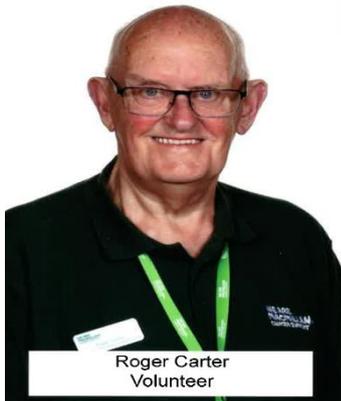
OUR STAFF The service consists of three full time staff members – Helen Jones - Service Manager, Mandy Davies – Assistant Manager and Holly Smith – Macmillan Support Worker. Holly's position has been funded via the West Yorkshire and Harrogate Cancer Alliance for a 12 month secondment, from June 2020 – May 2021. Due to the increased demands on the service, a business case was submitted to our hospital trust, to try to secure permanent funding for a support worker position within the service. At the time of writing this report, the funding has kindly been agreed by CHFT and we are currently recruiting to a permanent support worker role. We are extremely grateful that the trust has recognised the value of our service in enhancing patient care for people affected by cancer and funded a third staff member going forwards.

'Your support changed my outlook on my situation, from cancer-centered to 'me-centered'. Then, as a person I felt informed, not alone, truly cared for and in safe hands. I felt 'I can do this'. I thank God for your call and skills. I thank you for using them to make my entire life better.' Patient, 2020

OUR VOLUNTEERS

The service is supported by three teams of invaluable volunteers – the first, Macmillan Information Service volunteers who meet and greet patients, run support groups and provide hospitality at events and courses as well as providing face to face and telephone support; the second – Headstrong volunteers who provided a fortnightly hair loss support service and thirdly – patient reps who attend courses to share their story, help to lead the cancer patient focus group and represent the patient voice in various settings.

Although our volunteers have not been able to come into the hospital since March 2020, many have been phoning patients for emotional support/buddying, which some describe as having been a life line and reducing their isolation, particularly as people have faced cancer and the Coronavirus pandemic. Our volunteers have also embraced the virtual delivery of support, helping with our various support groups, courses/education programmes and patient focus groups, all of which have run online since the pandemic began. With the help of our volunteer walk leaders, we were also able to set up a virtual walking group, where the volunteers would film walks and play these in the online meeting.



In 2020, we sadly lost two of our amazing volunteer team to cancer. The first, Roger Carter, had volunteered with the information service for four years and supported hundreds of other patients. The second, Steve Thackray, was one of our patient reps who had been instrumental in



co-designing our First Steps programme and in running the patient focus group. We are so grateful for the fantastic contributions that Roger and Steve made to our service, and they will be hugely missed, not only by their families, but by our staff and volunteer team too.

We asked our volunteers for some feedback about volunteering in the rather unusual year of 2020 and this is what they said:

'This had been a strange year with volunteers not being allowed into the hospitals. Until the first lockdown we had the new display area in the HRI which was a great improvement and over the first three months was settling down. I have learnt new skills with Zoom and Teams which has been good to still to be able to talk to colleagues. The contact through the Information Centre has been excellent.'

'Volunteering this last year has been strange but the staff team have worked so hard to ensure the service can work even though it is a virtual experience and have kept us volunteers up to date on all the events being held online. I took part as a guest on

ihope and the staff made a brilliant team whilst facilitating and the guests really warmed to them. The virtual meetings online meant we volunteers were able to see each other and chat - I appreciate being able to keep in touch with people. I can't wait to be back in the information centre, till then keep on doing what you do so well.'

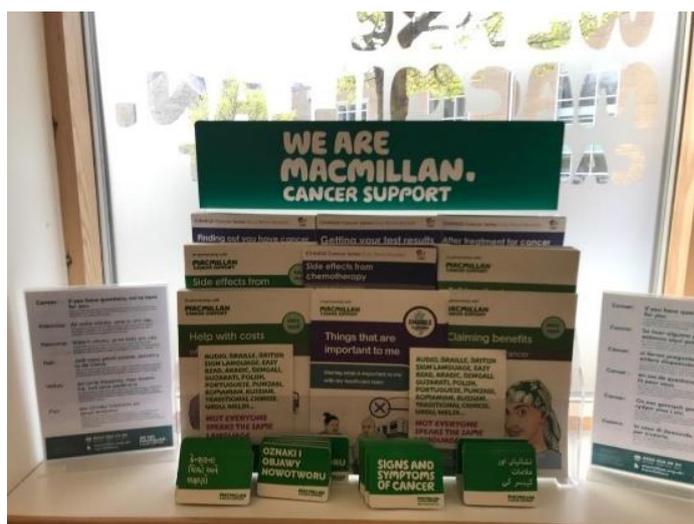
'The Team have done amazing in setting up Groups online for patients. I've been able to dip in to these services at times and I'm really proud of everyone involved in making this happen, making a difference in these very uncertain times!'

'2020 was definitely a surreal year for volunteering because it was none existent and I've really missed it. The feeling of usefulness and passing on our expertise has really hit hard. I've missed the routine and connecting with the other volunteers and the patients, having a laugh, sometimes a bit too loudly and being told off that the consultants can't concentrate. lol. I feel for the patients because they haven't had that extra link in the chain of their journey for hair and scalp care, headwear trying on and another ear to listen too them, someone not involved with them on a personal level. I know the ladies appreciated this and the humour and a light-hearted hour just for them. Until I've written it down I didn't realise how much I've missed it.'

Our staff and volunteer team have worked closely with the Trust cancer team in 2020, in particular Christopher Button, Lead Cancer Nurse and Nicky Hill, prehabilitation lead, to promote service developments and improved patient experience.

EQUALITY & DIVERSITY ASSESSMENT OF THE SERVICE

Information displayed in the centres is predominantly English, however at each site some cancer awareness information is provided in the commonly used languages in the region (Punjabi, Urdu, Gujarati and Polish). The service is able to order materials from Macmillan, in different languages, as well as using the Trust's interpreting service to have materials translated into different language. 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.



Within both of the information centres, information is provided in various formats such as Easy Read information for people with learning disabilities, Braille, Audio and

children's books. A hearing loop is available at CRH for service users with a hearing impairment.

In 2020 the service has been part of a project with NHS England looking at what support is needed in diverse communities, when a cancer diagnosis is made. This has focused particularly on how to encourage patients and communities to engage with the First Steps Cancer Programme, which then triggers other support.

Sadly the Coronavirus pandemic has impacted the plan of the service to attend community outreach events at Mosques and community venues, to further promote links with minority ethnic groups across the region. It is hoped that attendance at events can resume in the next couple of years.

'I can't describe how relieved I feel after contacting the Macmillan Information Service. You think you can manage and so just get on with things. Your service got lots of support in place for myself and my husband, which just means a great deal and is a huge help to us, thank you.' Family Member, 2020

WHAT SUPPORT DID WE PROVIDE IN 2020?

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.

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. The team provide flexible support as identified 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.

As well as the personalised conversations, 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.



CO-ORDINATING THE HEALTH & WELLBEING PROGRAMME

A key role of our service is to co-ordinate and organise the Trust's Health and Wellbeing/Patient Education Programme for cancer patients and their families. At the start of 2020, we had three courses running face to face, which were:

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

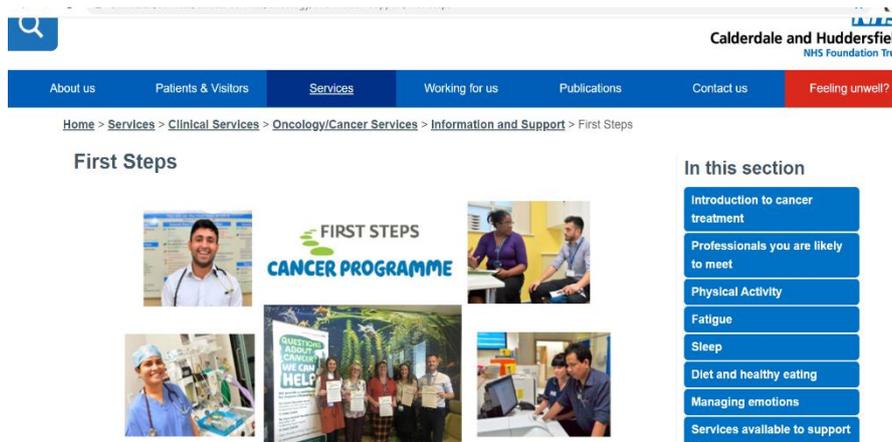
When the Coronavirus pandemic struck in 2020, we were committed to moving our health and wellbeing support online as soon as possible and so we held several virtual patient focus groups to ask patients how we should do this. The patients were then able to co-design the virtual delivery of our various courses and educational sessions. It is important to state at this point, how grateful we are to an amazing IT support team at CHFT, in particular Richard Hill and Clare Sibbald whose dedication, expertise and patience helped us to get set up with Microsoft Teams at the start of the pandemic and to be able to offer various online courses and support groups, at a very early stage.

Without their technical expertise, we would have struggled to deliver so much crucial support for patients and family members.

1. FIRST STEPS CANCER PROGRAMME

Our patients told us that they wanted First Steps to be run like a book club – with lots of information on our hospital website and videos they could watch on different topics, at their leisure. They also suggested a monthly online meeting or discussion group to come together with staff and ask any questions about the First Steps content.

The patient recommendations accelerated the team's plans to update the oncology pages of the hospital website and record various videos of different talks and presentations. The videos were also put into



a DVD format to be sent out with paper information for those who struggled with technology. First Steps started to run as a monthly online discussion group in June 2020, for newly diagnosed patients and family members, and as in the face to face sessions, we have included a patient sharing their story at the start of each discussion group, which has been appreciated by the attendees. The sessions have received very positive feedback from patients in 2020:

'Knowing there is so much support at all stages greatly reassured me, many useful aspects covered.'

'It was good to discuss emotions and wellbeing because at the diagnosis stage you focus on treatment.'

'We are a very informed family but this course reinforced our knowledge – the sleep advice was very useful and listening to a patient's story.'

'It was good to include speakers who have 'lived' the cancer road.'

'Wish I had this course when I had a diagnosis of cancer 2 years ago, this is my second episode. Really helpful to have information given verbally, felt personal. A very worthwhile course.'

Unfortunately patient numbers for First Steps have been low since launching the virtual programme, though statistics show that many more people are accessing the First

Steps information on the website, which is encouraging. We continue to explore new ways to increase attendance, including the introduction of a letter from a patient encouraging newly diagnosed patients to book on.

2. HEALTH & WELLBEING EVENTS

Our first end of treatment Health and Wellbeing Event was planned for 30th March at Southwood, Halifax, but had to sadly be cancelled due to the country going into lockdown on 23rd March. We ran a virtual health and wellbeing event in October 2020, with 25 patients attending. 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. The morning session consists of generic information around keeping physically active, managing emotions, diet, sleep and fatigue. In the afternoon there is a specific session with the clinical team, whereby patients can ask any questions and learn about managing side effects. At the end of the day, our service was able to talk about ongoing support which could be offered and the iHOPE course which was being introduced in November 2020. All of this facilitates the national agenda of supported self-management – empowering patients to be in control during their treatment and recovery.

Our one virtual Health and Wellbeing event received positive feedback, as below and four more events are planned for 2021.

'Thank you for organising and facilitating the course, my partner and I enjoyed it and found the content valuable.'

'Overall it was a good session and I appreciate you all taking the time to do it, especially as the nurse we had wasn't meant to be working!'

'It reassured me that I am doing the right things. I've worked hard to keep my emotional wellbeing in good shape and the advice the psychologist gave was perfect.'

'Very engaging session which introduced interesting ideas and concepts. It was reassuring to know that concern about the recurrence of cancer after the end of treatment is very common.'

'The day was informative but would have been better earlier in my recovery.'

'Again, a very engaging session particularly the focus on resilience / strength training which made me realise that this kind of exercise isn't all about machismo or body fascism. Resilience fitness is neglected in my current exercise regime and I need to address it.'

'Fatigue was what I really wanted to find out about, found all of it very useful and informative.'

'The session with the clinical team was the most beneficial part of the session for me. Being able to ask questions and being able to hear other people's experiences.'

'The clinical session was excellent because it was a small group and we were all able to ask our questions and the team were lovely.'

"The Macmillan cancer support team is very organised and plays a key role for cancer patients in CHFT. I have been very impressed and satisfied with the promptness of their support to the patients and I have received excellent feedback from patients. The team show professionalism and pleasing attitudes towards the patients, colleagues and support staff. I would hope this support to continue for our cancer patients and our Oncology team in CHFT."

Dr Ramanujan, Medical Oncology
Consultant

3. THINKING AHEAD PROGRAMME

After successfully running two face to face Thinking Ahead courses in November 2019 and March 2020, we consulted with previous attendees as to how this course could be delivered online during a pandemic. This course is specifically for patients who have an incurable cancer diagnosis, and their relatives. Topics include managing uncertainty, fatigue, diet, keeping active, advance care planning, estates planning and finance, an introduction to hospices and more. The patients recommended running this over seven weeks, with shorter sessions of an hour to an hour and a half, to allow more time for discussion. 11 people



attended our first virtual Thinking Ahead course, in September – October 2020, with a mix of people who had different cancer diagnoses, as well as family members. Despite

some technical hitches along the way, the course was a success and positive feedback was received, as follows:

'It's been good to 'do' something – I've been in limbo as no treatment is being offered, so the course has been a good focus.'

'It's brilliant that the Trust offers such a course as this – it's helped me to feel informed and well supported, and my wife too.'

'I thought at the beginning that I wasn't sure I needed to do the course, but I am very glad that I did as it has been very helpful.'

'Good course – there is need for education not sympathy when you are faced with incurable cancer. We want to know how to empower others to talk to you and the course has helped with that.'

'I feel as if the course has helped me learn to live with secondary cancer. Some elements were 'close to the line' - you really don't want to talk about this, but actually a 'heads up' made me think and helped me to get things sorted.'

'The session on Advance Care Planning gave us the opportunity to start talking about this and the 'what if's' as a family. We didn't know how to tackle that conversation before starting the course.'

'The course has given me lots of new knowledge and it has been really valuable to talk to one another. I feel TA has helped me prepare for the future.'

4. IHOPE PROGRAMME

Our service has sought to continue to develop and introduce new initiatives despite the global pandemic, and one such initiative in 2020 was the introduction of the iHOPE programme – Macmillan's six-week health and wellbeing programme to support self-management. This is a positive psychology course, aimed to

reduce the stress of cancer and is appropriate for anyone with a cancer diagnosis. Helen, Mandy and Barbara, one of our volunteers, had previously trained as face to face HOPE course (Help Overcoming Problems Effectively) facilitators with Macmillan, though the pandemic meant there was not an opportunity to deliver a face to face course. However Macmillan adapted the course and offered further training, which Holly was included in, in order for us as a team, to deliver a virtual iHOPE course. We ran our first virtual



iHOPE course in November-December 2020, as a national pilot for Macmillan, with the addition of weekly meetings on Microsoft Teams to discuss the week's learning and topics (most districts run the course via a website without a weekly online meeting). Feedback from the 20 patients who enrolled in our first course, was extremely positive, all valuing the weekly meetings, and their recommendation to the national Macmillan team was that weekly meetings enhanced the iHOPE course. After the first iHOPE course and passing assessments as facilitators, Macmillan gave permission for us to continue to offer the iHOPE programme as part of our patient education, health and wellbeing package – only one of five trusts nationally to be given this authorisation.

Macmillan analysed the data and feedback from patients and said the course had made a statistically significant difference in mental wellbeing in the patients who had attended the course. Below are some comments from the participants:

“I was a little sceptical about taking part in the course to begin with, I’m unsure why. However, I am so glad I made the decision to take part. It has given me lots of strategies and tools to use and a different way to look at certain situations. Everyone in the group has been so supportive of each other.”

“In my opinion, the weekly online group was a major factor in helping me to complete the iHOPE course and benefit from it. Sharing experiences and feelings with others made me feel as if I was not alone.”

“Thank you so much for facilitating the iHOPE course. I have really enjoyed doing it and learnt a lot. I especially think that the weekly Microsoft Team meetings we had to talk about our progress and keep in touch with one another, were very beneficial.”

“I just want to thank you for allowing me to do the course. I found each week incredibly thought provoking, and I have made copious notes, which I have been re-reading. I found the parts on unhelpful thinking especially pertinent. What a very clever course - I have so much more understanding of my thought process now, and a load of strategies to use.”

One of our participants, David Blunt, made a video to encourage other patients to join the iHOPE course, which is available at this link:

David talks about his experience of joining a recent iHOPE course



How do I book a place?

<https://www.cht.nhs.uk/services/clinical-services/oncology/information-support/health-and-wellbeing-programme/ihope-help-overcoming-problems-effectively>

David is also about to train as an iHOPE course facilitator, to help us lead iHOPE courses in 2021 and beyond, as well as joining us as a patient rep and volunteer in 2021.

'I have attended several courses, Thinking Ahead, iHope, etc which were superb, thought provoking and emotional, but handled so well, despite being virtual and always putting us patients needs first, which is not easy, when sometimes all you need is a hug.'
Patient, 2020

INFORMATION AND PROMOTION



We have continued to provide a high level of information in 2020, though we were instructed by our infection control team, to remove all of our paper booklets from the information pods around the hospital in March 2020, and were only able to keep physical copies in our two information centres. We were also asked to quarantine any booklets if somebody picked them up and put them down again. We produced laminated cards for every booklet in all of our

information pods, which contained a QR code so that patients could scan the QR code and access the booklet directly from the Macmillan website. We have also sent many more electronic booklets via email to patients, but despite this, have still distributed 2,338 booklets over the year.



In 2020 our **newsletter** became an even more important way to keep in touch with patients, staff, volunteers and other organisations, and we began to produce this monthly rather than every other month. As well as informing patients of support group and course dates, the newsletter also aimed to reduce isolation and give crucial information about accessing Covid support.

Welcome to our Newsletter December 2020

MACMILLAN CANCER SUPPORT Calderdale and Huddersfield NHS Foundation Trust

We are the Macmillan Information and Support Service based on the Greenlee Oncology Unit at Huddersfield Royal Infirmary and at the Jayne Garforth Macmillan Unit at Calderdale Royal Hospital. We're here to help everyone with cancer live life as fully as they can, providing practical, topical and emotional support. So whatever cancer throws your way, we're right there with you. Why not contact us to find out how we can help on: 01484 343614 (HR) 01422 222709 (CRH) or Email us at cancer.information@nhs.net

TELL US WHAT YOU THINK!

Welcome to our final newsletter of 2020! It has been a privilege to support you all during this very challenging year and we hope you found our support useful. If you would like to give us any feedback about our support in 2020, please send an email to cancer.information@nhs.net or give us a ring on one of the above numbers.

FIRST STEPS **VIRTUAL FIRST STEPS PROGRAMME**

Our information and support session for people recently diagnosed with cancer continues monthly, online. The aim is to help you support yourself and know who can support you, as you start your cancer journey. We have recorded various videos and put information on our Trust website which can be read and watched at your own leisure. Please either Google 'CHFT First Steps' or follow the link <https://www.cht.nhs.uk/services/clinical-services/oncology/information-support/first-steps>. Then, join us on Friday 4th December at 10am or Tuesday 15th December at 6pm for an online discussion group with professionals, where you will have a chance to ask any questions. The next session will be on Friday 8th January at 10am.

END OF TREATMENT VIRTUAL HEALTH & WELLBEING EVENT

This event aims to support you to live a healthy lifestyle following cancer/cancer treatment. The event is on **Tuesday 26th January 2021, 10am until 2.30pm** via Microsoft Teams. It will involve discussing various aspects of living with and beyond cancer that may be important in ensuring that you move forward and enjoy a healthy lifestyle.

Both patients and family members are welcome to join the above events. **To book onto First Steps on the Health and Wellbeing Event** please complete the consent form on our trust website at this link, which will generate a booking email: <https://www.cht.nhs.uk/services/clinical-services/oncology/information-support/first-steps/book-on-first-steps-discussion-group/>. If you have any difficulties booking, or if you do not have the technology and would like some information to be sent in the post, please contact Heather Miner on 01484 343490 or e-mail Heather.Miner@nhs.net.

Edition 16 December 2020

VIRTUAL CHRISTMAS SING-ALONGS!

Wednesday 16th December 2pm-3pm Join us for some carols and a Christmas Quiz on Microsoft Teams. (Christmas hats optional!) Everyone welcome!

VIRTUAL SUPPORT GROUPS IN DECEMBER 2020 & JANUARY 2021

The dates for our online support groups, via Microsoft Teams are:

Virtual Macmillan Health Walk Virtual Macmillan Coffee Support Group

Thursday 3rd December 1pm-2pm Wednesday 9th December 2pm-3pm
 Thursday 7th January 1pm – 2pm Wednesday 20th January 2pm – 3pm

Please contact us to book a place. You will need to have a device with a webcam and microphone, which are built into most laptops/tablets and smartphones.

BAME PROJECT We are currently involved in a Quality Improvement Project with NHS England, to work more closely with Black, Asian and other Minority Ethnic Groups. This is particularly focused on support at the time of a person's cancer diagnosis and access to our First Steps Cancer Programme. If you are part of the BAME community, we would love to hear your views about what support is needed and how this should be delivered. Do contact us to find out more or get involved- thank you.

FIRM ROOTS CHRISTMAS CELEBRATION

Firm Roots is a national Christian cancer support organisation, with a monthly support group in Huddersfield. They are holding a Firm Roots Christmas Celebration on zoom on Thursday 10th December, 6.30pm to 8.30pm. Everyone is welcome to join for carols, reflections and prayers for people affected by cancer. Contact Helen.Jones@firmroots.co.uk or phone us at the information service for booking details.

DEBT ADVICE

If you are struggling financially, there are a number of organisations who provide free debt advice and debt counselling. You can speak to a debt advisor on the Macmillan Support Line - 0800 908 0000. Other organisations offer debt support such as CAP (Christians Against Poverty) - 0800 328006, Step Change - 0800 1381111 and CAB (Citizens Advice Bureau) - 0800 1448848.

CHRISTMAS AVAILABILITY

Our services will be slightly reduced over Christmas and we will be closed on bank holidays. Please leave a message if you need us and we will return your call as soon as possible. You can also contact the Macmillan Support Line on 0800 908 0000.

Sending our best wishes for Christmas and the New Year to you all

From the Macmillan Cancer Information & Support Service
 Calderdale and Huddersfield NHS Foundation Trust, Greenlee Unit, HR and Jayne Garforth Information Centre, Macmillan Unit, CRH, Tel: HR - 01484 343614; CRH - 01422 222709
 Email: cancer.information@nhs.net

We also began to send our newsletter to GP practices across Calderdale and Huddersfield to make GPs more aware of the service and virtual support we provide, which has positively impacted our communication with GPs and led to increased referrals from GP surgeries. 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. Our monthly newsletter now goes out to around 850 people, including those who receive the newsletter by post as well as email.

Our **Facebook Page** has again been an important way for us to communicate with our patients, family members, organisations and the public, throughout the pandemic, as well as for promoting cancer awareness information. 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 through their social media channels.

The service is invaluable to staff and patients. You are a fantastic source of information, advice and support, and make such a difference to the patient journey (and to staff sanity!!) Nothing is ever too much trouble. You think outside the box, are willing to go the extra mile for patients and offer a true personalised, holistic service.

Jenny Jones, Trainee Oncology Advanced Clinical Practitioner

PRACTICAL SUPPORT

During the year 2020, 60% of all the enquiries we received were about practical support, which is a slight increase since 2019. This includes signposting and many onward referrals in order for people to access tailored support for themselves and family members. In 2020 we made 731 referrals to different organisations for people to access practical, emotional and financial support, as well as signposting to numerous organisations/professionals for support. During the pandemic, many referrals were made to the local Covid response teams for shopping help in particular, as patients were shielding. Practical referrals were sent to Gateway to Care for home adaptations and care assessments, wheelchair providers, housing teams, hospice care- co-ordinator teams and many more. In 2020 we helped 134 people apply for a Blue Badge for disabled parking, which is often very much appreciated by patients who often struggle with fatigue. We were also contacted frequently about work support in the context of the pandemic and cancer, and issued many NHS England and Trust isolation letters in order for patients and family members to continue to be paid whilst they had to isolate, or to provide evidence for furlough if a family member was under treatment.

In 2020 we continued to liaise with lots of different professionals on behalf of patients, such as clinical teams, GPs, psychology staff, hospice staff, housing teams, university tutors and community organisations. The purpose of our liaison was to reduce the pressure on the patients to have to liaise with different services and to enhance their experience and sense of support and co-ordination.

Other kinds of practical support offered this year have been:

- **Macmillan Health Walk** – run by our dedicated volunteers (trained as Walk Leaders with Kirklees council) this ran in January to March 2020 at Greenhead Park. Since May 2020 we have run a virtual walking group, often using films from our volunteers and continuing peer support online. In 2021, we look forward to returning to face to face walks and plan to extend this to also run a monthly walk in Calderdale.



- **Travel Insurance Information** – booklets and lists of insurance agencies provided, as well as signposting to travel insurance suppliers on the Macmillan and Cancer Research UK websites.

- **Promoting Physical Activity and Healthy Lifestyles**- continued links with Kevin Kipling, senior lecturer in Sports Science at The University of Huddersfield and with Kirklees Wellness Service - both have given talks at various virtual courses to promote the importance of physical activity with patients.
- **Transport** – we signposted to Calderdale’s community transport service, directed patients to the hospital transport service for appointments and referred to the Covid response team for transport help.
- **Wills** – In 2020 we provided information about will writing services and funeral costs, often directing people to Macmillan’s free will service.
- **Toilet & Restaurant Cards** – We provided Macmillan toilet cards and radar keys for patients who need access to toilets in shops etc, as well as some cards from the oesophageal patients association which patients can show in restaurants/cafes etc.

'I can honestly say the service you provide to support people with cancer is a very needed service that is paramount to have. I cannot thank you enough for the support I received while going through my treatment.'

Patient, 2020

EMOTIONAL SUPPORT

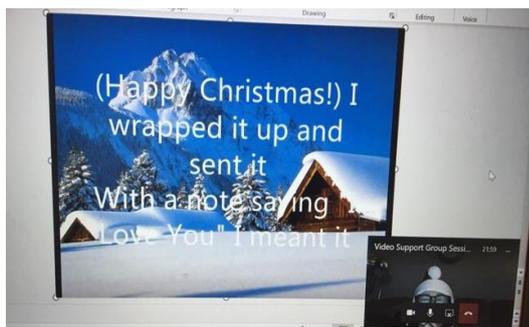
In 2020, 24% of our service activity was to provide emotional support. Exactly 50% of all our contacts were with people who simply wanted to talk about their experience (1583 people) and much of our positive feedback is around patients recognising the benefit of just having someone to listen to them. The listening ear that we provide to patients through drop in, telephone or video consultation, is therefore a key element of the emotional support provided by the service, and has been extremely important in throughout the pandemic. Patients have told us they at times struggle to share their fears and worries with family members or busy clinicians. Of our contacts, 345 people asked about counselling and psychological support and 52 people talked about relationship issues.

Part of our emotional support over 2020 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 supported some bereaved families, again being a

listening ear and signposting to hospices and other support services such as bereavement support groups.

MACMILLAN SUPPORT GROUPS

As well as being able to deliver our various patient education courses online, we were also committed to running our Macmillan support groups virtually via Microsoft Teams, and have been able to offer this support since May 2020. We have consistently run our monthly virtual walking group as described above, and our monthly coffee support group, with up to 20 people joining for a chat and peer support. Our singing group was slightly less popular and so was run intermittently through the year, with a Christmas sing along special which proved



popular. Our monthly Thinking Ahead support session has been on hold as we have set up other virtual support, but is planned to launch again in 2021. Our volunteers and patient reps have again been an enormous help in terms of helping to run the support groups virtually, as well as providing vital emotional support and a listening ear to all who attend.

FINANCIAL SUPPORT

We know that cancer often causes our patients significant worry about finances, especially if people have to give up work due to their cancer treatment. This situation is exacerbated in a pandemic where jobs are under threat and the needs for welfare benefits is all the greater. 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 2020 we referred a total of 396 people for benefits advice with 183 referrals to Eileen Murray, Macmillan Benefits Advisor at Advice Kirklees, 205 referrals to Age UK in

both Calderdale and Huddersfield and the remaining 8 direct referrals for PIP special rules done by our service. Unfortunately, there has remained a gap in benefits provision for residents living in Calderdale who are under 50, who have been signposted to the welfare benefits team on the Macmillan Support Line. Advice Kirklees and Age UK provide information to Macmillan about benefit gains and one off payments/arrears for patients referred in 2020, 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 **£1,195,978.68** – which is an increase of £50,480.83 since 2019 and despite a pandemic. The breakdown of these figures is as follows:

Macmillan Information Centre Referrals	No of referrals from our service	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:
2020 Advice Kirklees	183	£617,762.86	£59,811.00	£677,573.86
2020 Age UK	205	£467,302.13	£26,941.51	£494,243.64
Estimates for other referrals (PIP special rules)	8	£22,372.47	£1,788.71	£24,161.18
Totals	396	£1,107,437.46	£88,541.22	£1,195,978.68

We signposted regularly to the **Macmillan Support Line** in 2020 which is now open seven days a week, 8am – 8pm. The MSL is a fantastic resource for patients and carers and offers financial advice such as mortgage advice/debt advice, pensions, utility bills/debt advice, work support/advice, as well as access to welfare benefits advisors.

Grants

In 2020 we were successful in gaining a huge **£44,685.00 in Macmillan Grants** for 141 patients in particular financial need, which was a slight reduction compared to the 2019 figures, even though we applied for more grants than in the previous year. Macmillan Grants are means tested and provide a grant of around £300- 350 for those on a low income to help with costs arising from having cancer, such as help with heating costs, clothing and transport.

In 2020 we also applied to **other charities** for patients in extreme need and were successfully awarded the following:

- Robert Sinclair Foundation – two grants of £1000 for patients with incurable cancer with young families.
- Yorkshire Energy – negotiated the clearing of a £4,200 energy debt for a patient.
- Percy Bilton Charity – awarded a fridge freezer, double bed and mattress, tumble dryer and washing machine for different patients.
- Charles Brooke Convalescent Fund – awarded three washing machines and a mattress for patients.
- Energy Trust – two new boilers installed; one patient had a full new central heating system installed for free and free loft insulation following our referral.
- Virgin Media – negotiated cancellation of a £260.00 early disconnection fee due to a cancer diagnosis and moving in with a family member.
- Mummy’s Star Charity - £500 grant for childcare costs and baby items.

Being able to apply for additional grants for patients, has benefitted some of those in extreme need, and enhanced and supported their general wellbeing. We are very grateful to the above charities for being able to support our patients in the time of the pandemic when all charities have suffered a loss in income.

‘I have worked with the team for several years now and last year was like no other. The team however took it all in their stride. Which is why they are so truly incredible.’

**Adele Burrough
Macmillan Fundraising Manager
Yorkshire**

2020 DATA SUMMARY

WHO DID WE HELP?

3166 CONTACTS IN 2020

The year 2020 saw an increase in our contacts with 348 more contacts than in 2019 (where we had 2818 contacts overall), which constitutes a 12% increase.

Of these – 1508 people accessed the service in Calderdale Royal Hospital and 1658 people accessed the service within Huddersfield Royal Infirmary. Compared to the previous year, the contacts at Calderdale increased by 249 in 2020 and in Huddersfield by 97 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.

2219 contacts were from people who had used the service in the past and the remaining 947 were with people new to the service. In Calderdale and Huddersfield there were 3171 patients diagnosed with cancer for the first time or with a recurrence in 2020. This means that the Macmillan Information Service supported 29% of all newly diagnosed patients in 2020, which is a slight decrease of 6% from last year. This also means that 71% of all newly diagnosed patients are not accessing the support of the Macmillan Information Service, and so ongoing efforts need to be made in 2021 to encourage further referrals and signposting to our service.

The following charts use data taken from our **3166 direct contacts** with people affected by cancer, in the year 2020.

MEN 30% **WOMEN** 69% **UNKNOWN** 1%

These are similar percentages to the last two years.

ETHNIC GROUPS

	2019	2020
White British	91%	94%
Pakistani	2.3%	1.9%
Black African/ Black Caribbean	1.1%	1.1%

Other White	0.8%	0.7%
Other Asian	0.7%	0.4%
Indian	0.3%	0.1%
Not asked/other	3.8%	1.8%

Our ethnicity figures are similar to the last two years 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 (2.4% of our contacts were from Asian communities compared to a population of 8.3% in Calderdale and 14.8% in Kirklees). This will continue to be an area for ongoing development in 2021.

AGE BRACKETS

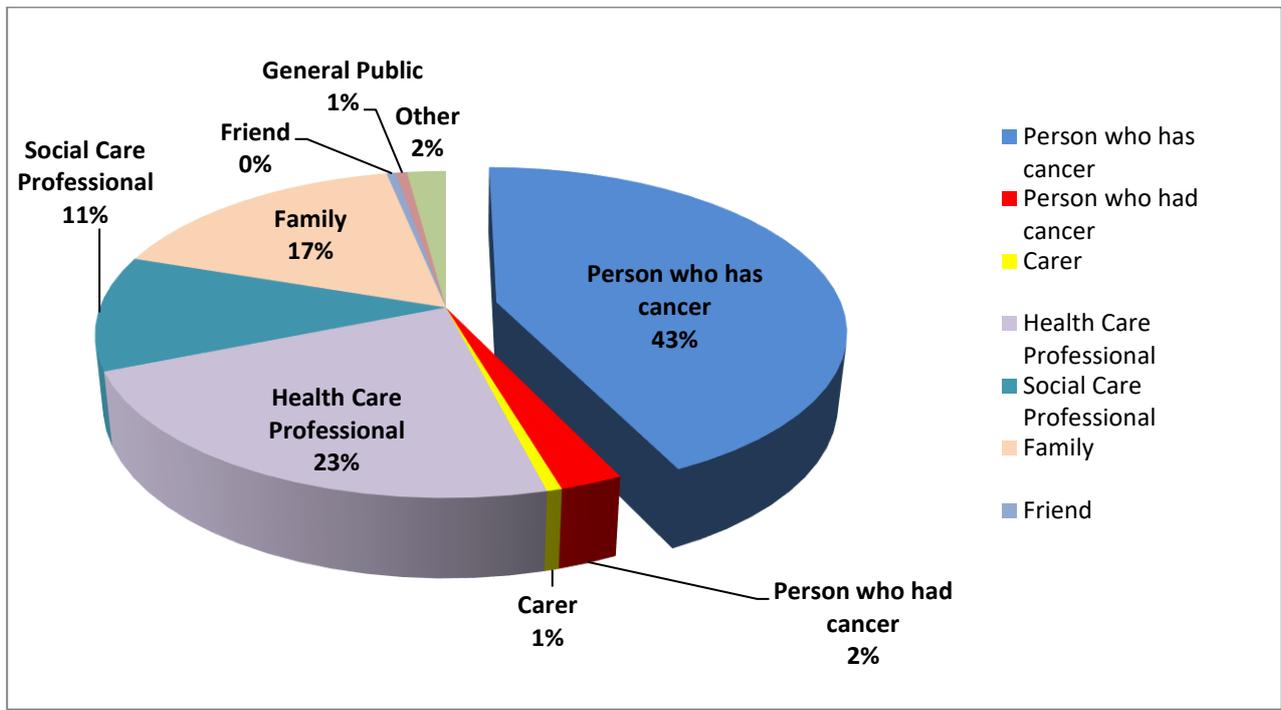
Last year the most common age group of patients we supported was 45-54. In 2020, our most common age group is slightly older at 55-64 years. In terms of highest to lowest percentages of age groups these are – 55-64 years (30.6%), 45-54 years (26%), 65-74 years (20%), 75-84 years (9.9%), 35-44 years (6.7%), 85+ years (3.4%), 25-34 years (2.3%), 15-24 years (0.2%). For 0.9% of our contacts, the age of the person was unknown.

'Helen, Mandy and Holly have been amazing and nothing is too much trouble to direct you to the right services, courses, all sorts of information and support. So grateful to these hardworking ladies.'

Patient, 2020

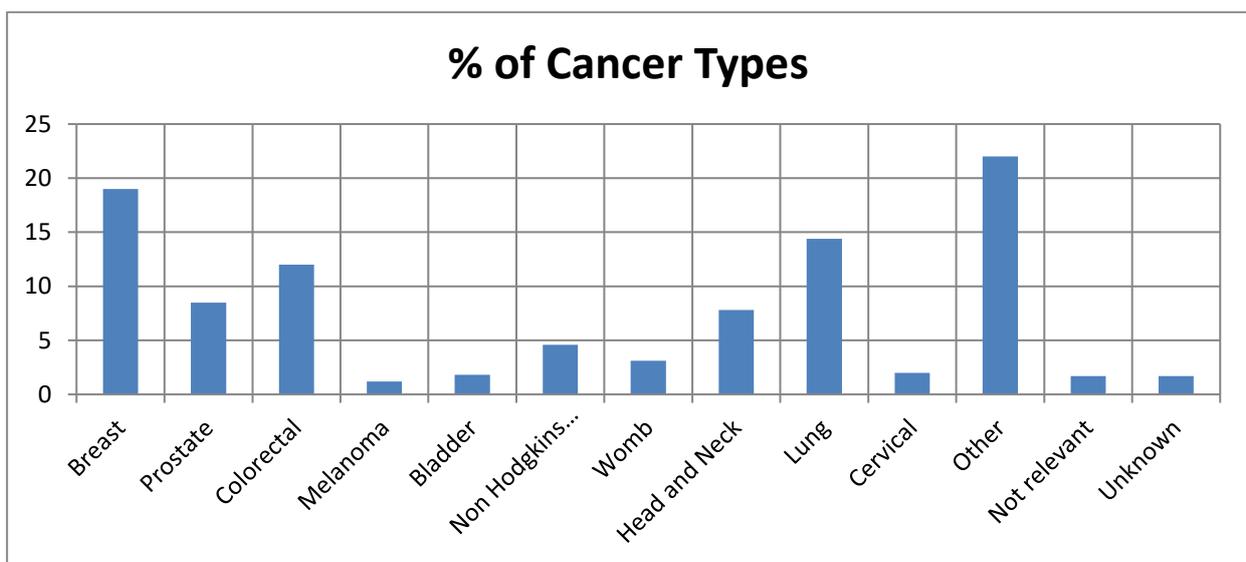
WHO WERE OUR CONTACTS?

45% of our contacts were with people who currently have or previously had, a cancer diagnosis, which is a slight drop since 2019. However, we have had more contacts with health (22.8%) and social care (11.4%) professionals on behalf of patients, compared to 2019.



WHAT CANCER DIAGNOSIS DID PEOPLE HAVE?

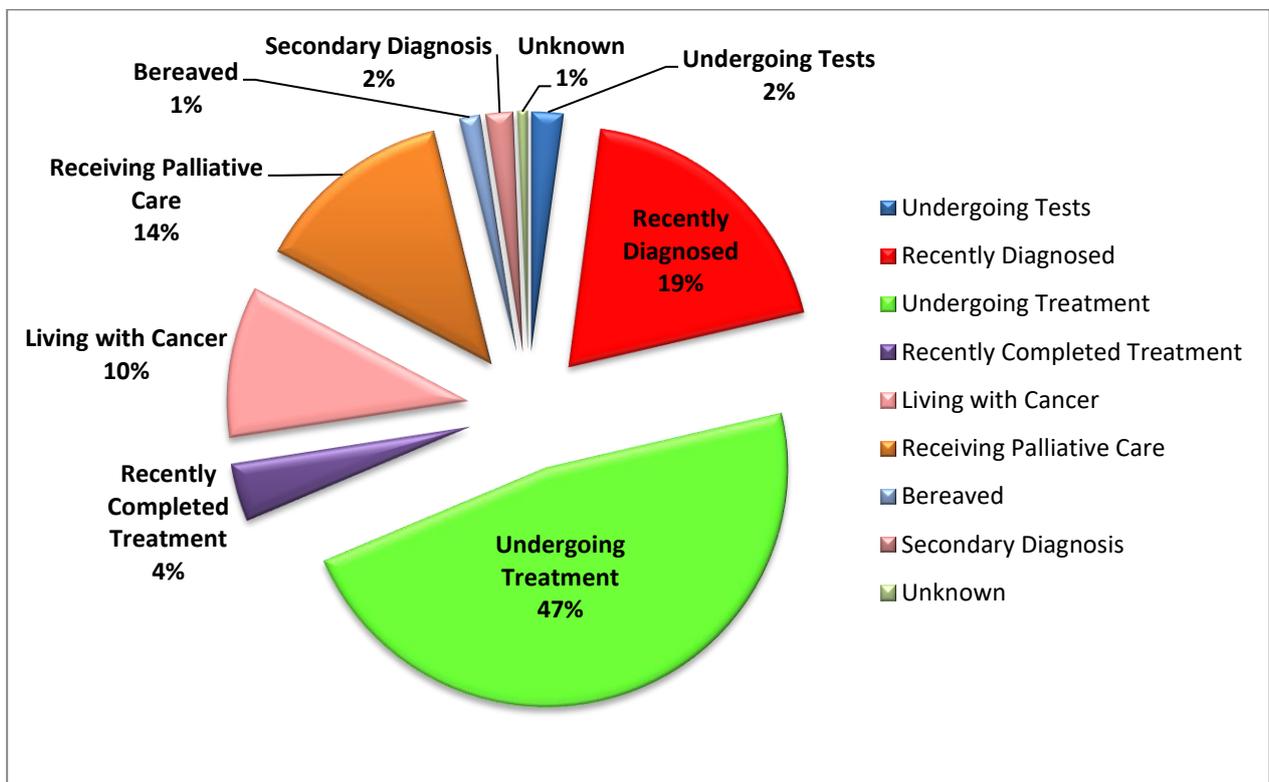
Breast cancer patients were again the most common people who contacted us during the year, and figures have increased from 10% of contacts being breast patients in 2018 to 19% in 2020. These figures were followed by lung, then colorectal, then prostate cancer patients. This year we again saw an increase in the percentage of head and neck cancer patients, haematology patients and upper GI cancer patients being referred to or accessing our service.



"To me the Macmillan team, Helen, Mandy and Holly are life savers and I cannot thank them enough. I'm not sure I would of survived through Covid without them."
Patient 2020

WHAT WAS THE STAGE OF CANCER PATHWAY?

As in previous years, we were most commonly contacted by people undergoing treatment, which is to be expected in a hospital context (47%). This year we had a significant increase in people who were recently diagnosed (19% of contacts compared to 11% last year), and those receiving palliative care or having a secondary diagnosis (15.2% compared to 10.8%) which we believe is partly due to our First Steps and Thinking Ahead Programmes.



WHAT DID PEOPLE ASK US ABOUT?

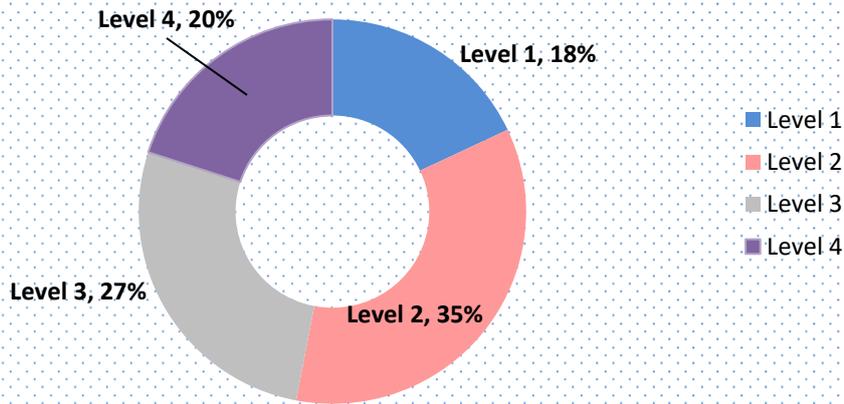


In 2020 we had more requests for practical help and support than in previous years, which is likely to be due to the Coronavirus pandemic and people needing more help with things like shopping and work support. Both our requests for emotional support and clinical support were slightly lower in 2020. Our highest individual statistics were people simply wanting to talk and requests for benefits and financial advice.

HOW COMPLEX WERE OUR CONTACTS?

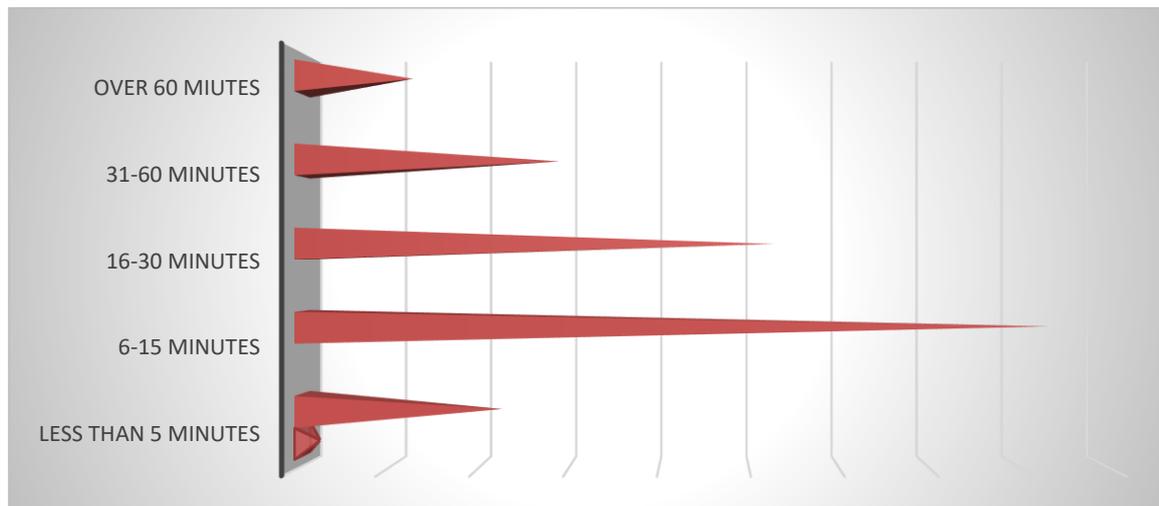
According to Macmillan data collection, our contacts with patients are graded in terms of the level of support required and complexity of each case. Level 1 contacts tend to be those queries easily answered such as paying in a donation; level 2 contacts may require some information and emotional support; 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. In 2020 we had significantly more level 4 cases, compared to previous years, indicating increased complexity and the frequent need for multi-referrals and support for individual patients.

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.



“As clinical staff we continue to rely on the Macmillan support team to provide the non-clinical advice and guidance we simply don’t have time or the knowledge to be able to offer. As staff, it means we know that our patients are provided with the skills to cope, not only with the medical treatment and their recovery, but with the social and psychological impact of a cancer diagnosis.”

Sarah Topen, Specialist Head and Neck Cancer Dietician

PATIENT FEEDBACK

In 2020, our feedback was collected via our volunteers who contacted a number of patients by phone, 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 and have emailed requests for feedback throughout the year.

Of the patients and family members 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; 93% 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 – 81% said they did not know where else they would have gone for support; 5% said the CAB, 5% Age UK, 3.5% Macmillan Support Line and 3.5% said 'Google'.

Numerous comments and quotes were given to us about the support provided by the service in 2020, several of which are already featured in this report. Below includes some highlights from quotes, but much more detailed patient and professional feedback is included as an appendix to this report, which we would encourage the reader to view.

"Cancer can strike anyone and does. There may be underlining lifestyle indications, but fate and chance are often the chief harbingers. What is not fateful or left to chance is the care of patients before, during and after treatment. The mighty NHS- surely the greatest Civic creation ever launched- attacks the cancerous invaders with full medical might, but during this battle we all need our hands held and our worries calmed. This is where the Macmillan support team show their strength for the undertaking and their compassion for individuals. They are part of the whole NHS organisation, with dedicated smaller teams to the fore. One such is that of Helen, Mandy and Holly- a goodly trio. Long may they continue to care for us."

"As with everyone my initial diagnosis was traumatic for me and my family. Macmillan made me feel like an individual that someone cared about, and not just a NHS number. A big thank you to Holly and the rest of the team in this respect. I now feel I am in a better place and facing the future with positivity."

"I have incurable cancer and dealing with the diagnosis is tough and then getting further problems after a consultation, even harder. Facing up to it all often on your own, with the restrictions...If it hadn't been for the Macmillan

team (Helen, Mandy and Holly) I'm not sure I would of survived. I have a loving supporting family, but some things are hard to discuss with them, but the team have helped me. Starting with the video groups when we first went into lockdown. Strange to start with, but the warm smiles and a listening ear, soon have us thinking all is well.... To me the Macmillan team, Helen, Mandy and Holly are life savers and I cannot thank them enough."

"I was so impressed with the way they worked together that I gave a video feedback and also requested that I join the Macmillan team as a volunteer. I would like to thank Macmillan and the 3 staff at CHT for the support they gave (and still are giving) me."

"I am loving being a part of something. I think we are very lucky that we have Helen, Mandy and Holly looking out for us, encouraging us, explaining things to us. My first thought if I am struggling is to call Macmillan. Helen has sorted so many things for me. They are a rock in my jar."

"You need someone there to catch you when you feel like falling, to help you in every aspect of cancer and not just the treatment, it affects finances, family and mental health of those affected and those who are carers... It's a lifeline at the end of the phone etc, until you deal with cancer you don't know the true impact it has on people. The fear doesn't leave you, it's always in the background."

"My dad and I took part in the iHope course which gave us helpful tips enabling us to set short term achievable goals to help us see a way through the 'fog'. At a time when we were feeling vulnerable and isolated, we became aware of the support available to us. Just to know that there are people there to help us and support us should we need them is a great source of comfort to us and makes the journey ahead seem not quite as daunting. The support service staff have always been very helpful and prompt in replying to us, which makes us feel not alone."

"I have been very grateful to all at Macmillan, I think that you are all fantastic and do a great job. From my first experience with you people, to my completion of my chemo, absolutely fantastic, forever grateful. Hugs all round."

"Thank you for your support in 2020. The First Steps programme was especially helpful. I also benefitted from the iHope course."

“Thank you once again for your continued and essential support to myself, our cohort and to all cancer sufferers. It is invaluable and I hope you and your colleagues continue for as long as this dreadful disease blights our lives.”

“I feel happy knowing that if I have further questions I know where to go to ask them and I know support is there for me. You are all doing an invaluable job and I thank you all.”

“I have relied on Macmillan numerous times for different things. I have found this last year particularly difficult. I look forward to coffee walking and singing group on teams. I love talking to Holly and the team. Nothing is too much trouble - follow up calls if you are a bit low. The iHOPE program was amazing. Holly is so kind and listens and remembers things to mention to know she cares.”

“Even though I don’t attend each coffee group I am always made to feel welcome and don’t feel awkward for dipping in and out. They are doing a fab job and I think that there will be people receiving their diagnosis now who will rely on them even more because the support networks they would usually rely on are not there. Keep up the good work ladies.”

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, steering group meetings, trust cancer board meetings and some joint outpatient appointments with other staff, as well as some external meetings. We also answer cancer information and support queries from staff and volunteers across the hospital sites, as well as externally. We asked our clinical staff across the trust, as well as community staff we work with, about the value of our Macmillan Cancer Information Service to them and their patients on 2020 and were given the following feedback. Again highlights are featured below, with more detailed comments in the appendix:

“The Macmillan Information Service has been invaluable in helping my clinics run to time! As the diagnostics and treatments become more and more complex, it’s good to be able to spend clinic time concentrating on some of

the more “medical” things, and be able to redirect patients to the service for some of their (very important) “practical” questions. It definitely improves patient experience a lot, and means that I don’t have to rush things, and can give proper time to patient’s questions about treatment, prognosis etc.”

Dr Nick Brown, Medical Oncology Consultant

“One of the frustrating things about my role is I often don’t have time (despite desperately wanting to!) to provide the level of holistic support that you and your team do. To know there is a team available to do this is wonderful. I know you are extremely busy as a team but you always make time for patients and staff alike, and I know you put in many hours extra to ensure this is done. Holly has been a great addition to the team and I would absolutely support the fact that you need at least 3 people to keep the service running to the level that you do.”

Jenny Jones, Trainee Oncology Advanced Clinical Practitioner

“The challenges cancer patients face have only increased during the COVID pandemic, and the need for the Macmillan support team has never been more vital - with the addition of more staff this has allowed continued development of the services available to reach out to patients who otherwise might feel over looked and forgotten. As clinical staff we continue to rely on the Macmillan support team to provide the non-clinical advice and guidance we simply don’t have time or the knowledge to be able to offer - for the patient it is vital that this support continues to be available and as staff, it means we know that our patients are provided with the skills to cope, not only with the medical treatment, their recovery, but the social and psychological impact of a cancer diagnosis.”

Sarah Topen, Specialist Head and Neck Cancer Dietician

“I would like to say that you are an asset to our greater multidisciplinary cancer team within the trust, which extends to the community. I know you have all been stretched a lot further in the advent of COVID as many of your volunteers have been shielding. I am sure you have brought more comfort to many patients in this uncertain time, when things are already uncertain for many with their cancer diagnoses alone... I am grateful for the work that you put in and also the support that you all give our team emotionally when we have a difficult day.”

Anthony Thomas, Acute Oncology CNS

“As always your team continues to enhance our team. I feel we work closely to achieve the best outcome for supporting patients where needed. The virtual health & wellbeing sessions continue to be extremely helpful for those who attend and we appreciate all the hard work that you put into them.”

Lesley Walker, Gynea Lead CNS

“Having the Macmillan support is of great value to us, we are able to refer to Macmillan with the knowledge that patient's needs and questions will be met and correct signposting and support is given to our patients. Many of our patients are grateful for the contact and support that they receive at a time when it is needed. I feel your support and information is of great support, both patients and our Lung service.”

Michelle Davies, Lung CNS

“As you are aware the Head and Neck team are very grateful for your team’s input. We have patients with devastating diagnoses with treatment that is physically and psychologically difficult. Holly is frequently assisting our patients with financial referrals and an excellent “ear” to talk with. We would welcome that she stays and we understand the quantity of work your team undertakes.”

Andrew Mason, Head and neck CNS

“I can't even express what a massive help Holly has been to a few of my very complex haematology patients. She has seen them the same day and quickly referred onto appropriate teams and followed up on these referrals when needed, always ensuring the patient is fully informed. It is also really helpful to see the plans clearly documented on EPR. This has significantly helped the CNS workload especially during the COVID pandemic.”

Rebekah Ramsden, Haematology Specialist Nurse

“I love your service!! As Oncology clinic sister the Macmillan Information and Support service is invaluable to me, I pass so many complex patients to Helen and the team who arrange and plan some really beneficial holistic outcomes for the patients. Staffing the Macmillan office on Greenlea is also a valuable service, often our more anxious patients or those who have got a lot going on at home besides having cancer, really benefit from talking to the team on a one to one basis. The wide range of patient information and the ' virtual services' and support groups is also fantastic and has reached a new level during Covid. The Macmillan service really complements the fantastic work the Unit provides to our patients.”

Sister Allison Ramsden, Oncology Outpatient Sister, Acting Oncology Manager

“Thank you for all you and your team do. Your service is and has been invaluable for our complex case patients. This has been even more evident in the past 12 months with Covid restrictions and the resulting burden it has created. We are seeing ever more complex, and a growing number of late

stage cancer patients whose needs are multi-factorial. Being able to refer patients who have considerable physical, psychological, financial and family issues and knowing your service will make a positive and lasting difference is vital. We have also seen a significant increase and change in our workload since the Covid restrictions and having to release staff to the wards gives us reassurance that when referred to your service, our patient's needs will be met."

Lung Cancer Specialist Nurse Team

"I see the Macmillan Cancer Information service as an extension to our teams. By working together we can ensure that not only the physical/psychological but social circumstances are addressed for patients. We can't treat one without the other. Patients don't just come with a cancer diagnosis, they come with families, jobs, existing issues that impact on their cancer. As a CNS I try my best to address as much as possible but my time can be limited and I need often to focus on the physical, but equally we can't treat the physical without the other aspects being addressed. The Cancer Information Service have a vast knowledge of service and facilities in local communities that can help and support and can sign post patients to and support them through this process which in turn ensures their cancer treatment is the best it can be."

Wendy Markey, Upper GI CNS

'I have worked with the team for several years now and last year was like no other. The team however took it all in their stride. Which is why they are so truly incredible. I am always truly humbled by how they support people and do their utmost to help local people living with cancer. I have personally approached the team for support with my own family and experienced first-hand the kindness and expertise of these incredible ladies. They are an asset to Macmillan and the trust, and I will very much look forward to getting back out to fundraising to help support the work they do.

**Adele Burrough
Macmillan Fundraising Manager – Yorkshire**

'I really appreciate knowing Macmillan are there and receiving regular updates on groups and courses. We share a lot of this information on our social media pages to get the word out.'

**Joanne Grantham
Senior Social Prescribing Link Worker, Central Halifax PC**

'Overgate Day Hospice has contributed to the 'Thinking Ahead' programme since it started. Currently we discuss 'Hospice Services' on the programme. We have always felt very welcome and the feedback Patients and Carers have given us has spoken very highly of the programme and the support they have had.'

Teena Attiwell, Day Hospice Sister, Overgate Hospice

'In the last 12 months, despite the Covid Pandemic, Helen, Mandy and Holly, have successfully maintained their service adapting to different ways of working and continued to make regular referrals for cancer patients to me for benefits advice. This has helped people with cancer access benefits quickly in their time of need. They are so professional in what they do and always willing to help!'

Eileen Murray, Macmillan Benefits Advisor, Kirklees Council

OUR DEVELOPMENT PLANS FOR 2021

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

1. Continuing to offer high quality, personalised information and support according to the patient/carers need. As part of the NHS long term plan, we need to continue to deliver personalised, tailored support based around whatever 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.

2. Embedding the Health and Wellbeing/Patient Education Programme – virtually and face to face.

It has been a privilege to run so many education and support programmes for patients over the last year develop virtual delivery of these. Going forwards we are committed to continuing to offer First Steps, Thinking Ahead, iHOPE and end of treatment Health and Wellbeing Events, both virtually and face to face when we are allowed. We particularly want to encourage more attendance at most of these, as numbers can be quite low, despite there being significant need across the trust. We will continue to work with our trust and community colleagues to promote the courses in order to increase uptake.

3. Wider Promotion of the Service – especially for newly diagnosed patients.

This year saw more referrals to our service than ever before, but we are still only supporting 29% of newly diagnosed patients in our trust. As a charity, Macmillan are keen to be offering support from the point of diagnosis, which we fully endorse. Because referrals to First Steps are low, many patients are only learning about our service as they complete treatment, this missing out on vital support that could have been available to them. There also remains the perception that

Macmillan are for end of life only, and so we need to endeavour to change this perception, helping patients, family members and the public, know that we are there to support people right through the cancer journey, from the point of diagnosis. We hope that closer working with the new rapid diagnostic service, as well as the prehab lead, will support this in 2021.
consistent referral.

4. Continued Patient Engagement and Co-design.

In 2020, our patient focus groups and patient reps played a key role in shaping our service development, particularly as we looked to them for advice about delivering everything virtually. 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 2021. Our Cancer Patient Focus Group will remain a key part of listening to the patient voice and implementing recommendations, going forwards.

5. Supporting, re-establishing and growing the Volunteer Team and Patient Reps.

As a service, we have greatly missed our dedicated team of volunteers during the last year and are looking forward to them hopefully returning in 2021 as restrictions ease. Thankfully we have been able to keep in touch virtually and some volunteers have been able to offer patient support calls and help with support groups. In 2021, we plan to support a return to duty for our Information Service and Headstrong volunteers – easing the transition and supporting the team as much as possible. We also plan to grow our patient rep volunteer team – increasing the number of patient reps who can support other patients and represent the patient voice at various meetings in the trust and externally. Patient reps have been a fantastic addition to our volunteer team over the last year and we are looking forward to further developing the team in 2021.

6. Further close working with GPs and community services across Calderdale and Huddersfield.

During 2020 we have established stronger links with GP surgeries and social prescribing teams, which has encouraged mutual referrals. We look forward to making further community connections as organisations emerge from the pandemic, in order to increase our knowledge base around support services locally.

7. Hard to Reach Communities.

Our statistics show that we are not reaching sufficient patients from ethnic minority groups, so it is essential for us to continue to look at ways to link with various communities in 2021. We will continue to work with the trust cancer

team to address inequalities, particularly through the NHS improvement collaborative work that is happening in 2021.

- 8. Maintain and develop the high quality service provided** by the Macmillan Information and Support Service team, as demonstrated in this report.



Appendix One – Patient and Professional Feedback in 2020:

A. Patient Feedback 2020:

“Cancer can strike anyone and does. There may be underlining lifestyle indications, but fate and chance are often the chief harbingers. What is not fateful or left to chance is the care of patients before, during and after treatment. The mighty NHS- surely the greatest Civic creation ever launched- attacks the cancerous invaders with full medical might, but during this battle we all need our hands held and our worries calmed. This is where the Macmillan support team show their strength for the undertaking and their compassion for individuals. They are part of the whole NHS organisation, with dedicated smaller teams to the fore. One such is that of Helen, Mandy and Holly- a goodly trio. Long may they continue to care for us.”

“The support given is invaluable. Cancer strikes not only physically but mentally also. To know there is a real person at the end of the telephone line, rather than a pre-recorded voice with button choices, lifts one’s belief in survival. Human contact is essential, not only for support when you’re feeling wretched but also for that practical and individual advice only an experienced staff member can give. I know first hand the adverse effects of over reliance on computer systems.”

“As with everyone my initial diagnosis was traumatic for me and my family. Macmillan made me feel like an individual that someone cared about, and not just a NHS number. A big thank you to Holly and the rest of the team in this respect. I now feel I am in a better place and facing the future with positivity.”

“Your support changed my outlook on my situation, from cancer-centered to me-centered. Then, as a person I felt informed, not alone, truly cared for and in safe hands. I felt 'I can do this'. I thank God for your call and skills. I thank you for using them to make my entire life better.”

“I would like to offer my feedback on the Calderdale and Huddersfield NHS trust, Macmillan cancer support team. This last year has been very difficult for everyone, with the coronavirus. But dealing with the virus and having cancer at the same time, has made things even harder. I have incurable cancer and dealing with the diagnosis is tough and then getting further problems after a consultation, even harder. Facing up to it all often on your own, with the restrictions...If it hadn't been for the Macmillan team (Helen, Mandy and Holly) I'm not sure I would of survived. I have a loving supporting family, but some things are hard to discuss with them, but the team have helped me. Starting with the video groups when we first went into lockdown. Strange to start with, but the warm smiles and a listening ear, soon have us thinking all is well... if I looked a bit of it on a link, I have had a text or phone call from the team to check I am ok. When I was having weekly chemo, one of the team would nip in and just have 5 minutes natter, to break the day and see how I was. I have joined every meeting possible, not only for company but to see a friend, as that is how I see the team. I have also attended several courses, Thinking ahead, iHope, etc which were superb, thought provoking and emotional, but handled so well, despite being virtual and always putting us patients needs first, which is not easy, when sometimes all you need is a hug. To allow for holidays and illness, I cannot see how the service would run as effectively with

only two in the team. I haven't been on the edge of needing help that much, but when I have, it is so reassuring to speak to someone who knows you and understands what you are going through..... for someone newly diagnosed with cancer, the support the team can offer is vital, from just pointing the patient in the right direction, to a virtual hug and offer support. To me the Macmillan team, Helen, Mandy and Holly are life savers and I cannot thank them enough."

"My husband was diagnosed with Prostate Cancer in 2013 and sadly was diagnosed with Bladder cancer in 2018 at HRI. He was treated at St James in Leeds and we managed well with his first cancer, but his second diagnosis knocked us both for six as this second would completely change his quality of life. I remember turning to Macmillan upstairs on one particular day when I went between the chapel and the lady on duty at Macmillan. All she did was listen and I was so grateful for that fact on that particular day. I felt completely lost and at that point the outcome was uncertain. Doctors/ consultants/ specialists are so important: they are at the coal face and usually very professional. What they have difficulty with is the emotional toll taken on the family and this is where Macmillan is invaluable. I had my 'breakdown' that day and Macmillan was there for me for that hour and helped me get through the day. I have also phoned Macmillan for help on clinical issues. I cannot tell you how important that support is. 2/3 years on, my husband is well and recently had clear scans. Macmillan HRI keeps in touch and I am thankful for that. In this time of Covid I imagine the need for the three of you is even greater. There must be so much uncertainty. Thank you for being there. I will never know when I might need you again."

"Nobody has been here for me apart from you and you have done an absolutely mint job! I can't thank you enough! I have been speaking to my friends and I have been telling them how amazing Macmillan have been. You're amazing. I have never asked for anything in my life, but you guys have been there for me and helped me through, I can't thank you enough"

"Last year I was diagnosed with kidney cancer and, whilst I was treated very well clinically by the team at HRI, it was always (thankfully) a bit of a whirlwind from diagnoses to operation and recovery. I was advised to contact Macmillan by my cancer nurse and found that the support they gave mentally was excellent. I attended First Steps and the iHope courses which were led by 3 Macmillan staff. It was noticeable that all the staff worked well together and 'bounced' ideas off one another. I did make comment at the time that they seemed to support the 'patients' round the clock and was very surprised at the hours they worked to give this support. I believe the fact that there were 3 of them involved that it was beneficial to the patients as there seemed to be always one ready to respond immediately. I was so impressed with the way they worked together that I gave a video feedback and also requested that I join the Macmillan team as a volunteer. I would like to thank Macmillan and the 3 staff at CHT for the support they gave (and still are giving) me."

"I can't describe how relieved I feel after contacting the Macmillan Information service. You think you can manage and so just get on with things. Your service got lots of support in place for myself and my husband, which just means a great deal and is a huge help to us, thank you."

"Wow! I can't believe you have done so much for us already! You have done it quicker than anybody could have ever done. We thank you so much, we really appreciate it"

"I am loving being a part of something. I think we are very lucky that we have Helen, Mandy and Holly looking out for us encouraging us. Explaining things to us. My first thought if I am struggling is to call Macmillan. Helen has sorted so many things for me. They are a rock in my jar."

"Finding out you or a family member has cancer is scary and overwhelming for all those concerned, knowing you have a dedicated team who are there to support you should not have a price on it. You need someone there to catch you when you feel like falling, to help you in every aspect of cancer and not just the treatment, it affects finances, family and mental health of those affected and those who are carers. The carers need just as much help and support if not more to help those suffering treatments and in recovery. The bottom of your world falls out and the person who is diagnosed is too ill to help. It's a lifeline at the end of the phone etc, until you deal with cancer you don't know the true impact it has on people. The fear doesn't leave you, it's always in the background, don't take away the very people who are there to help."

"My dad and I took part in the iHope course organised through the cancer support service. We found the course of great benefit. In particular it helped us to appreciate things and although life is not fair try and see the positives not just the negative. It also gave us helpful tips enabling us to set short term achievable goals to help us see a way through the 'fog'. At a time when we were feeling vulnerable and isolated, we became aware of the support available to us. Just to know that there are people there to help us and support us should we need them is a great source of comfort to us and makes the journey ahead seem not quite as daunting. The support service staff have always been very helpful and prompt in replying to us, which makes us feel not alone."

"Woah, I am really impressed at this service, it's amazing, incredible! People like you really help people like me."

"I have been very grateful to all at Macmillan, I think that you are all fantastic and do a great job. From my first experience with you people, to my completion of my chemo, absolutely fantastic, forever grateful. Hugs all round."

"Thank you for your support in 2020. The First Steps programme was especially helpful. I also benefitted from the iHope course."

"Thank you once again for your continued and essential support to myself, our cohort and to all cancer sufferers. It is invaluable and I hope you and your colleagues continue for as long as this dreadful disease blights our lives."

"I was a little sceptical about taking part in the iHOPE course to begin with, unsure why. However, I am so glad I made the decision to take part. It has given me lots of strategies and tools to use and a different way to look at certain situations. Everyone in the group has been so supportive of each other. The facilitators, Helen, Mandy and Holly have all been fantastic throughout!"

"I have just recently used the service by attending the End of Treatment workshop. My case was strange in that I had a Hysterectomy for suspected endometrial cancer. The histology showed it was very early stages and would require no further treatment. I was therefore diagnosed and discharged at the same time. I was very glad I attended the virtual workshop as I was able to ask questions which I couldn't otherwise do as I have no follow up. I found the experience very helpful and well organised. I feel happy

knowing that if I have further questions I know where to go to ask them and I know support is there for me. You are all doing an invaluable job and I thank you all."

"I have relied on Macmillan numerous times for different things. I have found this last year particularly difficult. I look forward to coffee walking and singing group on teams. I was missing out on these because of technology. I met Holly safely in the hospital and Holly got me back online. Holly was so patient. I love talking to her and the team. Nothing is too much trouble - follow up calls if you are a bit low. The iHOPE program was amazing. Holly is so kind and listens and remembers things to mention to know she cares."

"I can honestly say the service you provide to support people with cancer is a very needed service that is paramount to have. So many people are finding out that they have cancer now, therefore extra staff for the service is paramount. I cannot thank you enough for the support I received while going through my treatment in 2019/ 2020, especially Mandy. It really helped me and I am so pleased to hear that her post has now been made permanent. The staff provide services that support you through treatment and after treatment. Like the very worth while support groups such as coffee afternoons, walking groups and singing sessions. Also the monthly newsletter. Anything you needed to ask they were always there for you. I really hope that Holly can become a permanent staff member to a very needed service to support cancer patients going through their journeys."

"I was diagnosed with bowel cancer in March 2020 and have followed a treatment plan which finished in December 2020. I have benefited from the Macmillan Cancer Information and Support Service in two main ways: firstly, I was grateful to be invited to participate in an online focus group held in August which aimed at exploring the impact of the COVID pandemic on the treatment experiences of cancer patients. The focus group was independently facilitated by Macmillan and attended by a senior oncologist and a senior operational manager from Calderdale and Huddersfield NHS FT. Macmillan colleagues did a great job organising the focus group and facilitating the discussion in a structured and impartial way which allowed all participants, both patients and their carers, to have their say. Helen, Mandy and Holly created a safe space where participants felt they could contribute openly and honestly about what had worked well, and what not so well, in terms of key issues like the shift to virtual communications and coping with visitor restrictions. The second way that I have benefited from Macmillan was through a recent invitation to participate in a post-treatment course delivered via Microsoft Teams in January 2021. Again, Macmillan facilitated the course very capably ensuring that it ran to time and that participants had the opportunity for comment and questions. Macmillan's technical delivery of the course was of a very high standard: there was a virtual pre-meet the day before the course so that all participants could get used to the Teams technology and the virtual sub-groups that were created during the course to allow detailed discussions between patients and healthcare professionals worked seamlessly. Throughout my cancer journey so far, it has been reassuring to know that Macmillan is there as a source of information and independent advice. They have communicated regularly with me so that I am aware of the range of courses and other resources that are available without resorting to a 'hard sell'. Holly has made an integral contribution to all this activity and her technical expertise and knowledge of Teams, mobile phones etc. has been invaluable in ensuring that patients and carers have been able to contribute effectively to the virtual engagement events that Macmillan have organised."

"I was lucky enough to be given a place on the Hope Programme which was facilitated by Mandy, Holly and Helen. It was the first time they had facilitated this course and they did brilliantly. They worked really hard to develop skills around IT to enable us to meet as a group each week which was invaluable to getting the most out of the course. I previously attended the first steps group, walking group and coffee afternoons. As the pandemic took hold they have again developed skills to continue these groups. Unfortunately due to my work I have not been able to attend as many of these as I would like, but I still receive the invitations so that if I am able to attend I can. Even though I don't attend each coffee group I am always made to feel welcome and don't feel awkward for dipping in and out. They are doing a fab job and I think that there will be people receiving their diagnosis now who will rely on them even more because the support networks they would usually rely on are not there. Keep up the good work ladies."

"I just wanted to say thank you and well done for all your efforts online. We only made it a couple of times and mum did get something from seeing other people's faces. I particularly wanted to say thank you to Mandy for being very human and having a good sense of humour! It really helps. You are all great but think I spoke to Mandy most."

"I have used the service on a regular basis for all sorts of advice since being diagnosed with cancer last June, and have found Helen, Holly and Mandy a great source of information. If they didn't have an immediate answer to my question, they would source the information from outside agencies. As a Huddersfield patient, I found their location accessible, especially during fortnightly chemotherapy sessions."

"The Macmillan service has been amazing in 2020 Feb to 2021 Feb....running courses and the Buddy system and there for all sorts of info and support. Helen, Mandy and Holly have been amazing and nothing is too much trouble to direct you to the right services within MacmillanSo grateful to these hardworking ladies."

For us, Holly /s Macmillan
M is for multi tasking
A is for admirable
C is for caring
M is for makes a difference
I is for illimitable
L is for laudable
L is for likeable
A is for adept
N is for nil desperandum

B. Professional Feedback 2020:

"The Macmillan Information Service has been invaluable in helping my clinics run to time! As the diagnostics and treatments become more and more complex, it's good to be able to spend clinic time concentrating on some of the more "medical" things, and be able to redirect patients to the service for some of their (very important) "practical" questions. It definitely improves patient experience a lot, and means that I don't have

to rush things, and can give proper time to patient's questions about treatment, prognosis etc."

Dr Nick Brown, Medical Oncology Consultant

"The Macmillan cancer support team is very organised and plays a key role for cancer patients in CHFT. I have been very impressed and satisfied with the promptness of their support to the patients and I have received excellent feedbacks from patients. I personally have witnessed very prompt and excellent support offered to patients during these very difficult times. I also would like to highlight the role of Helen Jones and Mandy Davies with their professionalism and pleasing attitudes towards the patients, colleagues and support staff. I would hope this support to continue for our cancer patients and our Oncology team in CHFT."

Dr Deivasikamani Ramanujam, Medical Oncology Consultant

"My feedback re the information service- what did we ever do without it!! The service is invaluable to staff and patients. You are a fantastic source of information, advice and support, and make such a difference to the patient journey (and to staff sanity!!) Nothing is ever too much trouble. You think outside the box, are willing to go the extra mile for patients and offer a true personalised, holistic service. One of the frustrating things about my role is I often don't have time (despite desperately wanting to!) to provide the level of holistic support that you and your team do. To know there is a team available to do this is wonderful. I know you are extremely busy as a team but you always make time for patients and staff alike, and I know you put in many hours extra to ensure this is done. Holly has been a great addition to the team and I would absolutely support the fact that you need at least 3 people to keep the service running to the level that you do."

Jenny Jones, Trainee Oncology Advanced Clinical Practitioner

"The challenges cancer patients face have only increased during the COVID pandemic, and the need for the Macmillan support team has never been more vital - with the addition of more staff this has allowed continued development of the services available to reach out to patients who otherwise might feel overlooked and forgotten. As clinical staff we continue to rely on the Macmillan support team to provide the non-clinical advice and guidance we simply don't have time or the knowledge to be able to offer - for the patient it is vital that this support continues to be available and as staff, it means we know that our patients are provided with the skills to cope, not only with the medical treatment, their recovery, but the social and psychological impact of a cancer diagnosis."

Sarah Topen, Specialist Head and Neck Cancer Dietician

"Thank you for all your involvement thus far in our patient care. I would like to say that you are an asset to our greater multidisciplinary cancer team within the trust, which extends to the community. I know you have all been stretched a lot further in the advent of COVID as many of your volunteers have been shielding. I am sure you have brought more comfort to many patients in this uncertain time, when things are already uncertain for many with their cancer diagnoses alone. Also I would like to highlight that I have found that the addition of Holly to the team is extremely helpful. With her background expertise in physio/OT areas, I think this must fit the team well as many patients require gateway to care advice, which I know some of our patients will find helpful. I realise that Helen has to concentrate on service development from time to time, and with more staffing, it is reassuring to know that either Mandy or Holly, (both

being highly approachable, knowledgeable and hardworking, are there). I am grateful for the work that you put in and also the support that you all give our team emotionally when we have a difficult day.”

Anthony Thomas, Acute Oncology CNS

“As always your team continues to enhance our team. I feel we work closely to achieve the best outcome for supporting patients where needed. The virtual health & wellbeing sessions continue to be extremely helpful for those who attend and we appreciate all the hard work that you put into them.”

Lesley Walker, Gynae Lead CNS

“Having the Macmillan support is of great value to us, we are able to refer to Macmillan with the knowledge that patient's needs and questions will be met and correct signposting and support is given to our patients. Many of our patients are grateful for the contact and support that they receive at a time when it is needed. I feel your support and information is of great support, both patients and our Lung service.”

Michelle Davies, Lung CNS

“As you are aware the Head and Neck team are very grateful for your team and Holly's input. We have patients with devastating diagnoses with treatment that is physically and psychologically difficult. Holly is frequently assisting our patients with financial referrals and an excellent “ear” to talk with. We would welcome that she stays and we understand the quantity of work your team undertakes.”

Andrew Mason, Head and neck CNS

“I can't even express what a massive help Holly has been to a few of my very complex haematology patients. She has seen them the same day and quickly referred onto appropriate teams and followed up on these referrals when needed, always ensuring the patient is fully informed. It is also really helpful to see the plans clearly documented on EPR. This has significantly helped the CNS workload especially during the COVID pandemic.”

Rebekah Ramsden, Haematology Specialist Nurse

“I love your service!! As Oncology clinic sister the Macmillan Information and Support service is invaluable to me, I pass so many complex patients to Helen and the team who arrange and plan some really beneficial holistic outcomes for the patients. Staffing the Macmillan office on Greenlea is also a valuable service, often our more anxious patients or those who have got a lot going on at home besides having cancer, really benefit from talking to the team on a one to one basis. The wide range of patient information and the ' virtual services' and support groups is also fantastic and has reached a new level during Covid. The Macmillan service really complements the fantastic work the Unit provides to our patients.”

Sister Allison Ramsden, Oncology Outpatient Sister, Acting Oncology Manager

“Thank you for all you and your team do. Your service is and has been invaluable for our complex case patients. This has been even more evident in the past 12 months with Covid restrictions and the resulting burden it has created; We are seeing ever

more complex, and a growing number of late stage cancer patients whose needs are multi-factorial. The restrictions have placed a considerable burden on our mutual workloads adding complexities in the planning, coordination and provision of care, services and facilities both at hospital and inside the home. Being able to refer patients who have considerable physical, psychological, financial and family issues and knowing your service will make a positive and lasting difference is vital. We have also seen a significant increase and change in our workload since the Covid restrictions and having to release staff to the wards gives us reassurance that when referred to your service, our patient's needs will be met. Holly has been extremely professional, thorough and compassionate in her work and she is an asset to your team. It's been an absolute delight knowing she/your team put the patient first. We sincerely hope Holly is a more permanent member of the team and look forward to working together for patient benefit."

Lung Cancer Specialist Nurse Team

"I see the Macmillan Cancer Information service as an extension to our teams. By working together we can ensure that not only the physical/psychological but social circumstances are addressed for patients.. We can't treat one without the other. Patients don't just come with a cancer diagnosis, they come with families, jobs, existing issues that impact on their cancer. As a CNS I try my best to address as much as possible but my time can be limited and I need often to focus on the physical, but equally we can't treat the physical without the other aspects being addressed. If patient's don't have anywhere to live we can't given them treatment, if patient can't work because of cancer treatment we have to address this as not being able to pay bills, have money for food etc, will impact on treatment"

The Cancer Information Service have a vast knowledge of service and facilities in local community's that can help and support and can sign post patients to and support them through this process which in turn ensures their cancer treatment is the best it can be"

Wendy Markey, Upper GI CNS

'I have worked with the team for several years now and last year was like no other. The team however took it all in their stride. Which is why they are so truly incredible.

I work with them as one of their local fundraising managers and sadly this year we haven't been as involved as we normally would, but the team have still taken the time to meet virtually and also supported us with videos for supporters amongst other things. I am always truly humbled by how they support people and do their utmost to help local people living with cancer.

I have personally approached the team for support with my own family and experienced first-hand the kindness and expertise of these incredible ladies.

They are an asset to Macmillan and the trust, and I will very much look forward to getting back out to fundraising to help support the work they do.

Adele Burrough
Macmillan Fundraising Manager – Yorkshire

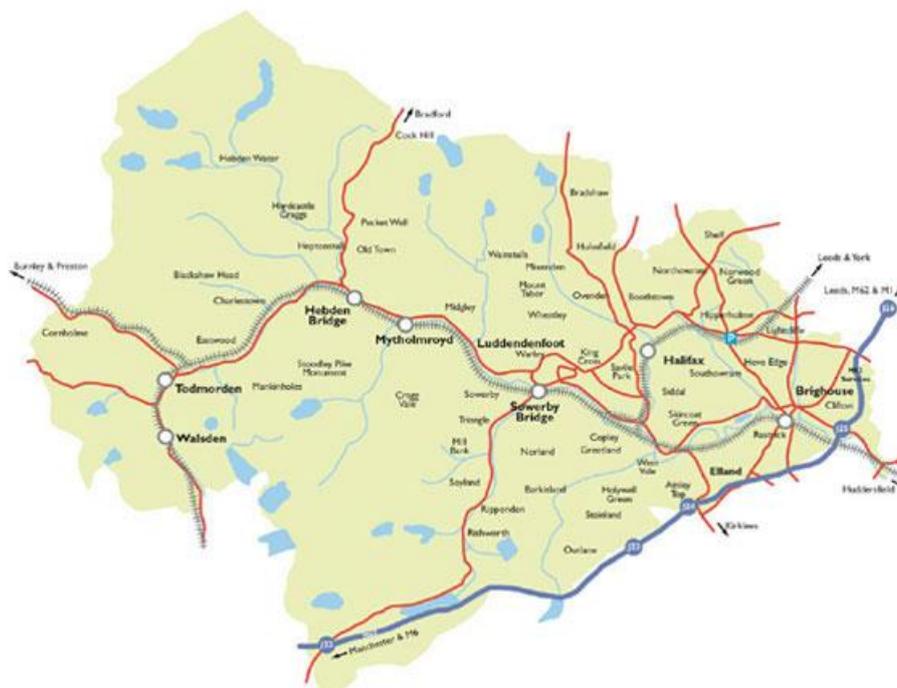
Appendix Two – The Demographic Population in Kirklees and Calderdale:

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 2020 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 2020. 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>

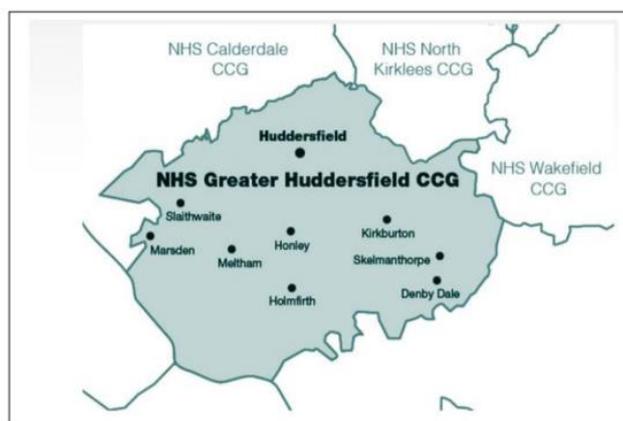
KIRKLEES

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/>