

MACMILLAN CANCER INFORMATION & SUPPORT SERVICE Annual Report 2022



Team Members:

Helen Jones, Mandy Davies, Holly Smith & Kajal Sokhal

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

Report to cover period from 3.1.2022 to 30.12.2022

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'I find all your resources, sessions, and advice invaluable as I navigate my cancer journey. When I was diagnosed, I felt lost and overwhelmed and your support has made a huge difference to me, and I now know what support I can access. I feel much more in control, knowledgeable, supported and most importantly for me I've got back some of the confidence I lost and feel more like me! THANK YOU! Patient, 2022

'The Information and Support Service at CHFT is one of Macmillan's Award-Winning Services and we are very proud and privileged to work in partnership with the team. The team do whatever it takes and strive to provide excellence in supporting the patients of Greater Huddersfield and Calderdale when diagnosed with cancer.

Lisa Spivey, Macmillan Partnership Manager, West Yorkshire

Introduction

The CHFT Macmillan Cancer Information & Support Service (MCISS) provides high quality cancer information and support to the local population, as well as to health and social care professionals in the trust and community. The service offers personalised emotional, financial, practical and information support to patients and family members, as well delivering various education programmes to encourage supported selfmanagement, in line with national cancer strategy. The service began in 2012, initially funded by the charity Macmillan Cancer Support and over the years CHFT has taken over the funding of staff posts and service costs. The service is based in the Jayne Garforth Macmillan Centre in Calderdale Royal Hospital and the Resource Room in Greenlea Oncology Unit at Huddersfield Royal Infirmary.

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 2022, including examining the data of who we supported, the education programmes run and patient and professional feedback. 2022 saw a huge increase in demand for the service, with contacts almost doubling from 4,013 contacts in 2021 to 7,837 contacts in 2022 – a significant 95% increase in contacts. This service was maintained despite reductions in staffing as our two band 4 support workers, Holly Smith, and Kajal Sokhal, left the service in September and November respectively, with one new support worker, Kate Stott, joining the team in January 2023. The significant increase in contacts and people accessing the service indicates wider recognition for the crucial non-clinical support offered by our service, which, in partnership with the clinical teams, aims to support a person's individual needs as they face cancer, thus treating them as a whole person rather than a medical condition.

Service Outcome Objectives

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 deliver 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 delivers national cancer strategy around supported self-management and the personalised support agenda identified in the NHS Long Term plan.

Our 2022 Key Statistics

7,837

Contacts A huge 95% increase

from 2021 (4,013

contacts)

82% of people said contact with our service reduced their anxiety (16% did not have anxiety)

47% of people said they would have gone to other health professionals if our service did not exist – saving time and money.

41% weren't sure where they would have gone; 12% would have referred to the internet



£1,409,758.83

in estimated benefit gains for local people from our referrals

901 onward referrals

made to other organisations for support

£102,185 awarded in Macmillan Grants for our patients (£54,650 in 2021)

36% of all newly diagnosed patients in CHFT seen by the service (compared to 25% in 2021)

'Medicine may treat the disease, but the Macmillan support team see the whole person which I think is vital to their health and wellbeing.' Family Member, 2022

Growth of our service over the last six years

Key statistics demonstrating the impact of, and significant growth in the service over the last six years are as follows:

	2016	2018	2020	2021	2022
Number of WTE Staff:	1	2	3 (from June 2020)	3/4	4/3/2
Number of individual contacts for the service:	672	1900	3,166	4,013	7,837
Number of onward referrals:	76	402	731	761	901
Benefit Gains for patients from service referrals	£282,285	£1,091,069.48	£1,145,497.85	£1,305,799.27	£1,397,679.54
Macmillan Grants Awarded:	£7060	£20,866	£44,685	£54,650	£102,185
		Patient Educati	i <mark>on Sessions</mark> (P	ES) delivered pe	r year
	2016	2018	2020	2021	2022
Types of PES	0	1	4	4	5
Number of PES (half days):	0	6	30	65	65
PES Attendances by patients/family:	0	150	356	368	366
Support Group Attendances:	0	0	288	129	151

Organisational Profile

Calderdale and Huddersfield NHS Trust provide care to a population of over 460,000 people and in 2022 the Trust had a total of 3,677 patients with a new or secondary cancer diagnosis (339 more than in 2021). Of these, 3,238 were patients with a new primary cancer diagnosis and 436 had a recurrence or secondary diagnosis.

In the year 2022, the Macmillan Cancer Information and Support Service had contact with 1,322 newly diagnosed patients, equating to 36% of those newly diagnosed within the trust. This is a significant increase compared to previous years where 25% of newly

diagnosed patients in 2021 and 29% in 2020, accessed the service. This shows that more health professionals are referring to or signposting to the service on diagnosis, as well as there being an impact of increased service promotion and word of mouth between patients recommending the service, all of which has increased access.

Our Staff Team

For eight months of 2022, the service consisted of four full time staff members – Helen Jones - Service Manager, Mandy Davies – Assistant Manager, Holly Smith and Kajal Sokhal – Macmillan Information Service Support Workers. Sadly, Holly left the service in September 2022 to take up another position in the trust and Kajal left in November, at the end of her fixed term (12 month) contract. The service was then under a lot of pressure to meet high levels of demand in November and December 2022, with only two staff members. Holly's position as permanent support worker was advertised and appointed to, and Kate Stott joined the team in January 2023. Unfortunately, further funding for a second support worker has not been secured and CHFT were not able to support a recent business case for additional staff. Macmillan have recently awarded funding for the introduction of a new project post in the service, for two years starting in 2023. This will be an exciting development within the service, for a band 4 support worker to offer end of treatment Holistic Needs Assessments, to improved personalised care and links to support in the community, once treatment finishes.

Due to the increased demands on the service and pressure on the team, we are hoping to further increase the number of staff within the team in 2023/4.

'The CHFT Macmillan Information Service is invaluable. The team work so hard to provide support to so many patients, often in hugely challenging circumstances, and in my view are miracle workers! They are experts in providing holistic care, and they make a huge difference to the lives of patients and staff alike. Personally, I am so grateful for all they do, and appreciate how they "go the extra mile" day in and day out for patients and their families.'

Jenny Jones, Oncology Advanced Clinical Practitioner

Our Volunteers

In 2022, the service was supported by our invaluable volunteers – both Macmillan Information Service volunteers and patient representative volunteers. Our volunteers meet and greet patients, run support groups, and provide face to face and telephone support. The patient rep volunteers also attend courses to share their story, help to lead the cancer patient focus group, attend and represent the patient voice in various settings, including helping us to interview. Unfortunately, we have been unable to relaunch the Headstrong service since the pandemic – the hair loss service run by another group of our volunteers. This has been due to a combination of Headstrong volunteers leaving the service or retiring, trust policy to pause the recruitment of new volunteers and pressures on the staff team to meet increased demands on the service.



One of our patient rep volunteers, David Blunt, was selected as the national patient volunteer on the Macmillan Excellence Awards panel for the next three years, which is a remarkable achievement. He also presented about his role as a patient representative volunteer in workshops with Helen, at the national Macmillan Conference in London in November 2022, where he also announced winners and gave out excellence awards at the conference.

We asked our volunteers for some feedback about their volunteering in 2022 and this is what they said:

'As a volunteer now with some experience I feel much more qualified to make comments on the team at CHFT. Whilst I am still a 'cancer survivor' (I'm pleased to say) and still receive support from 'the team' I have been proud to be even more involved with Macmillan over the previous 12 months. I say proud because my initial reaction has proved even more positive, the team last year gave me opportunities which I never expected to have to handle but with their assistance and support I found it achievable and even more rewarding. Their ongoing commitment to their role and consequently to patients is a great example of the Macmillan ethos and because of that I, as a volunteer, find it so easy and rewarding to attempt to copy their example. I can only say if you have even a little spare time seriously consider becoming a volunteer.' David, patient rep volunteer.

'It is so good that the walking group has started up again after the very long break due to Covid. I certainly much prefer interacting with people face to face and it's good to see how patients support and encourage each other. It would be wonderful to have more volunteers as walk leaders.' Margaret, volunteer

'I was over the moon when we were able to open up our walking group again after the pandemic! It's an absolute pleasure to take a gentle stroll around the park with our lovely group and to be able to share coffee & chat time afterward in the cafe. Our supporters are extremely grateful for being able to access this service and we all look forward to our monthly meet!'

'I have volunteered for hundreds of hours in 2022 and regard it as a privilege. I always like coming into the centre and look forward to it.' Jeff, volunteer

'As a volunteer, life has not been easy as a volunteer, with a lack of footfall past the Macmillan Pod due to Covid. Have directed a few cancer patients to the Greenlea Unit and occasionally get verbal thanks for what Macmillan does. Most rewarding is the ad hoc contact with people who know where I work and ask for advice.' John, volunteer 'The Macmillan Men's support group meets monthly, and I am pleased to be involved in the organisation and facilitation of the group. I enjoy meeting new people and the opportunity to share and discuss cancer issues. It is pleasing to give support to other men with cancer and to hear their stories, particularly about the support they receive from Macmillan and the difference it makes to them. I was also invited last summer to be a patient representative with a group of CHFT staff planning a new 'Education and Exercise Programme' for men with prostate cancer who are on hormone therapy. A 12week programme was designed and launched this year with 15 men attending the first cohort in Halifax to be followed by the same course in Huddersfield. I was pleased to be involved in the planning and delivery, and to participate in this course, as I have prostate cancer. It has helped me, and others on the programme, to learn more about cancer and hormone treatment and to cope better with the side effects, plus get an hour's exercise in the hospital gym. It gives me great satisfaction to be the Macmillan Patient Representative involved in this.' Geoff, patient representative volunteer.

Equality & Diversity and Addressing Health Inequalities

As an information service, we provide information in accessible formats and other languages, with cancer awareness information provided in the commonly used languages in the region (Punjabi, Urdu, Guajarati 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. 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 also available at CRH for service users with a hearing impairment.



In 2022 the service has continued to be part of a project in Kirklees to look at what cancer information and support is needed in diverse communities. Following a survey in 2021 to identify need, the service has been involved in delivering some interpreted workshops to Asian communities around cancer awareness and support services. These workshops were delivered online and in community centres in partnership with cancer screening teams, Kirklees DART, and The Kirkwood.

'This service is invaluable and certainly makes you feel less alone knowing the support is there. Just speaking to someone is help in itself. They have a caring approach and the information you need to calm your fears and answer your questions.' Patient, 2022

Co-ordinating the Patient Education Programme

A key role of our service is to co-ordinate and organise the Trust's Patient Education Programme for cancer patients and their families, as part of national cancer strategy. Our work has involved the organisation, promotion, and delivery of five different patient education programmes which have all been run virtually on Microsoft Teams, throughout 2022. The aim of all the courses is to promote patients' health and wellbeing, as well as self-supported management, so that people know what to do to support themselves, and where to go to find further support. Enabling patients to help themselves, improves patient experience and reduces pressure on the clinical teams.

A summary of the programmes provided, as well as feedback is below. Our patient representative volunteers are involved in our patient education programmes – by sharing their stories in First Steps and importantly, we now have two patient rep volunteers trained as iHOPE course facilitators, David and Geoff, both of whom have jointly delivered iHOPE courses with the staff facilitators in 2022.

<u>First Steps</u> :				
Purpose:	Frequency:	Number of sessions in 2022:	Number of attendances:	
Information and support sessions for newly diagnosed patients and family members	Monthly	11	47 (55% were urology patients)	

Patient Feedback:

- I really enjoyed First Steps. It gave me a real lift and it was so informative. There is so much information to take in, so I found the way this session was delivered really easy to follow as you broke it down into topics and explained things really well.
- The session was very well organised, and the team were very knowledgeable and helpful on all aspects discussed and the interaction between the Macmillan team

and the invited members of the group was excellent.

- Helped me to get a feel for what is still to come.
- Helpful to be introduced to staff. The information was presented in a friendly, relaxed manner. The length of the session was about right but there is a lot to pack in during the time available.
- I learnt a lot from this session on various aspects that affect cancer patients.

<u>iHOPE Course</u>				
Purpose:	Frequency:	Number of sessions in 2022:	Number of attendances:	
Macmillan's health and wellbeing programme for stress and emotional resilience (for all cancer patients)	Course run three times per year	17	131	

Patient Feedback:

- To the facilitators and those on the iHOPE course. I have got more out of the course than I ever thought I would. I am grateful to you all!!
- The course has helped me to find ways of managing my recent diagnosis and in particular my feelings and emotions.
- It was great to see and hear from others who had cancer who really understood what it's like. I really liked learning about new mindfulness and wellbeing practices.
- It has given me lots of tools and techniques to help me manage the emotional rollercoaster of a cancer diagnosis from stress management, to coping with fatigue, learning about mindfulness and the importance of exercise. I also found it so helpful to meet other people who are going through a similar journey, to share our experiences and support each other was invaluable. The facilitator team was excellent, very supportive, empathetic, and kind.
- The iHOPE Course started to give me confidence. And I learnt that I am not alone.
- One of the biggest benefits was to be connected to others who are going through the cancer journey and who understand what each other are going through. I learnt a lot from speaking to other members of the group through discussions had during our weekly sessions. There was lots of useful information given during the I hope sessions and I definitely have successfully used some of the mindfulness and meditation techniques.

Thinking Ahead Programme

Purpose:	Frequency:	Number of sessions in 2022:	Number of attendances:
Support programme for patients with incurable cancer and family members, to help them self-manage and plan ahead	Course run three times per year collaboratively with Harrogate and Leeds trusts - hosted by CHFT	21	156 (77 patient attendances; 79 family attendances) CHFT: 108 Harrogate: 41 Leeds: 7

Attendee Feedback:

- Most valuable was the benefits, estates planning section and we enjoyed the music session. The whole experience was good as it started family conversations off.
- It was the first time I could safely say out loud that my husband is dying. The course gave me the space to share, and courage to talk to friends and family.
- Attending this course made conversations around end of life, feel more normal.
- All very useful and the sessions were well structured with a break and a variety of activities as they are challenging topics for people in seriously difficult situations.
- I thought the programme was very balanced for my needs.
- The course was a safe space to share my experiences and realise I am not alone. Importantly I learnt about support from the local hospice which I had not known before.
- Some people may be put off by accessing the course online and might not have access to technology, my Mum certainly would not have coped at her age. Also, someone may feel uncomfortable about being seen and interacting with the speakers, but they should be reassured that you can turn off the video and ask questions via the chat function, as you made clear from the start.
- Thinking Ahead Course was good for me, listening to the others on the course was informative. It was helpful both for the person with the illness and the family member.
- It was invaluable for the information on the various and varied organisations and support out there as it can feel very lonely when the only contact you have at first are the medical people who just deal with the practicalities of disease and treatment. If there were enough people, it might eventually work better if each health area could have its own course as not all the support organisations and activities were relevant to us all.

End of Treatment Events

Purpose:	Frequency:	Number of sessions in 2022:	Number of attendances:
To support people's health and wellbeing at the end of treatment and link to community support	Four, one day events per year	8	32 (Of these 40% were breast, 22% were colorectal and 19% were gynae patients).

Patient Feedback:

- I felt included, it was very useful and relevant, a friendly team which made it easy to ask questions. I felt cared for and by the end I felt empowered and ready to move forward. Thank you.
- I found all the sessions very informative. The psychology session in particular was helpful as I got through my cancer treatment successfully and without any problems. Suddenly I was on my own and feeling weepy and fed up when I should have been feeling ecstatic and I couldn't understand why. The slides were very useful in helping me to understand what I was going through was normal and gave me some possible ways of dealing with this.
- Interesting to be reminded of the importance of exercise which will encourage me to keep on my efforts.
- Very informative session with good tips and new things to try to help with fatigue and sleep.
- Good to know about services and I'm now interested in joining the iHope course.
- The session on the Macmillan information team and different services available was very informative and I am going to follow up by ringing my BCN to arrange for a Holistic assessment.
- Thank you all so much for your time and effort. I wasn't too sure what to expect but I found it a very positive experience and would recommend the course. It made me realise that I wasn't alone in my worries and that Rome wasn't built in a day, that may be I should slow down a little.
- Very welcoming, clear agenda for the day. Relaxed approach. Thank you.

Thinking Ahead Innovation Funding

In November 2022, we submitted a joint bid to the Cancer Alliance, with Harrogate and Leeds NHS Trusts, for innovation funding to formalise and develop the Thinking Ahead Programme, spread it across West Yorkshire and roll it out nationally. We were thrilled to win the bid after an interview process and be awarded $\pounds100,000$ for the project. Monies awarded include the appointment of a project manager, admin support and digital developments over an 18-month period. We look forward to supporting this

project in 2023/4, which will seek to formalise and disseminate the Thinking Ahead Programme, which we have had a key role in developing and delivering in our CHFT Macmillan Information and Support Service.

'The time and effort that goes into every patient would not be achieved without the Macmillan Information Team. Their knowledge and expertise knows no bounds. Without them our workload would increase exponentially and have a massive impact on our team. The team are always there to support staff as well and the feeling that we all work together for the greater good of the patient leads to greater job satisfaction.' Bernie Beith, Chemotherapy Sister

Body Matters

In 2022, in response to patient feedback from our iHOPE course, we also trialled a new programme called 'Body Matters.' Patients had raised concerns about issues with body image and sex following a cancer diagnosis, and the lack of support available for these. Patients told us such concerns were deeply personal, important, and hard to discuss, and that this was a topic rarely raised by health professionals. This concurs with a Macmillan survey in 2013 where 72% of respondents said cancer had affected their sexual relationship, with two thirds of these people feeling they couldn't talk to their GP about it. As a result of this feedback and our drive to be innovative and meet patient need, in January 2022 we introduced 'Body Matters', a monthly meeting on Microsoft Teams to give patients the chance to talk about and explore issues about sex and cancer. We had guest speakers such as a breast nurse talking about menopause, a urology consultant talking about erectile dysfunction and a psycho-sexual therapist talking about sex and intimacy after a cancer diagnosis.

Although Body Matters was well received by those who attended, numbers were low with only around 2 or 3 patients joining the session each month. On reflection, we also felt that Microsoft Teams was not the best forum to offer such a session and due to the low numbers, people possibly felt pressure to contribute when they may have preferred just to attend in the background and listen. We therefore paused Body Matters in the summer and may look to re-introduce it again in the future, potentially in a different format, if patients indicate this would be helpful.

Information and Promotion

We have continued to provide a high level of information and over 2022 returned to physical booklets in our information pods across the hospitals, as well as our centre and resource room. These had previously not been allowed in the hospital due to infection control measures in 202/21. We have also continued to send many



more electronic booklets via email to patients.

In 2022 our **monthly newsletter** continued to be an important way to connect with our patients, family members and health/social care professionals to keep them updated of our various courses and support groups and make them aware of other helpful information and services. Our newsletter was sent out by email monthly to 1,382 patients/family members/professionals/volunteers in 2022, as well as 240 sent by post. This means that over a 12-month period, a total of **19,464** newsletters were sent to patients/families/professionals/volunteers in 2022.

Our **Facebook Page** has also been an important way for us to communicate with our patients, family members, organisations, and the public, as well as for promoting cancer awareness information. We have used Facebook to raise awareness of the support and education sessions offered by our service, but also signposted to community support and information.

'I feel that the service offered by the Macmillan Information and Support Service is a key part in the recovery of people such as myself. I am really grateful for the help and support I have received and know this is ongoing throughout my treatment and afterwards too, should I need it. I had no idea before I had cancer that this kind of support existed and can't speak highly enough of the team. Their kindness, empathy and love for the job they do shines through.'

Patient, 2022

Who did we support in 2022?

The year 2022 saw a huge 95% increase in our contacts to **7,837** with 3,824 more contacts than in the previous year (where we had 4,013 contacts). We believe the increase in contacts is due to having four staff instead of three for a large portion of the year, as well as increased referrals from clinical colleagues. Of these – 4,126 contacts were at Calderdale Royal Hospital (an increase of 2,301 contacts) and 3,711 contacts were at Huddersfield Royal Infirmary (an increase of 1,523 contacts). These figures demonstrate a higher accessing of the service at CRH and clearly demonstrate the ongoing need to deliver the service out of the two hospital sites and maintain permanent staff members in each place. Of the contacts, 1322 people were first time users of the service.

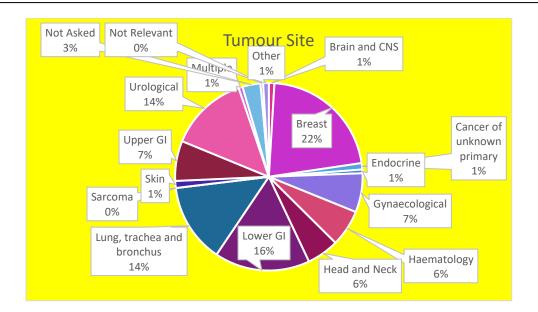
The following charts show a breakdown of who accessed our service in 2022.

Tumour Site:

In 2022, the largest group of patients we supported were breast patients (22%), followed by colorectal (16%), urology and lung (both at 14%). These statistics are in keeping with the biggest four tumour groups nationally. The most significant change in

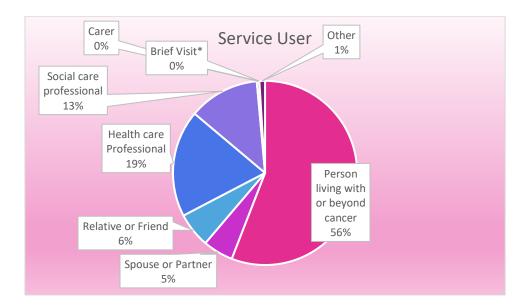
our statistics in 2022, was when we actively worked more closely with the colorectal/lower GI team and saw a rise from 382 contacts in 2021 with colorectal patients, to 1288 contacts in 2022. This shows that when we specifically encourage a referral process with a team and promote our service, our contacts significantly increase. Going forward and when we have additional staff, this will be an important way to grow contacts in future years.

'Thank you for the wonderful support you give the Colorectal Nurses and Colorectal patients. We could not do our job without you. Time is so precious for everyone, but your kind, knowledgeable and smiley team, are always there to enrich the journey of our patients. For that we are so grateful.' Helen Ilsley, Colorectal Cancer Nurse Specialist



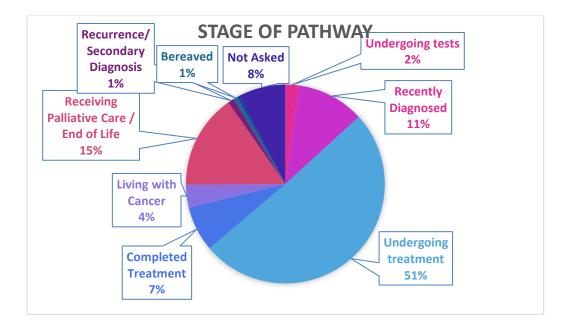
Service Users:

Most of our service users were people living with or beyond cancer, followed by health care professionals, social care professionals, then family members/carers.



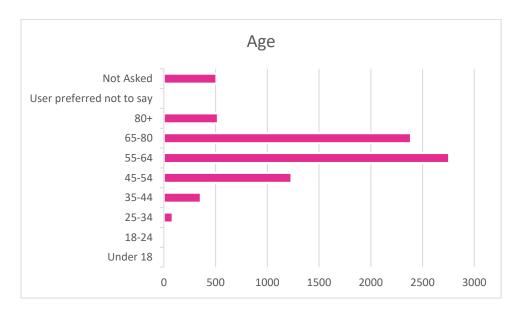
Stage of Pathway

The highest group of patients we supported were those currently undergoing cancer treatment, followed by those receiving palliative care or end of life support. We then supported equal numbers of patients who were recently diagnosed and those who had completed cancer treatment or were living with cancer.



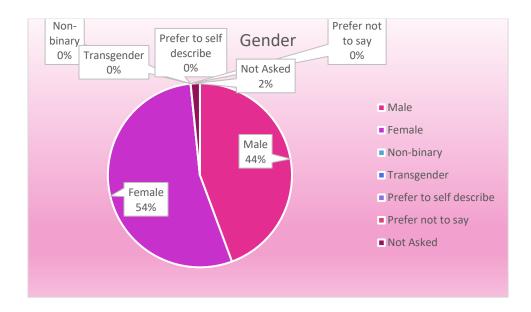
Age of Patients:

The highest group of patients we saw in 2022 were between 55 and 64 years. This differs from 2021, when the highest group of patients were aged 65-80, potentially indicating an increase in younger people being diagnosed with cancer. In 2022 we also saw more 45-54 years olds than those over 80, which has been the case for the last few years.



Gender:

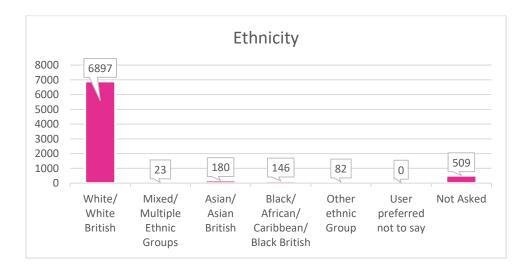
Over the last couple of years, we have seen a steady increase in the number of men accessing our service, from 30% in 2020, 43% in 2021 and 44% in 2022.



'Honestly, you have all been amazing from the start, I have had a great level of support which has given me confidence. You probably just think you are picking up a call, but it is more than that - you have lifted a huge weight off my shoulders. I could not have coped without your service – thank you.' Patient, 2022

Ethnicity:

As in previous years, the majority of people who access our service are white British (88%). Our contacts with black African/Carribean people (2%) are roughly equal to population statistics of 1.9% in Kirklees and 0.4% in Calderdale. However, sadly the number of our contacts with Asian/Asian British people has dropped significantly in 2022, from 3.6% (2021) to 2% (similar to 2020 and 2019). However, the population figure is 8.3% in Calderdale and 14.8% in Kirklees. This shows that far fewer Asian people are accessing the service than are representative in the populations of Calderdale and Huddersfield, and this needs to continue to be an area for our development in 2023.



'Our patients benefit hugely from the expert advice and support provided by the Macmillan information and support service. The listening ear provided gives our patients a safe space to really talk about any concerns they have, that they may not have remembered to mention in clinic. The support team are adept at updating us so that we can all work together to support our patients holistically. I see this service as essential in order to provide a good standard of care for our cancer patients. I have no doubt that their workload is ever expanding as our population of cancer patients and survivors grows, and their needs are more complex. We struggle with the limited time available in doctor and nurse-led consultations and the additional support of this service is truly invaluable and very much appreciated.' Dr Kate Rothwell, Consultant Haematologist

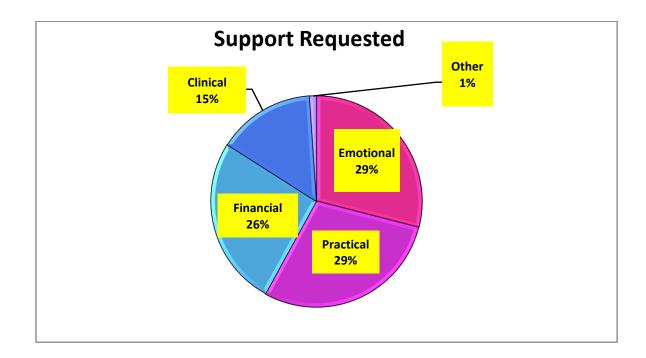
Other Information about our Contacts

The majority of our contacts with people were via phone (51%), then by email (28%), face to face (13%) and virtual meetings (5%). In terms of complexity of patients seen, in 2022, we saw more patients of a lower complexity rating than in 2021. (On a complexity rating of 0-4 with 4 being the most complex patients, 44% of our contacts were level 2 in 2021 compared to 23% in 2022). We also saw fewer extremely complex patients compared to the previous year – level 4 contacts were 29% in 2021 compared to 10% in 2022. It is likely that we supported more complex patients in 2021, due to the ongoing pandemic and people navigating both cancer and Covid.

As for the previous year, our most frequent length of time for contacts was between 6 and 15 minutes (35%), followed by contacts of 16 - 30 minutes (26%). We had a slight increase in contacts of 31 - 60 minutes (21% compared to 20% last year) and a reduction in contacts of over one hour (10% compared to 12% last year).

What support did people ask for?

In 2022, we provided equal amounts of emotional and practical support (29% of our contacts), followed by financial support for 26.5% of our contacts. This differed from previous years where emotional support has been highest, followed by financial support. There was a significant increase in requests for practical support in 2022 (29% compared to 20% in 2021), with the most common requests being for blue badges, carers support and travel/transport information. We had an increase in clinical support/information, such as people wanting to discuss the management of their treatment side effects and symptoms.



'The Macmillan information service are dedicated people providing a selfless, fabulous service when faced with so many uncertainties. They provide a safe place and a listening ear out of the family circle, who of course are involved in current care.' Patient, 2022

Practical Support

In 2022 we made 901 referrals to different organisations for people to access practical, emotional and financial support, as well as signposting to numerous organisations/professionals for support. 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 2022 we had over 1000 queries about Blue Badges for disabled parking. We were also contacted about work support, liaised with the two councils to help sort housing and other situations for various patients and liaised with school staff to support children of parents who were sadly dying. We also liaised regularly with clinical teams, GPs, psychology staff, hospice staff, Social Prescribing Link Workers, and community organisations. The purpose of our liaison was to reduce the pressure on the patients to have to liaise with different services themselves and to enhance their experience and sense of support and coordination. We also provided support and information such as travel insurance information, wills, power of attorney, radar keys for disabled toilets, Macmillan toilet cards, hospital parking permits and hair loss information and signposting.

Emotional Support

As noted above, 2022 saw a drop in the level of emotional support provided by our service to patients, family members and staff, essentially due to an increase in requests for practical help and clinical support. However, providing emotional support and a listening ear remains a key part of the service we offered, taking almost a third of our time. Most people simply wanted to talk, and patients have told us they at times struggle to share their fears and worries with family members or busy clinicians, and therefore appreciate the opportunity to talk to our staff and volunteers in a safe, confidential environment. This is therefore a crucial benefit which our service provides. Other emotional support requested was about referrals for counselling and psychological support, help with relationships, iHOPE course and some bereavement support.

'The team continue to deliver excellent levels of support to cancer patients across the Calderdale and Huddersfield locality. As well as the wide range of support services provided at the information centres, Calderdale is unique in offering a range of bespoke courses to cancer patients, including First Steps and iHOPE. What's also clear is that the team go the extra mile in providing a personalised and caring service to every individual they come into contact with, and this extends to practical, financial and emotional support. This all falls in line with Macmillan's wider objectives of delivering cancer support with Heart, Strength and Ambition and doing whatever it takes to give people the support they need. Well done to Helen, Mandy and the whole team at CHFT for the excellent service they continue to deliver.'

Macmillan Engagement Lead – West Yorkshire, Harrogate and South Yorkshire

Monthly Support Groups

A key part of the emotional support we run is via the peer support offered in our support groups, which are largely led by our volunteers. Our volunteers often organise and run the groups, as well as providing a listening ear and emotional support for the attendees. In 2022, we continued to run an online monthly coffee support group for those who preferred remote contact. This group had 50 attendances over the year. Another of our support groups, our walking group, is led by our volunteers Shaz and Margaret, along with one of our support workers, Kajal, and with help from another walk leader, Nicola - all of whom have trained with Kirklees Council as Walk Leaders. The walking group met virtually until May 2022 and then the face-to-face walking group was relaunched at Greenhead Park, Huddersfield, from June 2022. This group had 62 attendances during 2022 (21 virtual and 41 face to face).

2022 also saw the launch of a new support group for men affected by cancer – either themselves or supporting someone through it. This is again run by our Macmillan volunteers, Geoff and John, also with the support of David. The group have organised

speakers for each of the groups, had time to chat and had a quiz. In total there were 39 attendances in 7 meetings.

Many people have told us they have really benefitted from the peer support available in the support groups and being with others who understand what they are going through.

'Since my devastating incurable diagnosis nearly 5 years ago, my wife and I have come to really appreciate what Macmillan & their fantastic team of volunteers have done to help us 'live' with cancer, through adversity, to improve our minds & body. Their network of support groups, including those which we attend regularly, namely Walk in the Park, Coffee Mornings & for myself in particular Men's Cancer Support Group, have been able to bring us together with others affected by cancer, making new friends along the way, supporting each other. Macmillan have been the catalyst, providing invaluable support & advice for us all to try & make some sense of everything that has changed our lives for ever.' Patient, 2022

Financial Support

A total of 26.5% of all our contacts were asking for financial help, which included requests to be referred to our Macmillan benefit advisors at Advice Kirklees and Age UK. We have also applied for grants and other financial support, as well as signposting people to the financial advice available on the Macmillan Support Line where people can speak to a professional about concerns over mortgage payments, pensions, and other financial concerns such as managing debt.

Welfare Benefits

In 2022 we referred a total of 516 people for benefits advice, with many of our patients not realising they may be eligible for the disability benefits Personal Independence Payment and Attendance Allowance from the government, before having contact with our service. We made 230 referrals to Eileen Murray, Macmillan Benefits Advisor at Advice Kirklees, 249 referrals to Age UK in both Calderdale and Huddersfield and the remaining 37 direct referrals for PIP special rules were done by our service for Calderdale under 50s patients. Unfortunately, there has remained a gap in benefits provision in 2022 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 supported in 2022. Using these figures, we have been able to estimate the benefit gains and arrears for patients referred specifically by our Macmillan Information & Support Service as a huge **£1,409,758.83** which is an increase of £103,959.56 since 2021 and despite an ongoing pandemic. This money went directly to cancer patients to help them with the cost of living and into our local economy. The breakdown of these figures is as follows:

(PIP special rules) Totals	516	£1,340,668.23	£69,090.60	£1,409,758.83
Estimates for other referrals	37	£96,133.19	£4,954.17	£101,087.36
2020 Age UK	249	£558,999.33	£23,076.87	£582,076.20
2022 Advice Kirklees	230	£685,535.71	£41,059.56	£726,595.27
Referrals		Total gained in benefit income (regular ongoing payments)	Total gained through one off payments (grants, compensation and arrears, etc)	
Macmillan Information Service	No of referrals from our service	Confirmed Benefits from our referrals	One off Payments from our referrals	Total for our number of referrals:

We continued to signpost regularly to the **Macmillan Support Line** in 2022 which is 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.

`Thank you for fixing
me up so quickly as
I felt I was
drowning before I
spoke with you.'
Patient, 2022

'Helen and the team go above and beyond for the patients who come to them for support. Their patients are at the heart of everything they do, and they always make time for people. They follow up with appropriate actions swiftly and always provide an empathetic listening ear. Patients and volunteers have nothing but praise for the team and the services provided.'

Stacey Rhodes, Macmillan Senior Relationship Fundraising Manager – Yorkshire

<u>Grants</u>

In 2022 we were successful in gaining a huge **£102,185.00 in Macmillan Grants** for 256 patients in particular financial need, which was an increase of £47,535 for an additional 105 patients, compared to the 2021 figures. Macmillan Grants are means tested and provide a grant of £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 2022 we also applied to **other charities** for patients in extreme need, though other grants were not as accessible as in previous years due to so many charities being hit by the pandemic and cost of living crisis. We were successfully awarded the following:

- **£2,144.00** of nursery fees from the Robert Sinclair Davison Fund for a young palliative breast cancer patient
- **3** caravan holidays from the Mothers Union Charity 'Away From It All', for families in particularly difficult circumstances
- A **£500** grant from the Charles Brook Convalescent Fund for a patient who received one of the above caravan holidays but had no money for transport or holiday spends.
- **4** washing machines from the Percy Bilton Charity
- **2** hardship grants from the Roy Castle Lung Cancer Foundation for lung cancer patients
- A vacuum cleaner from the Friends of the Elderly Charity

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 and their families, especially when their resources are challenged.

Patient Feedback

In 2022, 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 emailed a questionnaire to our patient list and requested comments and feedback through this. We also have comment books and suggestion boxes in both of our centres.

Of the patients and family members who gave feedback:

- **96%** said they would recommend the service to someone else and **4%** said they were not sure.
- **98%** said that they felt listened to and understood.
- **82%** of patients and carers said that contact with our service had specifically helped to reduce their anxiety. (16% said they did not have any anxiety in the first place).
- People said they liked the environment of the Jayne Garforth Macmillan Centre in CRH, which they described as 'relaxed and welcoming', 'comforting and friendly', 'all very pleasant.'

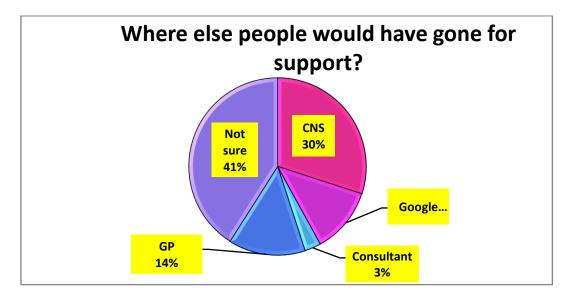
'HRI probably needs more space to meet the excellent facilities at CRH. Both are welcoming places.'

• Both of our centres at CRH and HRI were described by patients as `calm, friendly, welcoming, inclusive,', with `lots of helpful information.' People talked

also about CRH as 'relaxing, light, airy and pleasant.' Some people felt that the resource room on Greenlea at HRI was not visible enough, saying it needed more signage, people weren't sure if it was open or not, it was hidden away, and one patient said: 'HRI probably needs more space to meet the excellent facilities at CRH. But both are welcoming places.' As mentioned above in this report, the centre at CRH (Jayne Garforth Macmillan Centre) is the official, Macmillan funded and branded space, with our room at HRI being provided by the Trust to enable us to support patients at both sites.

As part of our feedback, we asked patients where they would have gone if they had not accessed support from our service. A huge 47% of people said they would have gone to their clinical team for support if our service had not been available (i.e., their CNS, consultant, or GP), showing that our support frees up our clinical colleagues to attend to clinical matters. 41% of people said they weren't sure where they would have gone had our service not been available, and 12% said they would have referred to the internet for help and support.

These figures provide evidence that having contact with our service saves significant time and reduces pressure on the clinical teams, as well as supporting patient experience, as noted in the professional feedback throughout this report.



'Being able to refer patients to the Macmillan Information Team for practical enquiries such as financial pressures, travel insurance, etc., really takes pressure off busy oncology clinics, leaving more time for discussion of medical and treatment matters. It also takes a lot of pressure off hard-pressed specialist nursing teams, allowing them to focus on their areas of expertise.' Dr Nick Brown, Medical Oncology Consultant

In the feedback we had one negative comment about a person feeling more supported by the Leeds Macmillan team than ourselves and a few comments about our education programmes being online and people struggling with technology/IT skills. We are aware this presents some challenges for patients and are looking at some more face-to-face sessions in 2023.

Numerous comments and quotes were given to us from patients and family members about the support provided by the service in 2022, several of which are already featured in this report. Below includes some highlights from quotes, but much more detailed patient feedback is included as an appendix to this report, which we would encourage the reader to view.

'I would like to thank Helen, Mandy, Holly and Kajal of Macmillan's for their encouragement and support. If anyone had a problem or concern, they were always ready with a solution and if they didn't have one there and then, they definitely would go and find one.'

'My husband and I have found the support given to us by the Cancer Support Service at CRH invaluable. When we needed help regarding appointments, advice and information, Mandy sprang into action and within minutes we'd received a call from an Upper GI CNS explaining the timeline of what will happen which gave us complete clarification. On another occasion when we decided that we needed to seize the day while my husband was well and in between treatments, Mandy (again!!) provided us with information regarding specialist travel insurance companies. This saved us an amazing amount of money and allowed us to go abroad twice since last summer. We will be eternally grateful to Mandy and the rest of the Team who provide a fantastic service.'

'You helped with practical and emotional support for both myself and my daughter with cancer. You were always there for help and support either face to face and over the phone. I feel that both myself and my daughter have been given time and been listened to which has been invaluable and helped to reduce a lot of anxiety. Medicine may treat the disease, but the Macmillan support team see the whole person which I think is vital to their health and wellbeing.'

'A fabulous service when faced with so many uncertainties, provided a safe place and a listening ear out of the family circle, who of course are involved in current care.'

'The Macmillan information service are dedicated people providing a selfless service.'

'The staff at Calderdale and Huddersfield Macmillan were compassionate, friendly and efficient.'

'I find all your resources, sessions, and advice invaluable as I navigate my cancer journey. When I was diagnosed, I felt lost and overwhelmed and your support has made a huge difference to me, and I now know what support I can access. I feel much more in control, knowledgeable, supported and most importantly for me I've got back some of the confidence I lost and feel more like me! THANK YOU!'

'Extremely supportive and helpful at a very vulnerable time.'

'This is an excellent service – all the staff are very helpful and supportive. When we needed you most - you were there, thank you.'

'People who are going through health worries need people who understand what is happening to them in the medical system. Macmillan support enables you to ask questions and talk to people - just what I needed and still do.'

'I need Macmillan to be there. Great support. Feel safe. Always positive.'

'Just speaking to someone is help, they have a caring approach and the information you need to calm your fears and answer your questions.'

'The service is invaluable and certainly makes you feel less alone knowing the support is there.'

'I am an independent and quite private person. I live alone and I am used to dealing with and solving my own problems and issues. My cancer diagnosis didn't hit me as hard as I had expected. I soon came to realise that the treatment regime proposed would be long and difficult. I pondered the question "would I be able to cope with it all on my own. "It was with some trepidation that I signed up for the First Steps programme. I haven't hesitated since then and have participated in everything Macmillan has to offer. The CHFT Macmillan team are brilliant and are always supportive and uplifting to be with. I am really glad that I was brave enough to take that "first step.""

'The team are well organised, very approachable and make you feel supported – thank you all.'

'The Macmillan staff gave me very helpful advice and reassurance. They are very accessible and very responsive to any queries/questions and if they are unable to help with something they are very good at signposting to other relevant services or people who can.'

'I have found it really helpful so far and it is very reassuring to know that it is there. It is vital that the service continues.'

'Macmillan continue to be a good source of information for cancer patients - which is especially relevant for bladder cancer - because it is so little known about in the general community.' 'I feel that the service offered by the Macmillan Information and Support Service is a key part in the recovery of people such as myself.'

'Macmillan offer a very valuable additional and supportive service to the NHS. They offered a contact for any problems which is so helpful especially when needing assistance with questions about appointments & treatments.'

'An excellent service. The adviser was ready to listen, speak and make helpful comment /suggestions. It was at a very early stage with recent diagnosis and operation scheduled a week later.'

'Brilliant. You encouraged me to listen to all that was available and helped me tailor it to suit me. If I don't know it's available, I can't access it. '

'I feel this is a very important service especially for those who don't have support from family or friends.'

'You listened, then offered me access to the various courses and support groups. I then did not feel alone.'

'I have hugely benefited from meeting people at events organised by Calderdale McMillan who have also had cancer and can really understand what it is like. I have joined in with the iHOPE course which was just right when I had just started the chemotherapy. I also joined the walking group which is great for the gentle exercise and socialising. The online coffee group is a fab way to meet up and stimulate the brain with the quiz. It's lovely to know there is someone to call on at MacMillan in Calderdale if needed.'

'I would not have contacted your service but once I had been given the details, I am so very glad I did. I feel I could ask/talk about anything and everything and get an answer and help and support. Thank you.'

'The Thinking Ahead programme was particularly helpful. I found the sessions on advanced care planning were most valuable as it helped give us permission to start talking about the reality of the condition and things that need to be addressed. I also found the practical sessions on estates planning, benefits and hospice care the most useful, especially the contacts and useful links it has given us as well as practical things to consider. Hearing other people speak about their journeys through this process also made it feel lighter somehow.'

'I was helped immensely in a really difficult time. Macmillan staff sorted so much out for me regarding money and put me in touch with recovery college where I have done courses to help me. I join in online meetings - it's like a family.'

'I couldn't ask for better service – just fantastic.'

'The service with its very comprehensive variety of courses, sessions and support groups really has something for everyone. I definitely had a good few takeaways.......'

'Once again, many thanks Helen. It is such a relief to have you onboard - thank you again for being there and for all your help - I thank Dr Ram for introducing me to you every day'.

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 delivery group meetings and some external meetings. We also answer cancer information and support queries from staff and volunteers across the hospital sites, as well as externally. Furthermore, we also provide some emotional support to clinical colleagues, who often find us a helpful place to debrief and offload after emotional encounters with patients. We asked our clinical staff across the trust, as well as some community staff we work with, about the value of our Macmillan Cancer Information Service to them and their patients in 2022. Their feedback is below and featured within the main report:

'Thank you for all your support, knowledge, and resources not just for my patients and relatives, but for myself as a professional also. You have been an asset to the greater trust team. Keep up the great work.'

Anthony Thomas, Macmillan Neuroendocrine Tumour CNS

'Helen, Mandy and Kate from the Macmillan Cancer information centres at Huddersfield Royal Infirmary and Calderdale Royal Hospital in Halifax make many referrals to our Macmillan Advisers for cancer patients needing benefits advice. They are so helpful in gleaning information to assist with what we need to be able to advise and help patients to claim benefits quickly at their time of need. We work in partnership with them so if we need to seek further information, they are only too happy to help. Thank you for everything you do to make the process seamless and also in particular the number of Macmillan Grants you apply for on behalf of cancer patients.'

Eileen Murray, Macmillan Benefits Advisor, Advice Kirklees

'The Macmillan information service is an invaluable service and one that goes from strength to strength every year. This service has a massive impact on the psychological wellbeing of the patient and their relatives. From the outset they are supported and listened to and signposted to the relevant areas that will be helpful to them. I find that with a lot of patients when they first come for treatment it's not always the worry of their treatment plan and side effects that has the greatest impact on them, it's the financial impact, the impact on the rest of the family and the psychological effects of their diagnosis. When these needs are addressed at the start of a person's cancer journey, they seem to cope much better with their treatment. The time and effort that goes into every patient would not be achieved without the Macmillan information team. Their knowledge and expertise knows no bounds, without them our workload would increase exponentially and have a massive impact on our team. The team are always there to support staff as well and the feeling that we all work together for the greater good of the patient leads to greater job satisfaction. Even sometimes what seems like a simple problem can take hours to sort but the team always are able to signpost you in the right direction and make it much easier. Everyone on that team exudes care compassion and goes over and beyond on a daily basis. In short, we could not deliver the care that we do with them.'

Bernie Beith, Chemotherapy CNS

'As a former member of the local Fundraising team and now working internally for Macmillan, as well as being a local telephone and community buddy. The service Helen, Mandy and the team provide is invaluable. Their commitment and passion is incredible. From regular updates to what services and groups can be accessed to being a lifeline to many across the districts. I have had first-hand experience when supporting a telephone buddy how their service supported the user and how it made such a huge difference. I am very proud to talk about the local services and just recently I will be taking on the role of chair of the local fundraising group and I am excited to work with the team to share their offer wider and to more people that would absolutely benefit from their support. They are a true pleasure to know and work with.'

Adele Burrough, Macmillan Stewardship and Development Manager

'Thank you for the wonderful support you give the Colorectal Nurses and Colorectal patients. We could not do our job without you. Time is so precious for everyone, but your kind, knowledgeable and smiley team, are always there to enrich the journey of our patients, for that we are so grateful.'

Helen Ilsley, Colorectal Cancer Nurse Specialist

'Our Macmillan team provide exemplary service to the oncology patients. Excellent leadership and all support workers are brilliant. *Specific mention about Mandy in helping a patient recently with unique situation understanding the complexities.* Excellent support offered by all of the staff to our group of patients.

Proud to be part of the team. I have never heard the word "no" to any help I request for the patients. Many thanks.

Dr Deivasikamani Ramanujam, Medical Oncology Consultant

'The Macmillan Information & Support Team are an invaluable asset. The team are able to provide our Lung cancer patients with advice, support and practical help which is

crucial to a point in their lives where they most need it and where any help is readily welcomed.'

Kully Sandhu, Lung Cancer Nurse Specialist

'The MacMillan information team are a very valuable service. They are always very helpful in any queries. They are also helpful completing benefit forms and chasing up benefit etc. Our patients sometimes are very complicated and need lots of support. The MacMillan information team are always willing to speak to the patients and offer listening ears and direct them to the services available. As a team they allow thew CNS team to focus on the specialist needs of the patients, and they help with the rest. If they do not know the answer the questions, they take the time to look and research and try and find out the answer! Thank you for your continued support. It is extremely valuable to both me and the patients.

Rebecca MacMillan, UGI Cancer Care CNS

'Being able to refer patients to the Macmillan Information Team for practical enquiries such as financial pressures, travel insurance, etc., really takes pressure off busy oncology clinics, leaving more time for discussion of medical and treatment matters. It also takes a lot of pressure off hand-pressed specialist nursing teams, allowing them to focus on their areas of expertise.'

Dr Nick Brown, Medical Oncology Consultant

'The CHFT Macmillan Information Service is invaluable. The team work so hard to provide support to so many patients, often in hugely challenging circumstances, and in my view are miracle workers! They are experts in providing holistic care, and they make a huge difference to the lives of patients and staff alike. Personally, I am so grateful for all they do, and appreciate how they "go the extra mile" day in and day out for patients and their families.'

Jenny Jones, Oncology Advanced Clinical Practitioner

'Patients covered by the Calderdale and Huddersfield hospitals are very well provided in terms of their Macmillan Information and Support Service.

They are updated with a monthly newsletter which gives them local and regional news plus they have a choice of patient support groups to attend.

As a worker for a very small local charity for people affected by cancer, they are a lovely team to work alongside and are very supportive and helpful.'

Jill Long, Engagement & Communications Officer, Yorkshire Cancer Community

'Our patients benefit hugely from the expert advice and support provided by the Macmillan information and support service. They are able to get answers to many of the questions where I do not have the knowledge to advise, particularly on financial matters and it will often help to relieve a considerable degree of uncertainty and stress. In addition, the listening ear provided gives our patients a safe space to really talk about any concerns they have, that they may not have remembered to mention in clinic. The support team are adept at updating us so that we can all work together to support our patients holistically.

I see this service as essential in order to provide a good standard of care for our cancer patients. I have no doubt that their workload is ever expanding as our population of cancer patients and survivors grows, and their needs are more complex. We struggle with the limited time available in doctor and nurse-led consultations and the additional support of this service is truly invaluable and very much appreciated.'

Dr Kate Rothwell, Consultant Haematologist

'I've had the pleasure of linking in with the CHFT information and support team over the past few years and from my observations, the team continue to deliver excellent levels of support to cancer patients across the Calderdale and Huddersfield locality. As well as the wide range of support services provided at the information centres, Calderdale is unique in offering a range of bespoke courses to cancer patients, including First Steps and iHOPE. These courses help patients adjust to living with and beyond cancer after they are discharged from their cancer treatment pathway. What's also clear is that the team go the extra mile in providing a personalised and caring service to every individual they come into contact with, and this extends to practical, financial and emotional support. This all falls in line with Macmillan's wider objectives of delivering cancer support with Heart, Strength and Ambition and doing whatever it takes to give people the support they need. Well done to Helen, Mandy and the whole team at CHFT for the excellent service they continue to deliver.'

Fraser Corry, Macmillan Engagement Lead – West Yorkshire, Harrogate and South Yorkshire

'The Information and Support Service at CHFT is one of Macmillan's Award-Winning Services we are very proud and privileged to work in partnership with the team. The team do whatever it takes and strive to provide excellence in supporting the patients of Greater Huddersfield and Calderdale when diagnosed with cancer.

Lisa Spivey, Macmillan Partnership Manager, West Yorkshire

Our Development Plans for 2023

We are excited to build on the success of our CHFT Macmillan Cancer Information and Support Service in the year of 2022, and will target the following areas in the year to come:

- **1. To increase our staff team.** As our data shows, we had a 95% increase in our contacts in 2022, compared to 2021, though we continue to only have three permanent staff in the team, and at the time of writing, no additional temporary staff. We will continue to present business cases to CHFT and apply for external funding to help us secure additional staffing to meet the increased demand on the service. Staff wellbeing and stress levels are being affected and this does need to be addressed.
- 2. To introduce our pilot project funded by Macmillan, offering end of treatment eHNAs for patients. Our service is well placed to offer Holistic Needs Assessments at the end of a person's cancer treatment, and as such we are excited by the award of funding from Macmillan for a two-year support worker post to provide this service, which will run between 2023 and 2025. We will select certain tumour sites to work with, plan and evaluate the project, reporting data to Macmillan and CHFT. This project will also assist our Trust data whereby HNA figures are reported quarterly to the cancer alliance and where we currently lie behind other Trusts in the region.
- **3. Continuing to offer high quality, personalised information, and support according to the patient/carers need.** As part of the NHS long term plan and CHFT cancer strategy, we aim to continue to deliver personalised, tailored support based around whatever matters to patients. This involves supporting the Care Plans written by our clinical colleagues as well as offering eHNAs and Care Plans from our service at the end of treatment.
- **4. Enhancing community links for patients.** In line with Macmillan's strategy for Information and Support Services nationally, we will continue to work with community and primary care networks to enhance patient experience and the smooth transition of care into the community, following secondary care input. This involves working closely with the Macmillan Personalised Care Lead for Calderdale and the Cancer Alliance Living With and Beyond Cancer team. The aim of our service is to be a cancer hub where patients can receive high quality information and support, but then be signposted to ongoing support outside the hospital context. In 2023, we will explore the possibility of developing 'spokes' from our service, into the community, subject to funding.
- 5. Patient Education Programmes further increasing attendance and reviewing delivery models. 2022 saw an increase in attendance at many of our programmes, particularly Thinking Ahead and iHOPE, though numbers for First Steps

and our End of Treatment Events remained low. In 2023 we will review face to face options for delivery of our programmes and seek to relaunch First Steps in a new and improved way, again offering face to face rather than virtual sessions. We will also work collaboratively with the new Thinking Ahead Project manager to support the development of TAP across the alliance footprint and nationally – sharing our experience and expertise, for the benefit of others.

- **6.** New volunteer recruitment. As many of our information service and Headstrong volunteers have now left the service or retired, we need to recruit more information service volunteers and patient rep volunteers in 2023. We also need to look at recruiting volunteers to relaunch the Headstrong hair loss service, though again our capacity issues and Trust hold on volunteer recruitment, have meant this has not been possible in 2022.
- **7. Continued patient engagement and co-design.** Again, due to service pressures, our Cancer Patient Focus Group has not been as active in 2022 as in previous years. However, we are committed to service development and keen to listen to the voice of our patients and family members in 2023. This will also involve a piece of work around redesigning and launching First Steps, where we will engage with a group of patients to mould and influence the delivery model.
- **8. Hard to Reach Communities.** Our 2022 statistics show again that we are not reaching sufficient patients from ethnic minority groups, so now that the pandemic is over, we need to look at ways to link with various communities in 2022. We will continue to work with the trust cancer team to address inequalities, particularly through the BAME Kirklees network and by linking with faith and community leaders, groups and settings.
- **9. Look to potentially offer more support on the hospital wards.** This was an aim for 2022, though due to service pressures, we struggled with the capacity to visit people on the wards as much as we had planned. We did respond to referrals and see people on the wards where possible. If we were given additional staff, this would also be a helpful development for 2023, and would enhance patient experience for hospital inpatients.
- **10. Maintain and develop the high-quality service provided** by the CHFT Macmillan Information and Support Service team, as demonstrated in this report. Despite the service pressures we have experienced in 2022, we are absolutely committed to providing the best possible service for our patients and family members, always putting the patient first and seeking to be the best we can be.

Report written by Helen Jones CHFT Macmillan Information and Support Service Manager 22.5.2022





Appendix One – Patient Feedback in 2022:

'My husband and I have found the support given to us by the Cancer Support Service at CRH invaluable. When we needed help regarding appointments, advice and information, Mandy sprang into action and within minutes we'd received a call from an Upper GI CNS explaining the timeline of what will happen which gave us complete clarification. On another occasion when we decided that we needed to seize the day while my husband was well and in between treatments, Mandy (again!!) provided us with information regarding specialist travel insurance companies. This saved us an amazing amount of money and allowed us to go abroad twice since last summer. We will be eternally grateful to Mandy and the rest of the Team who provide a fantastic service.'

'You helped with practical and emotional support for both myself and my daughter with cancer. You were always there for help and support either face to face and over the phone. I feel that both myself and my daughter have been given time and been listened to which has been invaluable and helped to reduce a lot of anxiety. Medicine may treat the disease but the Macmillan support team see the whole person which I think is vital to their health and wellbeing.'

'A fabulous service when faced with so many uncertainties, provided a safe place and a listening ear out of the family circle, who of course are involved in current care.'

'The Macmillan information service are dedicated people providing a selfless service.'

'Since my devastating incurable diagnosis nearly 5 years ago, my wife and I have come to really appreciate what Macmillan & their fantastic team of volunteers have done to help us 'live' with cancer, through adversity, to improve our minds & body. Their network of support groups, including those which we attend regularly, namely Walk in the Park, Coffee Mornings & for myself in particular Men's Cancer Support Group, have been able to bring us together with others affected by cancer, making new friends along the way, supporting each other. Macmillan have been the catalyst, providing invaluable support & advice for us all to try & make some sense of everything that has changed our lives for ever.'

'I think that the existing staff are already exceptionally busy and demand is increasing. A reduction in staffing would result in a reduced level of service at a time when staffing levels should be increased to cope with the demands.'

'The staff at Calderdale and Huddersfield Macmillan were compassionate, friendly and efficient.'

'I find all your resources, sessions, and advice invaluable as I navigate my cancer journey. When I was diagnosed, I felt lost and overwhelmed and your support has made a huge difference to me and I now know what support I can access. I feel much more in control, knowledgeable, supported and most importantly for me I've got back some of the confidence I lost and feel more like me! THANK YOU!'

'Extremely supportive and helpful at a very vulnerable time.'

'This is an excellent service – all the staff are very helpful and supportive. When we needed you most - you were there, thank you.'

'People who are going through health worries need people who understand what is happening to them in the medical system. Macmillan support enables you to ask questions and talk to people - just what I needed and still do.'

'I need Macmillan to be there. Great support. Feel safe. Always positive.'

'Just speaking to someone is help in itself, they have a caring approach and the information you need to calm your fears and answer your questions.'

'The service is invaluable and certainly makes you feel less alone knowing the support is there.'

'I am an independent and quite private person. I live alone and I am used to dealing with and solving my own problems and issues. My cancer diagnosis didn't hit me as hard as I had expected. I soon came to realise that the treatment regime proposed would be long and difficult. I pondered the question "would I be able to cope with it all on my own. "It was with some trepidation that I signed up for the First Steps programme. I haven't hesitated since then and have participated in everything Macmillan has to offer. The CHFT Macmillan team are brilliant and are always supportive and uplifting to be with. I am really glad that I was brave enough to take that "first step.""

'The team are well organised, very approachable and make you feel supported – thank you all.'

'The Macmillan staff gave me very helpful advice and reassurance. They are very accessible and very responsive to any queries/questions and if they are unable to help with something they are very good at signposting to other relevant services or people who can.'

'I have found it really helpful so far and it is very reassuring to know that it is there. It is vital that the service continues.'

'Thank you for the help and support you give especially at such a very difficult time. Surely the larger the team the more easily accessible the information is for people under the most tremendous stress.'

'Macmillan continue to be a good source of information for cancer patients - which is especially relevant for bladder cancer - because it is so little known about in the general community.'

'Honestly, you have all been amazing from the start, I have had a great level of support which has given me confidence. You probably just think you are picking up a call, but it is more than that you have lifted a huge weight off my shoulders.' 'I feel that the service offered by the Macmillan Information and Support Service is a key part in the recovery of people such as myself.'

'I could not have coped without this service – thank you.'

'I am really grateful for the help and support I have received and know this is ongoing throughout my treatment and afterwards too, should I need it. I had no idea before I had cancer that this kind of support existed and can't speak highly enough of the team. Their kindness, empathy and love for the job they do shines through. Once I am well again and back on my feet, I would love to be able to help and support others, maybe by volunteering through Macmillan!'

'Macmillan offer a very valuable additional and supportive service to the NHS. They offered a contact for any problems which is so helpful especially when needing assistance with questions about appointments & treatments.'

'An excellent service. The adviser was ready to listen, speak and make helpful comment /suggestions. It was at a very early stage with recent diagnosis and operation scheduled a week later.'

'Brilliant. You encouraged me to listen to all that was available and helped me tailor it to suit me. If I don't know it's available, I can't access it. '

'I feel this is a very important service especially for those who don't have support from family or friends.'

'You listened, then offered me access to the various courses and support groups. I then did not feel alone.'

'I have hugely benefited from meeting people at events organised by Calderdale McMillan who have also had cancer and can really understand what it is like. I have joined in with the iHOPE course which was just right when I had just started the chemotherapy. I also joined the walking group which is great for the gentle exercise and socialising. The online coffee group is a fab way to meet up and stimulate the brain with the quiz. It's lovely to know there is someone to call on at MacMillan in Calderdale if needed.'

'I would not have contacted your service but once I had been given the details, I am so very glad I did. I feel I could ask/talk about anything and everything and get an answer and help and support. Thank you.'

'The Thinking Ahead programme was particularly helpful. I found the sessions on advanced care planning were most valuable as it helped give us permission to start talking about the reality of the condition and things that need to be addressed. I also found the practical sessions on estates planning, benefits and hospice care the most useful, especially the contacts and useful links it has given us as well as practical things to consider. Hearing other people speak about their journeys through this process also made it feel lighter somehow.'

'I was helped immensely in a really difficult time. Macmillan staff sorted so much out for me regarding money and put me in touch with recovery college where I have done courses to help me through lockdown. I join in online meetings - it's like a family.'

'I couldn't ask for better service – just fantastic.'

'The service with its very comprehensive variety of courses, sessions and support groups really has something for everyone. I definitely had a good few takeaways.......'

'Once again, many thanks Helen. It is such a relief to have you onboard - thank you again for being there and for all your help - I thank Dr Ram for introducing me to you every day'.

'Just having someone you can ring when you need advice and support. You can feel very alone and frightened.'

'MacMillan supported me by providing and facilitating courses and groups (First Steps, Hope, Walking Group, Coffee Time Group, and the Patient Support Group.) This has allowed me to interact with other cancer sufferers and support and guide me on my cancer journey. Each member of the CHFT Macmillan team offers a different insight into each meeting. Their knowledge is extensive, and they are always encouraging and supportive, especially to group members who at times find the ordeal too overwhelming or emotive.'

'Do not underestimate the value of your service and thank you very much for all your support.'

'You were a telephone call away to answer my queries after treatment. Put me in contact with the right people to resolve issues. Quick response.'

'I really appreciate that this service is available if I ever need it.'

'My wife and I found our session with you very helpful and very professional, we both left your office feeling much better about our situation. Thank you.'

'Helen all your help & support has been vital & played a significant part in my own thoughts & wellbeing, thank you.'

'Thank you for fixing me up so quickly as I felt I was drowning before I spoke with you.'

'Thank you for just being there, not only for me but all the people who have gone before me and all those who will be coming after me. We need really do need and appreciate Macmillan Services.'

'I have learnt about cancer through first steps course and how to manage my cancer though the iHope course. I have gained support advice and friendship via the Coffee group and walking group. I have been valued, included, and supported as a volunteer. I can always turn to the Macmillan staff when I need help and advice.'

'You did so much to support me - financial information, helped complete the forms, information, financial support, arranged emotional support, thank you. '

'Macmillan after support has been exceptionally good. I have had numerous phone calls asking about my well-being and asking me if there is anything else they can do, both emotionally and financially. It was nice to think if I needed anymore support, I can always contact them, and I am thankful for that.'

'The Thinking Ahead course helped me feel like much more than an NHS number – I was seen and supported as a whole person and for that I am grateful.'

'Kajal, thank you so much for your time this morning. We both found it very helpful both for your empathy, and for defining clear ways forward. Thank you too for the email and the clear next steps.'

'Support pre, peri and post cancer diagnosis and treatments is vital and without the team I don't know where I would have gone to for help and support. The service is wonderful, but more is needed as people suffering and also relatives and friends also need support in these delicate times. Sometimes you feel as if you would rather die than continue with the treatments etc but with help you regain the will to carry on - thank

'Gave emotional support, and a wealth of information, you also helped me understand the journey I would be on.'

'The Macmillan team pointed me in the right direction for accessing the appropriate benefits and also organised courses to attend with useful information.'

'After an extremely traumatic time I felt you were always there to guide and help me. You also helped with my transition back to work.'

'Immediate provision of the services and information that was available to me. Teams sessions for question and answer and an opportunity to meet like people. Essentially making sure I realised I was not alone.'

'Staff are very supportive always there to offer comfort and advice, and most of all someone to talk to on the down days.'

'Dear Helen, Mandy, Holly and Kajal. I really appreciate the support you have offered David and I and our family over the last few years. Unfortunately, David died two weeks ago. He had a peaceful end which was due to the excellent advice with drug and care etc that we got. I have a phone number that I can call if my family and I need extra support in the future and it is a comfort to know that people like you are there for us. I wish you well in your essential work in the future.'

'I was trying to contact Age UK, and no one could help until I contacted MacMillan's, really not thinking they would be able to help me, but they did!!!!! The young lady more than helped, so actually contacted the person for me resulting in me receiving a Blue Badge. I have joined the sessions online which have been more than helpful, and the facilitators are brilliant - they listen, advise and support which is very much needed!! Looking at Q3, just answering `yes' is not enough!!! It is `YES, I most certainly was supported!!'

'You supported me as a newly diagnosed breast cancer patient by holding zoom events and constant emails and even just knowing you were there. This was all during the first lockdown and that was frightening enough but going forward you gave me a friendly ear to talk to and gave some really excellent advice - thank you.'

'At a time when my husband was diagnosed with bladder cancer, I was at a low point. In desperation I spoke to a lady at Macmillan at HRI. That and the lovely chapel at HRI, helped tremendously. An ear to listen is so important.'

'When I was initially diagnosed with cancer, I received a call from Mandy at Macmillan who let me know what services were available. It was so reassuring to have access to support at what is a very stressful time. Since then, the team have been very supportive and kind. I joined the iHope Course which was excellent and have got so much from this in terms of tools and tips to help manage stress, and just getting to know the Macmillan facilitators and meet others going through a similar journey to me was invaluable.'

'You supported me when I felt I couldn't speak with my family. Helped me get a blue badge. Helped me with my finances. Made me feel welcome.'

Your service offers a caring, listening ear when things were really bad. Offering courses and support groups. Sorting out financial help. Just making contact and being someone to turn to. Thank you.

I talked to one of the team whilst having a bad day in the Halifax unit. I was having an infusion at the time when a nurse on the ward suggested talking to one of the MacMillan team. Holly was compassionate, caring and gave me time. A true professional, she got me onto the I Hope course which has led to accessing other events.'

'I felt like you had all the time in the world for me which made a huge difference.'

'You listened well, gave advice, information, helped and supported when and where needed.'

'The Thinking Ahead Course was invaluable for the information on the various and varied organisations and support out there as it can feel very lonely when the only contact you have at first are the medical team, who just deal with the practicalities of disease and treatment.'

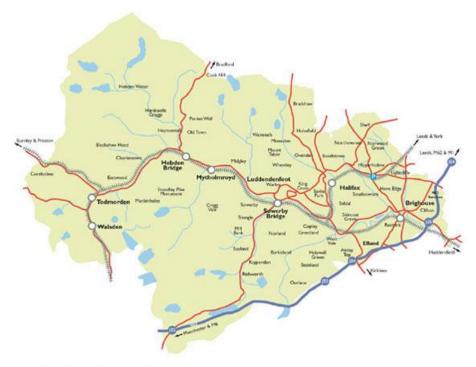
'Thank you for all that you have done for me and all the support you have given me over the last couple of years or so, not only have I enjoyed doing what I've done I have also found it immensely satisfying and rewarding. Whilst I know that you are all so busy and run off your feet you always find time to stop and speak to everyone who needs support, me included. Not only that but I feel I have also made some good friends on a personal basis. Once again, I thank you all for your kindness and 'for being there.'

<u> Appendix Two – The Demographic Population in Kirklees and Calderdale:</u>

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

<u>Calderdale</u>

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 square miles. The district is served by NHS Calderdale Clinical Commissioning Group. In June 2022, the Office for National Statistics (ONS) published Census 2021 population numbers for local authorities in England and Wales. According to Census 2021 there are 206,600 people in Calderdale (ONS Census 2021). This is an increase of around 2,800 people since the 2011 Census.¹



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The largest ethnic group in Calderdale is White British (82.7%), as recorded in the national Census 2021. The four largest minority ethnic groups are Pakistani (8.5%), Other White (2.4%), Indian (0.9%) and Irish (0.8%).²

For both males and females cancer is the biggest contributor to the life expectancy gap between Calderdale and England for which there are 26 excess deaths per year in males and 16 in females. This is followed by respiratory conditions (21 excess deaths in

¹ <u>https://www.calderdale.gov.uk/v2/residents/health-and-social-care/joint-strategic-needs-</u>

assessment/calderdale-demographic-information#age-gender [Accessed 9.5.2023]

males and 24 in females) and circulatory conditions (23 excess deaths in males and 9 in females).

Over 1,100 cases of cancer are diagnosed each year in Calderdale residents. Around 550 residents die each year from cancer.

During 2013/14 the incidence of cancer was 521 per 100,000. This is similar to the England rate of 515 per 100,000. The prevalence was 2.5%, which is similar to the England figure (2.4%). Both incidence and prevalence have increased since 2009/10.

The premature mortality rate from cancer is no longer greatly higher than that for England (145.3 per 100,000 compared to 138.8 per 100,000).³

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.

Attendance Allowance is a non-means tested benefit paid to people aged 65 years old and over who are severely disabled. In November 2021, 4,220 (10.7%) people aged 65 years old and over were entitled to Attendance Allowance. (Sources: <u>Stat</u> <u>Xplore</u> and <u>Census 2021</u>, Accessed 30th June 2022.)

<u>Kirklees</u>

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. According to the 2021 Census. the population of Kirklees was 433,216, with 22,0870 females and 212,346 males.⁴ 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).



 ³ <u>https://www.calderdale.gov.uk/v2/residents/health-and-social-care/joint-strategic-needs-assessment/health/cancer#local-picture</u> [Accessed 9.5.23]
 ⁴ https://observatory.kirklees.gov.uk/population/#/view-

report/63aeddf1d7fc44b8b4dffcd868e84eac/___iaFirstFeature/G3 [Accessed 9.5.2023]

The metropolitan district of Kirklees is served by two Clinical Commissioning Groups – NHS North Kirklees 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 approximately 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.⁵

date	2021	
geography	Kirk	lees
measures	value	percent
Ethnic group		
Total: All usual residents	433,213	100.0
Asian, Asian British or Asian Welsh	84,202	19.4
Black, Black British, Black Welsh, Caribbean or African	9,948	2.3
Mixed or Multiple ethnic groups	13,588	3.1
White	318,969	73.6
Other ethnic group	6,506	1.5

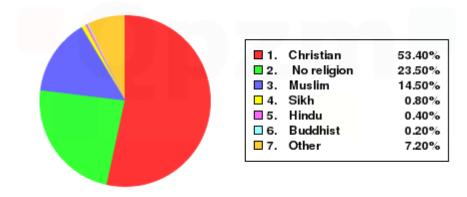
According to the 2021 census, 91.4% of the Kirklees population have English as their first language. Other languages in this area are as follows:⁶

⁵ <u>https://www.nomisweb.co.uk/sources/census_2021/report?compare=E08000034</u> [Accessed 9.5.23].

⁶ <u>http://localstats.co.uk/census-demographics/england/yorkshire-and-the-humber/kirklees</u> [Accessed 9.6.2023].

1. English	91.40%
2. Panjabi	2.40%
3. Urdu	1.60%
🗖 4. Gujarati	1.50%
5. Polish	0.70%
6. Arabic	0.30%
7. Kurdish	0.20%
■ 8. All other	0.10%
Chinese	
🔲 9. 🛛 Pakistani Pahari	0.10%
🔳 10. South Asian	0.10%
Language	
11. Other	1.60%

The religious make up of Kirklees is 53.4% Christian, 23.5% no religion, 14.5% Muslim, 0.8% Sikh, 0.4% Hindu, 0.4% Buddhist.⁷



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 (more than 1 in 4 deaths, 27%), compared to circulatory disease (more than 1 in 4 deaths, 27%) and respiratory disease (1 in 8 deaths, 13%).⁸ More people die from lung cancer than from any other type of cancer. In Kirklees between 2010 and 2015 there were approximately 4,500 diagnosed cases of cancer attributable to the top five most common cancers; lung, breast, prostate, colorectal cancer and non-Hodgkin's lymphoma.⁹

⁹ https://observatory.kirklees.gov.uk/jsna/specific-

⁷ <u>http://localstats.co.uk/census-demographics/england/yorkshire-and-the-humber/kirklees</u> [Accessed 9.5.23].

⁸ <u>https://observatory.kirklees.gov.uk/jsna/specific-groups-life-events/bereavement-and-end-of-life/</u> [Accessed 9.5.23].

conditions/cancer/#:~:text=In%20Kirklees%20between%202010%20and,commonly%20causes%20death %20(4).[Accessed 9.5.23].