NHS
Calderdale and Huddersfield
NHS Foundation Trust

MACMILLAN CANCER INFORMATION & SUPPORT SERVICE

Annual Report 2021

Professionals Excellence Awards
Winner 2021

Team Members:
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Covering Calderdale and Kirklees Region. Based from within Calderdale Royal Hospital and Huddersfield Royal Infirmary.
Report to cover period from 24.1.2021 to 31.12.2021

Report Contents:

Executive Summary

This report describes the activity, aims and impact of the Macmillan Cancer Information and Support Service at Calderdale and Huddersfield NHS Trust, in the year 2021. Throughout this year our patients and their families faced the trauma of an ongoing global pandemic as well as navigating cancer, but the service continued to adapt and respond competently and compassionately to the needs of its service users. The high-quality personalised support and information offered in 2021 for cancer patients and their families, was recognised by the team winning a national Macmillan Excellence Award in November, which was a huge honour. The team were also finalists in three categories of the NHS Patient Experience Network Awards 2021 and were also rated as 'excellent' (level 5) in the Macmillan Quality Environment Mark assessment in May. The service also had more contacts than ever before, with over 4,000 contacts in 2021. This all evidences the crucial non-clinical support offered to patients and their families 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.

This report highlights the objectives of the service in relation to the trust's delivery of personalised support for cancer patients, as well as Macmillan's strategic, national priorities and quality standards. As well as demonstrating the varied practical, emotional and financial support provided to patients, carers and health professionals during the year 2021, the report describes the cancer patient education programme co-ordinated by the service. The report contains a detailed breakdown of data from 2021, looking at who exactly our service supported and at what stage of the cancer pathway. Patient and professional feedback is featured throughout the report, as well as being included in the appendix. The report concludes with the development objectives of the service for 2022.

> **"The service and support that the Macmillan Information Team provides is amazing and so needed for people living with cancer trying to navigate difficult times."**
>
> **Patient, 2021**

> **"Her many, many friends and that includes you all, have been amazing and very supportive of K during her illness and we will forever be grateful. I cannot express enough our thanks, for all that you have done for her. You have held her hand through the very bad days and helped her carry on."**
>
> **Patient's Brother, 2021**

Introduction

The CHFT Macmillan Cancer Information & Support Service began in 2012 and the charity Macmillan Cancer Support funded the building of the Jayne Garforth Macmillan Information Centre at Calderdale Royal Infirmary (CRH), as well as funding some staff posts. Over the years, the trust has taken over the funding of staff posts, with Calderdale and Huddersfield NHS Trust now funding all of the staff and service costs. The service 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. As well as the Jayne Garforth Macmillan Centre in CRH, the service also runs out of the Resource Room in Greenlea Oncology Unit at Huddersfield Royal Infirmary.

In November 2021, after a rigorous assessment and interview process, the team in partnership with Christopher Button, Lead Cancer Nurse and Nicky Hill, Prehabilitation Lead, won a prestigious Macmillan Excellence Award at the national Macmillan Conference in Manchester. The award– 'Whatever it Takes' was an acknowledgement of the outstanding holistic support provided to patients during the pandemic. The team were also finalists in three separate categories in the NHS Patient Experience Network Awards, where they were able to showcase their work at a national level. For both awards, the patient voice was an essential part of the process, with two patient reps, Rob and David, also giving presentations about the support they received and talking about their involvement in service development and co-design.

> **"Winning a trophy is fabulous and well deserved but we patients are the ones that are the winners and it's the support, dedication and guidance that is so freely given when it is needed the most that makes you all winners in our eyes."**
>
> **David, Patient Rep, 2021**

> **"So proud of you all for the acknowledgement of your support, dedication and guidance that you freely give to people at one of the most traumatic and challenging times of one's life. Well done, truly well done."**
>
> **Rob, Patient Rep, 2021**

The service is grateful that the trust made our first Macmillan Information Service Support Worker post permanent in June 2021 and also kindly funded a second support worker post on a twelve-month fixed term basis, from November 2021. Sadly throughout 2021, the dedicated volunteer team for the service were unable to be physically present in the hospitals due to the Coronavirus pandemic, though some volunteers have been involved in virtual and telephone support for patients. Our volunteer patient reps have had a very active role in the delivery of our virtual patient education sessions and support groups, which has been much appreciated.

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

2021 was an extremely busy year for the service, which had over 4,000 contacts - more contacts than any previous year of its existence. The service maintained a high quality standard of care throughout this second year of the Covid pandemic, consulting with our Cancer Patient Focus Group at various points about service delivery, including the implementation of virtual support and education sessions. Despite various lockdowns in 2021, face to face, telephone and virtual support via Microsoft Teams, were all offered throughout the year, providing crucial holistic support alongside the clinical teams.

The service also continued to lead on delivery and implementation of the Patient Education/Health and Wellbeing Programme for cancer patients, across the Trust in 2021, which was all delivered virtually via Microsoft teams. This included the First Steps Cancer Programme for newly diagnosed patients and family members; Thinking Ahead for patients with incurable cancer and family member; End of Treatment Health and Wellbeing Events and iHOPE – Macmillan's health and wellbeing course to help manage the stress of a cancer diagnosis. The service also continued to provide virtual support groups throughout 2021 to offer key peer support. Several of our volunteer patient reps have been involved in the delivery of our patient education sessions throughout the year.

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

Our 2021 Key Statistics

One National Macmillan Award Won!

Finalists in three NHS Patient Experience Awards

4,013
Contacts
27% increase from 2020

£1,305,799.27
in estimated benefit gains for local people from our referrals

25%
of all newly diagnosed patients in CHFT seen by the service

£54,650
Awarded to our patients in Macmillan Grants

761
Onward Referrals to other organisations for support

79%
of people said contact with our service reduced their anxiety
(18%had no anxiety)

1185
Information booklets taken from our centres

14,280
Service newsletters sent out to patients, staff & organisations

One new support worker
on a 12 month contract to help meet increased demand on our service

497
Attendances at our patient education programmes and support groups

48% of people said they would have gone to health professionals if our service did not exist – saving time and money

Growth of our service over the last five years

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

	2016	**2018**	**2020**	**2021**
Number of WTE Staff:	1	2	3 (from June 2020)	4 (from Nov 2021)
Number of individual contacts for the service:	672	1900	3166	4,013
Number of onward referrals:	76	402	731	761
Benefit Gains for patients from service referrals:	£282,285	£1,091,069.48 (235)	£1,145,497.85	£1,305,799.27
Macmillan Grants Awarded:	£7060	£20,866	£44,685	£54,650
Number of people receiving the Service Newsletter per month:	N/A	N/A	552	1,190
Health & Wellbeing/**Patient Education Sessions** (PES) delivered per year				
Types of PES	0	1	4	4
Number of Patient Education Sessions offered	0	6	30	59
Number of attendances of patients/carers at PES:	0	150	356	301
Support Group Attendances:	0	0	288	196

> **"Keep doing such a fantastic job because we saw what a difference you make to very poorly people and thank you from the bottom of our hearts."**
>
> **Patient's friend, 2021**

> **"I feel cared for and protected and am amazed at the extent and quality of your service. You understood how I was feeling and I am so glad the service was there for me."**
>
> **Patient, 2021**

Service Outcome Objectives

Overall Service Aim

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

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

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

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

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

> **"You find hospital visits are there primarily for medical interventions - wellbeing and support gets overlooked, but that's where Macmillan have helped me enormously, with strategies for living with my cancer and knowing there is a community of support."**
>
> **Patient, 2021**

Organisational Profile

Calderdale and Huddersfield NHS Trust provide care to a population of over 460,000 people and in 2021 the Trust had a total of 3,338 patients with a new or secondary cancer diagnosis (167 patients more than in 2020). Of these, 2121 were patients with a new primary cancer diagnosis and 1217 had a recurrence or secondary diagnosis.

In the year 2021, the service had contact with 842 newly diagnosed patients, equating to 25% of those newly diagnosed within the trust. This is a lower figure than the previous year (29%) and the service is committed to continued promotion in order that more patients across the trust and region, can benefit from contact with and support from, the Macmillan Information and Support team.

Our Staff Team

The service consists of four full time staff members – Helen Jones - Service Manager, Mandy Davies – Assistant Manager, Holly Smith and Kajal Sokhal – Macmillan Information Service Support Workers.

Holly's post was initially funded on a temporary basis by CHFT, but we are grateful that after a successful business case, the Trust funded for this position on a permanent basis from in June 2021. In response to increasing demands on the service, CHFT funded a second band 4 support worker, on a twelve month fixed term contract, so Kajal joined the team in November 2021. We are extremely grateful that the Trust have recognised the value of our service in enhancing patient care for people affected by cancer and funded additional staff members. Our aim for 2022 will be to secure permanent funding for our second band 4 support worker role.

"The staff are very friendly and approachable; genuine and lovely and make me feel at ease."

Patient, 2021

"The whole team do things really well. They have gone out of their way to support me and my family too, so I am extremely grateful."

Patient, 2021

In September 2021, our fabulous band four support worker, Holly Smith, won a 'Rising Superstar' Award in our Trust CHuFT Awards, which recognise and celebrate staff achievements. This was in recogntion of Holly's passion for the service, compassionate work with patients and her invaluable technological support to lots of patients during the pandemic. Her work allowed many more people to get onto Microsoft Teams and access our various courses and support groups, at a time when many patients were feeling isolated and vulnerable due to Covid. There were six award categories and with over 6,000 staff working for CHFT, this was an incredible achievement. We are extremely proud of Holly and the photos below show how surprised she was to be a winner!

Our Volunteers

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

During the whole of 2021, our volunteers were not allowed to be physically present in the hospitals due to the Coronavirus pandemic. Our Head Strong service was also sadly suspended during this time. However, several of our information service volunteers have made support and feedback phone calls to patients and family members throughout the year, providing essential telephone support to those who were isolating and struggling emotionally whilst navigating cancer and a pandemic. Our volunteer patient reps have had an active role in our online/virtual provision, with many giving talks and sharing their story at our education programmes, helping with support groups, and as part of our Cancer Patient Focus Group. One patient rep, David, trained as an iHOPE Course facilitator and helped to lead four iHOPE courses in 2021, all of which received excellent feedback. Some of our volunteer patient reps have also helped us in presentations to trust boards and externally as part of our award process. Lastly, David also helped us interviewing for our recent support worker post.

Our volunteers and patients reps gave some feedback about volunteering in 2021:

'During 2021 I was involved in the early part of the year, following up patients by phone who had previously been in contact with the Information Centre. The responses from patients with regard to that contact were, in every instance, highly positive. In addition, I asked patients if any further support might be needed now. If that was the case then patients were advised that their request for that support would be passed onto relevant Centre staff.'

Jeff, Macmillan Information Service Volunteer

'Covid & Cancer what more could hit you in a single year? Can one think of any positives to come out of that? Surprisingly 'yes' I have had the benefit to assist in some small but satisfying way those who gave of their support to me when it was sorely needed. I was taken on as a volunteer with a particular remit to help facilitate on-line courses. To see the achievements of the participants on these courses is so satisfying and I sincerely thank the Macmillan team for the opportunity to be involved. Moving towards (hopefully) the end of Covid & also thankfully the end of my cancer journey (again hopefully) I look forward to being able to assist much more over time. Along with other volunteers it is amazing to see the support this team gives to everyone and I am proud to be able to now call them friends as well.'

David, Patient Rep Volunteer

'Volunteering with Macmillan has enabled me to establish relationships with the Macmillan staff who support me and value my contributions. Volunteering has helped me meet new people with whom I can share my thoughts about my cancer and thus gain advice and support. This has provided me with the opportunity to use my skills and experience to help others. I have gained a great deal of satisfaction from working with Macmillan. I have particularly valued the iHope course I completed and I enjoy the regular group meetings. Due to Covid, most of my volunteering has been online with Microsoft Teams, software I am now quite familiar with . After the two years of 'virtual meetings' it has been a pleasure to recently meet staff and other volunteers face to face for the first time; it's like a gathering of old friends who have been following the same journey via different routes and have finally made it to the same place at the same time. I hope we will be able to continue our face-to-face meetings.

The staff at Macmillan are always listening, supportive and empathetic to me and I greatly value their support. They are helping me along my cancer journey which in turn has enabled me to support others.'

Geoff, Patient Rep Volunteer

'We could not continue the high level of care that our patients receive without the help and support that we get from the Macmillan cancer support service. It means that the chemotherapy nurses can concentrate on the safe delivery of treatment in the knowledge that the emotional, financial, and psychological needs for the patient are being met. We have found that when needs are met properly the patient generally experiences a much better outcome. All the staff in the team are amazing and helpful and always have the best interests of the patient and their family and this shines through all the time. Helen, Mandy and all the team plus their volunteers are amazing people and the care and compassion that is shown to all the patients regardless of disease, age, etc. is a credit to the hospital. Thank you seems not enough.'

Bernie Beith, Senior Chemotherapy Sister

Equality & Diversity Assessment of the Service

In May 2021 our team underwent an MQEM assessment - Macmillan Quality Environment Mark. This included a review as to whether we were providing information in accessible formats and other languages. At each site some cancer awareness information is provided in the commonly used languages in the region (Punjabi, Urdu, Guajarati and Polish) an the service is able to order materials from Macmillan, in different languages, as well as using the Trust's interpreting service to have materials translated into different language. Patients and family members are also signposted to the Macmillan Support line where they can speak to an interpreter in their native language, about their cancer diagnosis and treatment. A translation service is also available for public use on NHS Choices website and printing facilities are available.

The Macmillan information and support service is one of the excellent service providers in CHFT. All the staff are brilliant and offer excellent support to patients and are very approachable. The service has set up very high standards and have initiated cancer support services and been a role model for other trusts. The Macmillan cancer support service is a great asset to the Oncology unit in CHFT.’ Dr Deivasikamani Ramanujam, Medical Oncology Consultant

Within both of the information centres, information is provided in various formats such as Easy Read information for people with learning disabilities, Braille, Audio and children’s books. As we have increased the number of easy read booklets available, we have noticed that these have been taken more readily than expected, indicating the benefit of easy read materials for people with learning difficulties and those who have English as a second language. A hearing loop is also available at CRH for service users with a hearing impairment.

In 2021 the service has been part of a project in Kirklees to look at what cancer information and support is needed in diverse communities. This has included a survey with over 120 responses from people from BAME communities and as a result, plans are in place to organise awareness and education sessions in some communities in 2022. The Coronavirus pandemic has continued to impact the plans of the service to attend community outreach events at Mosques and community venues, to further promote links with minority ethnic groups across the region. It is hoped that attendance at events can resume in the next couple of years.

Delivering the Personalised Support Agenda in 2021

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

NHS
Long Term Plan
#NHSLongTermPlan

Personalised, tailored conversations, providing holistic support to patients and family members, is an essential part of the delivery of care within the MCISS. The team provide flexible support as identified by the patient – listening to and responding to their unique concerns and needs. This involves working out what matters *to* people as well as *for* them. The whole team believe it to be a privilege to have time to listen and support people from diagnosis, throughout the pathway.

As well as the personalised conversations, we also have a key role to play in implementing the patient's Personalised Care and Support Plans after the CNS teams have carried out an electronic Holistic Needs Assessment. The eHNA identifies very varied and individual needs of a patient at different points in the journey, but particularly on diagnosis and at the end of treatment. The clinical teams throughout the trust therefore refer to our service to support the recommendations of the Care and Support Plan.

> **"Kindness and help are always on tap from your team."**
> **Patient, 2021**

> **It's great to know the Macmillan Information and Support Team are there to talk to. They don't just listen though – they help and take action.**
> **Patient, 2021**

Co-ordinating the Patient Education Programme

A key role of our service is to co-ordinate and organise the Trust's Patient Education Programme (previously 'Health and Wellbeing Programme') for cancer patients and their families. Our work has involved the organisation, promotion and delivery of four different patient education courses which have been run virtually on Microsoft Teams, throughout 2021. The aim of all of 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. This enabling patients to help themselves, improves patient experience and reduces pressure on the clinical teams.

Delivering patient education is part of the national cancer strategy and our trust has been a trailblazer in establishing various courses for patients and family members. All of our courses have been developed following the recommendations of our cancer patients focus group and have been service user lead and co-designed. This was acknowledged in the awards we won in 2021. Other trusts in the West Yorkshire and Harrogate Cancer Alliance have started to implement the programmes we have established, such as First Steps.

1. First Steps

First Steps is our information and support programme for recently diagnosed patients and family members and ran once per month in 2021 on Microsoft Teams. All newly diagnosed patients received a letter inviting them to join the First Steps session, as well as this being endorsed by clinical teams. Patients and family members are encouraged to watch the videos and read information on our hospital website before joining the session https://www.cht.nhs.uk/services/clinical-services/oncology/information-support/first-steps. This includes important information on an introduction to cancer treatment, who patients may meet in the hospital and community team, diet, physical activity, sleep, fatigue, managing emotions and support services. The online sessions are a chance to review these topics and for attendees to ask any questions.

Unfortunately despite the high number of patients diagnosed each month in our trust, uptake for the First Steps programme has been low, with around 5 patients attending each month. In total, there were 36 attendances at First Steps sessions in 2021, which is a somewhat disappointing figure for the whole of the year. We are keen to continue promoting this session as feedback show how helpful people find First Steps:

"Attending First Steps has helped me feel a bit safer and bit less bewildered by the whole process so far."

"Just to know the help is out there and available is a comfort."

"First Steps put my mind at rest on a number of fronts - I slept much better than in a while – knowing what I am experiencing is normal. I know where to turn for help and what's out there."

"Really useful session and I am grateful for the advice and support."

"I was made to feel very comfortable and relaxed. Felt positive regarding support always available both from staff and from patients who share their experiences."

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

2. End of Treatment Health and Wellbeing Events

In 2021 we planned and organised four online End of Treatment Health and Wellbeing Events to run in February, May, September and December. Sadly we had to cancel the May and December Events due to low uptake of fewer than 10 patients). These events ran from 10am until 2.30pm on Microsoft Teams and included generic information on the importance of keeping physically active, managing emotions, diet, sleep and fatigue. The afternoon included a specific session with the clinical team, whereby patients could ask any questions and learn about managing side effects. At the end of the day, our service gave a presentation about ongoing support and the iHOPE course, as well as there being a short talk about the Cancer Alliance patient panel people could get involved in. All of this facilitates the national agenda of supported self-management – empowering patients to be in control during their treatment and recovery.

12 patients attended the January event and 12 attended in September. Some feedback comments include:

"The course was so relevant and inspiring, giving you a bit of positivity when you feel there's no light at end of the tunnel or are struggling with side effects."

"I enjoyed all the topics discussed and it made me realise again that you're not alone, other people experience the same things as yourself and it's nice to chat and relate to others."

"It was a friendly, informal and supportive atmosphere with engaging professional input and the opportunity for patients to participate."

"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."

"Good to encourage partners/carers to attend. Not a fan of online events but this worked really well."

> **'The courses have helped me make changes to my lifestyle to better cope with my cancer. Cancer Related Fatigue was not something I had ever heard of before the courses run by Macmillan. I understand now how and why it affects me and it has been useful to share stories with others who have similar issues.'**
>
> **Patient, 2021**

3. The iHOPE Course

iHOPE is Macmillan's online self-management programme ('Help Overcoming Problems Effectively') for anyone who's had a cancer diagnosis, which empowers people living with cancer to manage their health and wellbeing and help with the stress of a cancer diagnosis. During 2021, this has proved to be the most popular of all education programmes we have offered for patients, with patients from a wide number of tumour groups attending. The HOPE programme was originally designed in Coventry and has been adapted and adopted by Macmillan, who train facilitators to run the course. Interestingly, the HOPE programme (iHOPE refers to the online version) is now being run by IAPT services nationally as a psychological intervention, which means that as trained facilitators, our patients can benefit from this worthwhile support.

The iHOPE course helps patients to gain knowledge, skills and confidence to cope with life's challenges, frustrations and fears, as well as supporting people to become more relaxed, improve in confidence, set positive goals, and learn stress and fatigue management skills. The course also includes a chance to build skills and character strengths to help deal with anger, depression, uncertainty and to live positively with fears for the future.

The iHOPE Course runs over six weeks with online materials to work through and videos to watch, plus a weekly meeting with the iHOPE facilitators on Microsoft Teams to talk about the topics of the week. Anyone with a cancer diagnosis at any stage of the pathway can take part in the course, and attendees in 2021 included those who were recently diagnosed, people undergoing chemotherapy, people at the end of treatment and those under best supportive care. All took away significant benefits from this positive psychology course which helped them deal with the uncertainty of a cancer diagnosis and reframe unhelpful thoughts, as well as access crucial peer support along the way.

Helen, Mandy and Holly are trained iHOPE facilitators and one of our patient reps, David, also trained as a facilitator in 2020 and has helped to co-lead all three courses in 2021. In 2022, there are also plans for two other patient reps to train as iHOPE facilitators to run future courses. Our three iHOPE Courses ran in February, June and October 2021, with a total of 164 iHOPE session attendances across the year.

Feedback from the iHOPE courses in 2021 included:

"I would recommend this course to anyone with cancer as it is interesting, helpful and supportive. Over the six weeks I learnt how to cope better with my cancer, including managing fatigue and sleep, and the importance of exercise. I now pace myself better and understand more about my cancer, the treatment and the side effects. The weekly group meetings were really helpful because I could talk with others with cancer and get support from the facilitators. The course is organised in such a way as to be interesting with videos, quizzes, challenges and learning opportunities at your own pace. Coping with cancer is challenging and this course is really useful and has helped me to be more positive. Thanks to the organisers, the group members and the facilitators."

"Your support was a big factor in my recovery after surgery. The skills I learned on the iHOPE programme helped to drive my return to 'normal' life. Thank you all of you."

"My dad now has a more positive outlook on life because of the iHOPE Course."

"I have so much more understanding of my thought process now, and a load of strategies to use."

"Sharing experiences and feelings with others made me feel as if I was not alone."

"The iHOPE course was very supportive. Each session was well thought out and easy to access and clearly laid out. I could work through each session online at my own pace and set realistic achievements to keep me motivated. The weekly group support sessions were invaluable and I really benefitted from having like-minded people to share my thoughts with. The team were fantastic, so knowledgeable and caring. It's been a while now but I still use a lot of the exercises to help me deal with any upsets or setbacks."

"I thought the iHOPE course was an excellent support for myself and others, coming to terms with a cancer diagnosis/treatment, and dealing with so many difficulties and worries. The course was planned to address these challenges in a supportive and informative way, as well as giving the opportunity to meet and engage with others in same/similar situations. I would definitely recommend the course to others."

As part of our accountability to Macmillan for running the iHOPE course, facilitators are assessed and monitored and provide an annual report to Macmillan which included some of the above feedback from participants. Sandra Rowlands, Professional Development and Knowledge Lead for Macmillan wrote:

David talks about his experience of joining a recent iHOPE course

How do I book a place?

'Thank you so much for sharing your experiences of running the iHOPE course in your organisation. I just want to extend my thanks and admiration for all the hard work you and your team do to support people affected by cancer. Your really are all wonderful and this is evidenced by the lovely comments from your participants which are great to see. Thank you once again for all you hard work and commitment.'

Further information about the iHOPE Course, including a video from David our patient facilitator, can be found on our hospital website at this link:

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

"I just hope every person diagnosed with cancer would reach out to you and accept your excellent service."

Patient, 2021.

4. Thinking Ahead Programme

Thinking Ahead is a health and wellbeing course for patients living with incurable cancer, who may or may not be receiving treatment, as well as their family members. The course was devised in Harrogate in 2018 and has been delivered in Calderdale and Huddersfield since 2019. The course runs online over seven weeks and includes sessions by many professionals such as a dietician, psychologist, palliative nurse/doctor, hospice staff, estates planner, benefit advisor and chaplain. Important topics relevant to people affected by incurable cancer are included such as managing uncertainty, keeping active, advance care planning, diet and appetite, managing fatigue, introduction to hospices and care in the last weeks and months of life. The course aims to keep people as well as possible for as long as possible and encourages living life to the full in a supported, self-managed way.

In 2021, it was a privilege to run three collaborative Thinking Ahead Courses with Harrogate and Leeds NHS Trusts, after data sharing agreements had been agreed between the hospital trusts. This meant that patients from all three trusts could attend the course, along with family members/partners, as well as there being a pool of presenters from all three areas who could share their expertise.

Sadly again, uptake of the Thinking Ahead course has been low during 2021, despite this being a collaborative venture with three hospital trusts. This may be due to a combination of people not wanting to attend virtual courses and also the difficulty of the content, meaning people were reluctant to sign up to take the course. Furthermore, there may be barriers in terms of clinical staff not feeling it is appropriate to signpost people to the course or to have these potentially difficult conversations, which importantly endorse the course.

There were a total of 77 attendances at the three Thinking Ahead programmes in 2021, with a breakdown of figures as follows:

‘The Thinking ahead programme has been wonderful in helping my patients with incurable cancer to start planning in advance in a constructive manner. `
Dr Nick Brown, Medical Oncology Consultant

Attendance Figures for the Thinking Ahead Programme, 2021

	March – April Thinking Ahead Course 2021				
	CHFT	Leeds	Harrogate	Total Patient/Carer Numbers:	Total number of attendances:
Number of Patients:	3	1	1	5	16
Number of Carers:	3	0	0	3	8
	June – July Thinking Ahead Course 2021				
	CHFT	Leeds	Harrogate	Total Patient/Carer Numbers:	Total number of attendances:
Number of Patients:	3	0	0	3	18
Number of Carers:	2	0	0	2	9
	November – December Thinking Ahead Course 2021				
	CHFT	Leeds	Harrogate	Total Patient/Carer Numbers:	Total number of attendances:
Number of Patients:	1	0	1	2	13
Number of Carers:	1	1	1	3	13
Totals for all three Thinking Ahead Courses:					
	CHFT	Leeds	Harrogate	Total Patient/Carer Numbers:	Total number of attendances:
Number of Patients:	7	1	2	10	47
Number of Carers:	6	1	1	8	30

As part of our plan to raise awareness of the benefits of the Thinking Ahead course, we were able to apply to the CHFT charity in April 2021, for funds to make a film of patients and a family member who had attended the Thinking Ahead course, promoting the benefits of it to other patients and carers. We are extremely grateful to our patients Karen and Kathy, as well as Kathy’s husband, Peter, for their courage and integrity in making the film to

encourage other people to book onto the course. Four short films were produced and are available to view on You Tube - the links can be found at the bottom of this page on our hospital website: https://www.cht.nhs.uk/services/clinical-services/oncology/information-support/thinking-ahead-programme

In 2021, we have started to work with the WY&H Cancer Alliance to increase promotion of the Thinking Ahead Programme as a valuable resource for patients who have an incurable cancer diagnosis but are not yet at the end of their lives. In November 2021 the alliance kindly awarded a bursary with the intention to further promote the programme, including funding flyers, posters, banners and another film aimed at encouraging professionals to refer and have the necessary conversations with patients.

Despite the numbers being low, feedback has been consistently excellent for the Thinking Ahead Programme and comments from attendees has included:

"I feel so much calmer having done the Thinking Ahead Course and knowing that I am not alone in supporting my husband."

"The course is really about caring for the whole person, rather than being lost as an NHS number."

"All the topics have been useful – I didn't know what I needed to know."

"It's so helpful to have the support from lots of knowledgeable staff and to have conversations with other people in a similar situation."

"The course gives a good chance to talk to people who have an understanding of what our lives are like rather than friends who don't understand. It was a good opportunity to meet different staff and talk to various professionals."

"The Thinking Ahead course helped me to put things into perspective. I hadn't really thought about future wishes, care plans and wills but now I understand my options. It was all delivered in a caring way rather than being a checklist."

"I wish the clinical team had told me about the Thinking Ahead Course – a leaflet wasn't enough to get me to join, but I am glad I did."

'A wonderful team who go over and above to help patients and their families. They work so hard to provide holistic, patient-centred care and are a huge asset to the service. I don't know what we would do without the team!!'

Jenny Jones, Oncology Advanced Clinical Practitioner

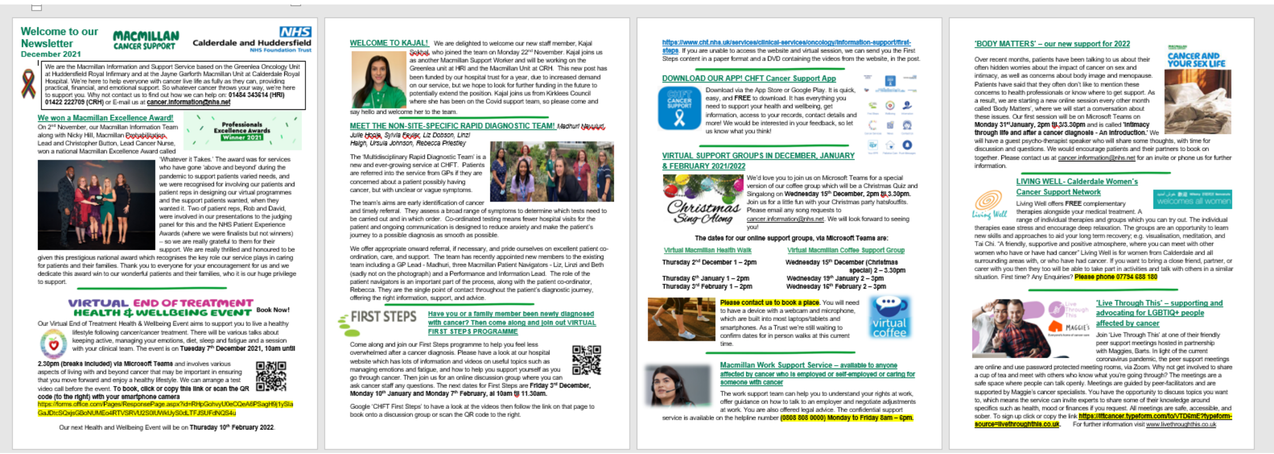
'At Calderdale and Huddersfield NHS Trust we have a brilliant Macmillan Information support team. As a CNS I find that I use them often, they are always so helpful and friendly, they can't do enough to help. I think they are an asset to this Trust. I know my patients really appreciate their input too as they help my patients in many different ways.'

Miriam Slade, Urology CNS

Information and Promotion

We have continued to provide a high level of information in 2021, though due to infection control measures, no physical booklets were allowed on the hospital information pods, only in the two centres. Laminated cards for every booklet have been displayed in all of our information pods, which contained a QR code so that patients could scan the QR code and access the booklet directly from the Macmillan website. We have also sent many more electronic booklets via email to patients. In 2021, we gave out/posted 1185 physical booklets (443 from CRH and 742 from HRI).

In 2021 our **monthly newsletter** continued to be an important way to connect with our patients during the pandemic and make them aware of the vital support that was available. This included not only information about support groups and education sessions run by our service, but also important information about Covid support in the community and other useful information which helped to increase connection and reduce isolation in the pandemic. As well as going out to patients and family members, the monthly newsletter is also sent out to our hospital staff, volunteers, GP surgeries, community staff and social prescribing teams.



Welcome to our Newsletter
December 2021

MACMILLAN CANCER SUPPORT

NHS
Calderdale and Huddersfield
NHS Foundation Trust

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

We won a Macmillan Excellence Award!

Professionals Excellence Awards
Winner 2021

On 2nd November, our Macmillan Information Team along with Nicky Hill, Macmillan Prehabilitation Lead and Christopher Button, Lead Cancer Nurse, won a national Macmillan Excellence Award called 'Whatever it Takes.' The award was for services who have gone 'above and beyond' during the pandemic to support patients varied needs, and we were recognised for involving our patients and patient reps in designing our virtual programmes and the support patients wanted, when they wanted it. Two of patient reps, Rob and David, were involved in our presentations to the judging panel for this and the NHS Patient Experience Awards (where we were finalists but not winners) – so we are really grateful to them for their support. We are really thrilled and honoured to be given this prestigious national award which recognises the key role our service plays in caring for patients and their families. Thank you to everyone for your encouragement for us and we dedicate this award win to our wonderful patients and their families, who it is our huge privilege to support.

VIRTUAL END OF TREATMENT HEALTH & WELLBEING EVENT **Book Now!**

Our Virtual End of Treatment Health & Wellbeing Event aims to support you to live a healthy lifestyle following cancer/cancer treatment. There will be various talks about keeping active, managing your emotions, diet, sleep and fatigue and a session with your clinical team. The event is on **Tuesday 7th December 2021, 10am until 2.30pm (breaks included) via Microsoft Teams** and involves various aspects of living with and beyond cancer that may be important in ensuring that you move forward and enjoy a healthy lifestyle. We can arrange a test video call before the event. **To book, click or copy this link or scan the QR code (to the right) with your smartphone camera** https://forms.office.com/Pages/ResponsePage.aspx?id=RHpGohvyU0eCQeA6PSagH9j1ySlaGaJDtcSQxjsGBoNUMEo4RTVSRVU2S0lUWkUyS0dLTFJSUFdNQS4u

Our next Health and Wellbeing Event will be on **Thursday 10th February 2022**.

WELCOME TO KAJAL! We are delighted to welcome our new staff member, Kajal Sokhal, who joined the team on Monday 22nd November. Kajal joins us as another Macmillan Support Worker and will be working on the Greenlea unit at HRI and the Macmillan Unit at CRH. This new post has been funded by our hospital trust for a year, due to increased demand on our service, but we hope to look for further funding in the future to potentially extend the position. Kajal joins us from Kirklees Council where she has been on the Covid support team, so please come and say hello and welcome her to the team.

MEET THE NON-SITE-SPECIFIC RAPID DIAGNOSTIC TEAM! *Madhuri Nayudu, Julie Hoole, Sylvia Fowler, Liz Dobson, Linzi Haigh, Ursula Johnson, Rebecca Priestley*

The 'Multidisciplinary Rapid Diagnostic Team' is a new and ever-growing service at CHFT. Patients are referred into the service from GPs if they are concerned about a patient possibly having cancer, but with unclear or vague symptoms.

The team's aims are early identification of cancer and timely referral. They assess a broad range of symptoms to determine which tests need to be carried out and in which order. Co-ordinated testing means fewer hospital visits for the patient and ongoing communication is designed to reduce anxiety and make the patient's journey to a possible diagnosis as smooth as possible.

We offer appropriate onward referral, if necessary, and pride ourselves on excellent patient co-ordination, care, and support. The team has recently appointed new members to the existing team including a GP Lead - Madhuri, three Macmillan Patient Navigators - Liz, Linzi and Beth (sadly not on the photograph) and a Performance and Information Lead. The role of the patient navigators is an important part of the process, along with the patient co-ordinator, Rebecca. They are the single point of contact throughout the patient's diagnostic journey, offering the right information, support, and advice.

FIRST STEPS **Have you or a family member been newly diagnosed with cancer? Then come along and join out VIRTUAL FIRST STEPS PROGRAMME**

Come along and join our First Steps programme to help you feel less overwhelmed after a cancer diagnosis. Please have a look at our hospital website which has lots of information and videos on useful topics such as managing emotions and fatigue, and how to help you support yourself as you go through cancer. Then join us for an online discussion group where you can ask cancer staff any questions. The next dates for First Steps are **Friday 3rd December, Monday 10th January and Monday 7th February, at 10am till 11.30am.**

Google 'CHFT First Steps' to have a look at the videos then follow the link on that page to book onto a discussion group or scan the QR code to the right.

https://www.cht.nhs.uk/services/clinical-services/oncology/information-support/first-steps. If you are unable to access the website and virtual session, we can send you the First Steps content in a paper format and a DVD containing the videos from the website, in the post.

DOWNLOAD OUR APP! CHFT Cancer Support App

Download via the App Store or Google Play. It is quick, easy, and **FREE** to download. It has everything you need to support your health and wellbeing, get information, access to your records, contact details and more! We would be interested in your feedback, so let us know what you think!

VIRTUAL SUPPORT GROUPS IN DECEMBER, JANUARY & FEBRUARY 2021/2022

Christmas Sing-Along

We'd love you to join us on Microsoft Teams for a special version of our coffee group which will be a Christmas Quiz and Singalong on **Wednesday 15th December, 2pm till 3.30pm.** Join us for a little fun with your Christmas party hats/outfits. Please email any song requests to cancer.information@nhs.net. We will look forward to seeing you!

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

Virtual Macmillan Health Walk	Virtual Macmillan Coffee Support Group
Thursday 2nd December 1 – 2pm	**Wednesday 15th December (Christmas special) 2 – 3.30pm**
Thursday 6th January 1 – 2pm	**Wednesday 19th January 2 – 3pm**
Thursday 3rd February 1 – 2pm	**Wednesday 16th February 2 – 3pm**

Please contact us to book a place. You will need to have a device with a webcam and microphone, which are built into most laptops/tablets and smartphones. As a Trust we're still waiting to confirm dates for in person walks at this current time.

virtual coffee

Macmillan Work Support Service – available to anyone affected by cancer who is employed or self-employed or caring for someone with cancer

The work support team can help you to understand your rights at work, offer guidance on how to talk to an employer and negotiate adjustments at work. You are also offered legal advice. The confidential support service is available on the helpline number **(0808 808 0000) Monday to Friday 8am – 6pm.**

'BODY MATTERS' – our new support for 2022

CANCER AND YOUR SEX LIFE

Over recent months, patients have been talking to us about their often hidden worries about the impact of cancer on sex and intimacy, as well as concerns about body image and menopause. Patients have said that they often don't like to mention these concerns to health professionals or know where to get support. As a result, we are starting a new online session every other month called 'Body Matters', where we will start a conversation about these issues. Our first session will be on Microsoft Teams on **Monday 31stJanuary, 2pm till 3/3.30pm** and is called **'Intimacy through life and after a cancer diagnosis - An introduction.'** We will have a guest psycho-therapist speaker who will share some thoughts, with time for discussion and questions. We would encourage patients and their partners to book on together. Please contact us at cancer.information@nhs.net for an invite or phone us for further information.

LIVING WELL- Calderdale Women's Cancer Support Network

Living Well

welcomes all women

Living Well offers **FREE** complementary therapies alongside your medical treatment. A range of individual therapies and groups which you can try out. The individual therapies ease stress and encourage deep relaxation. The groups are an opportunity to learn new skills and approaches to aid your long term recovery; e.g. visualisation, meditation, and Tai Chi. "A friendly, supportive and positive atmosphere, where you can meet with other women who have or have had cancer" Living Well is for women from Calderdale and all surrounding areas with, or who have had cancer. If you want to bring a close friend, partner, or carer with you then they too will be able to take part in activities and talk with others in a similar situation. First time? Any Enquiries? **Please phone 07794 688 180**

'Live Through This' – supporting and advocating for LGBTIQ+ people affected by cancer

Join 'Live Through This' at one of their friendly peer support meetings hosted in partnership with Maggies, Barts. In light of the current coronavirus pandemic, the peer support meetings are online and use password protected meeting rooms, via Zoom. Why not get involved to share a cup of tea and meet with others who know what you're going through? The meetings are a safe space where people can talk openly. Meetings are guided by peer-facilitators and are supported by Maggie's cancer specialists. You have the opportunity to discuss topics you want to, which means the service can invite experts to share some of their knowledge around specifics such as health, mood or finances if you request. All meetings are safe, accessible, and sober. To sign up click or copy the link **https://lttcancer.typeform.com/to/VTD6mE?typeform-source=livethroughthis.co.uk**. For further information visit www.livethroughthis.co.uk

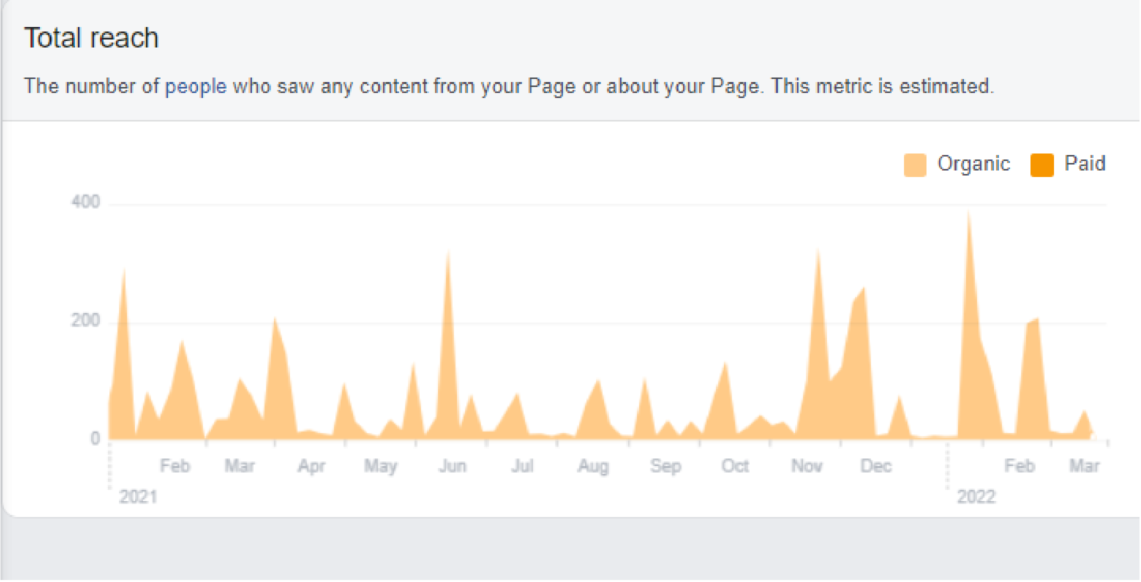
Our newsletter was sent out by email to 722 patients in 2021, as well as 160 sent by post, so over a 12 month period, these figures make a total of 10,584 newsletters sent to patients/families in 2021. The newsletter was also sent by email to 308 professionals/volunteers, making 3696 per year. The overall total number of newsletters sent out to patients and professionals in 2021 came to a fantastic total of 14,280 newsletters.

> **"I really value the newsletters and the constant feeling of support from you. My treatment is hopefully finished but knowing the endless support is there is so reassuring and I'm sure there are many people who truly value the service - thank you."**
>
> **Patient, 2021**

> **'I love getting your information as it helps me to keep up to date with what's going on in Huddersfield and Calderdale. I also signpost patients and carers in your area to your newsletter and courses as they are such a valuable resource.'**
>
> **Jill Long, Yorkshire Cancer Community**

Our **Facebook Page** has again been an important way for us to communicate with our patients, family members, organisations and the public, throughout the pandemic, as well as for promoting cancer awareness information. We have used Facebook to raise awareness of the support and education sessions offered by our service, but also signposted to community support and information. We are also grateful to the CHFT comms teams, regional Macmillan comms lead and Macmillan in Yorkshire Facebook page, Yorkshire Cancer Community, and West Yorkshire and Harrogate Cancer Alliance and, for further promoting our events and the contents of the newsletter through their social media channels.

The chart below shows the reach of our Facebook page across the year, which essentially shows consistent engagement and some posts being accessed by almost 400 people.


Total reach

The number of people who saw any content from your Page or about your Page. This metric is estimated.

'Your team work extremely hard to support patients throughout their cancer pathways, really helping rebuild their lives or give them a sense of security. From a CNS point of view, the Macmillan information team are always happy to help me and take pressure of my role where possible with my ever expending caseload. They always find the answers to my questions or queries. A very much valued team in my eyes - thank you Helen and the team.'

Rebecca Macmillan, Upper GI Specialist CNS

Practical Support

During the year 2021, 20% of all the enquiries we received were about practical support, which is a slight decrease since 2020. This includes signposting and many onward referrals in order for people to access tailored support for themselves and family members. In 2021 we made 761 referrals to different organisations for people to access practical, emotional and financial support, as well as signposting to numerous organisations/professionals for support. During the pandemic, referrals were made to the local Covid response teams for shopping help in particular, as patients continued to shield. 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 2021 we helped 395 people apply for a Blue Badge for disabled parking, which is often very much appreciated by patients who often struggle with fatigue. We were also contacted about work support in the context of the pandemic and cancer, and liaised with the two councils to help sort housing situations.

One example of practical support provided was when we were asked in April to help a newly diagnosed stomach cancer patient, with housing. When we met with him, it transpired that he had been living in a shed on an allotment for the last seven years and had no money or possessions. We liaised urgently with the housing team at the council and got him into emergency accommodation that night. We then worked with the housing support team at the hostel and in the council to help him set up a bank account, apply for benefits, organise food parcels and over time, secure permanent accommodation. We also applied for a Macmillan Grant and to various organisations for clothing and toiletries, and ended up taking two car loads of donated clothes to the hostel for him. Some of the clothes did not fit and so he was able to give them away to others at the hostel - he said he had never been able to give anything away before and this gave him a new confidence. Since this time, we have stayed in regular contact with this patient to provide ongoing emotional and practical support. We asked him and his consultant for some feedback about the difference we had made and this is what was said:

“As a black, homeless man I felt like a loner and a prisoner, with nobody talking to me or taking any notice of me – I was invisible. Since having cancer and meeting the team, I cannot believe what a difference they have made to my life and I keep singing Macmillan’s praises to everyone I meet. You cannot know how difficult it is to go through cancer unless you go through it yourself. I got a roof over my head the day I met Helen and they have helped me get clothes, food parcels, benefits and a grant which is amazing and now I feel clean. I did not even have a bank account before. The team have worked with my new support worker and the council so I can get permanent accommodation once I have my surgery in a few weeks time. I have also been helped to do some exercise and put weight on to help me recover more from the chemotherapy and surgery.

Helen contacted some groups to get me some clothes and one of them was a church. Since then, they have given me food parcels and I have got to know them and am starting to help with their community allotment which gives me a sense of purpose and giving something back to help others. I am even thinking of joining the church to get to know more people.

It feels as if the team and Macmillan are such positive people who have the power to do good and to change negative situations. You are like the caring mother I never knew I needed or had. You have all been a blessing from heaven and have made such a big difference to me - I did not know people like you still existed in the world but now I know people care. I feel as though I matter and can now talk to people as equals.”

Patient, 2021

Comments from this patient’s consultant:

‘We discovered this patient’s social issues when he came to discuss chemotherapy. I think it was the first time he had disclosed the circumstances of his living conditions. This was a Tuesday afternoon and to be honest I had no idea what could be done, but my first thought was absolutely that Helen would know! She met him at 4pm that afternoon. By the next day he was warm, dry and safe in a hostel and already had his first food parcel! In the weeks that followed Helen and her team were completely dedicated to making sure the patient was being rehoused, applying for benefits, food parcels, helping him to reactivate his bank account and liaising with other community services. Less than 2 weeks later and he was offered a flat. I cannot emphasise enough what a difference this has made to the care the patient has received. He was facing two months of intensive chemotherapy and then major surgery with curative intent and I have no doubt his care would have been compromised if he had had to go on living in his previous circumstances. Helen and her team have not just made a difference to his medical care but his life! If this does not personify ‘One Culture of Care’ I don’t know what does.’

Dr Sam Turnbull – Medical Oncology Consultant

In 2021 we continued to liaise with lots of different professionals on behalf of patients, such as clinical teams, GPs, psychology staff, hospice staff, housing teams, university tutors, schools 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 co-ordination.

Other kinds of practical support offered this year have been:

- **Travel Insurance Information –** booklets and lists of insurance agencies provided, as well as sigposting to travel insurance suppliers on the Macmillan and Cancer Research UK websites.
- **Promoting Physical Activity and Healthy Lifestyles-** continued links with Kevin Kipling, senior lecturer in Sports Science at The University of Huddersfield and with Kirklees Wellness Service - both have given talks at our virtual courses to promote the importance of physical activity with patients.
- **Transport** – we signposted to Calderdale's community transport service, directed patients to the hospital transport service for appointments and referred to the Covid response team for transport help.
- **Wills** – In 2021 we provided information about will writing services and funeral costs, often directing people to Macmillan's free will service.
- **Toilet & Restaurant Cards** – We provided Macmillan toilet cards and radar keys for patients who need access to toilets in shops etc, as well as some cards from the oesophageal patients association which patients can show in restaurants/cafes etc.

A free service providing practical support for anyone experiencing hair loss as a result of cancer treatment.
www.headwrappers.org
Registered charity no: 1177981

VIRTUAL HAIR LOSS SUPPORT GROUP SESSIONS

Scarf tying techniques

Free headscarf and accessories posted to your home

Practical tips for hair and scalp care

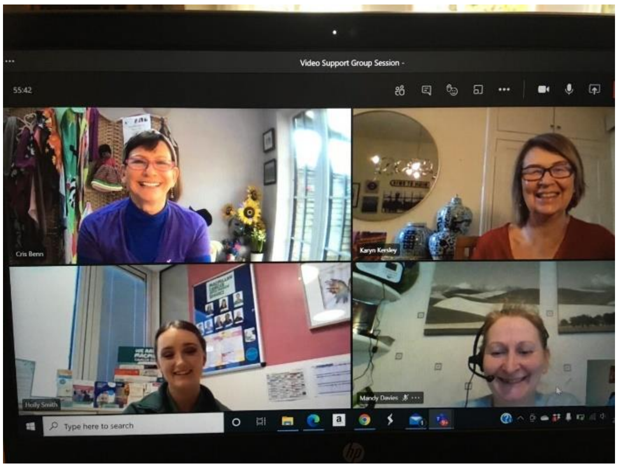
Talk through concerns over hair loss

Feel more confident coping with hair loss

2nd Tuesday of every month at 7pm
and
3rd Wednesday of every month at 11am

To register for a place please email: advice@headwrappers.org or visit our website www.headwrappers.org

Another kind of practical support we offered in 2021 was to partner with the charity **Head Wrappers** (www.headwrappers.org), to offer a virtual hair loss support session for patients undergoing chemotherapy. Our Headstrong volunteers who previously saw patients 1:1 to talk about scalp care and head ware, were sadly missed in both 2020 and 2021, but Head Wrappers online sessions gave our patients the chance to join hair loss support sessions, where tips and guidance were given about tying head scarves, head ware etc, as well as receiving a free gift including a scarf to practice tying in the sessions. Sadly again, the uptake of these virtual sessions has been low throughout 2021.



Our team meeting the Head Wrappers Volunteers, February 2021

Head Wrappers

Emotional Support

2021 saw a huge rise in the emotional support provided by our service to patients, family members and also staff. The figures rose from 24% of contact being for emotional support in 2020 compared to 41% in 2021. Much of our positive feedback remains around patients and family members recognising the benefit of having someone to listen to them, which is a crucial part of the emotional support we provide. The listening ear provided to people through face to face appointments/drop in, telephone or video consultation, is therefore a key element of the emotional support provided by the service, and has been extremely important throughout the pandemic. Patients have told us they at times struggle to share their fears and worries with family members or busy clinicians. Of our contacts, 454 wanted to simply talk, 1734 requested specific emotional support and 30 people talked about relationship issues.

Part of our emotional support over 2021 has been to make formal referrals for patients who need more than a listening ear and we have therefore referred to the trust's psycho-oncology service and signposted patients and family members to local counselling services. We have also supported some bereaved families/partners, again being a listening ear and signposting to hospices and other support services such as bereavement support groups.

Monthly Support Groups

We have continued to run our two support groups virtually via Microsoft Teams throughout the 2021, which have been an important part of connecting patients in the ongoing pandemic. The

groups were Macmillan Coffee Time and the Macmillan Virtual Walking group, as well as a Christmas sing along. The groups include time for patients and family members to chat and get to know one another, ask questions, have a quiz and watch a virtual walk. There were 129 attendances at support groups during 2021, so slightly lower compared to 2020. This may have been due to people being able to get out and about as restrictions lifted, as well as some tech-fatigue. However, many people have told us that the monthly virtual support groups have been a lifeline and they have really benefitted from peer support and being with others who understand what they are going through.

Our volunteers and patient reps have helped to run the support groups virtually, as well as providing vital emotional support and a listening ear to all who attend.

> **"It was good to meet online and chat and listen to others in a similar situation."**
>
> **Patient, 2021**

> **"I have found the simple act of meeting other cancer sufferers in a supportive and inclusive environment to be both helpful and encouraging."**
>
> **Patient, 2021**

> **"Whilst I may not attend many meetings and online get togethers, I know that you are always there should I or my family need help, it feels so reassuring to have you there. I receive my newsletter every month and look forward to see what is going on."**
>
> **Patient, 2021**

Financial Support

A huge 29% of all our contacts were asking for financial help. Worries about money have continued to be a major concern for our patients in 2021, as they have experienced cancer in the context of the global pandemic. Work situations and shielding have also impacted people's income and finance, and so this has again been an important part of our work to support patients in 2021. A key part of our work is to make referrals to benefit advisors, apply for grants and signpost people to the financial advice available on the Macmillan Support Line (0800 808 0000) where people can speak to a professional about concerns over mortgage payments, pensions and other financial concerns such as managing debt.

Welfare Benefits

In 2021 we referred a total of 469 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 216 referrals to Eileen Murray, Macmillan Benefits Advisor at

Advice Kirklees, 239 referrals to Age UK in both Calderdale and Huddersfield and the remaining 14 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 2021 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 2021. 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 **£1,305,799.27** which is an increase of £109,820.59 since 2020 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:

Macmillan Information Centre Referrals	No of referrals from our service	Confirmed Benefits Total gained in benefit income (regular ongoing payments)	One off Payments Total gained through one off payments (grants, compensation and arrears, etc)	Total for our number of referrals:
2021 Advice Kirklees	216	£576,749.04	£16,540.66	£593,289.70
2020 Age UK	239	£636,733.67	£36,796.83	£673,530.50
Estimates for other referrals (PIP special rules)	14	£37,337.92	£1,641.15	£38,979.07
Totals	**396**	**£1,250,820.63**	**£54,978.64**	**£1,305,799.27**

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

Grants

In 2021 we were successful in gaining a huge **£54,650.00 in Macmillan Grants** for 151 patients in particular financial need, which was an increase of £9,985 compared to the 2020 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 2021 we also applied to **other charities** for patients in extreme need, though several charities reduced the support they were able to offer due to their income being reduced in the pandemic. We were successfully awarded the following:

- A new boiler for a lung cancer patient, from Energy Watch UK.
- A grant for £1,300 from the Robert Sinclair Davison Foundation for a gynaecology patient who needed an urgent rental/housing deposit and was at risk of becoming homeless with four young children.
- One caravan holiday for an oesophageal cancer patient, from the Mothers Union.
- A new bed and bedding for a bladder cancer patient, from the Colne Valley Hardship Fund.
- Five packs of journals/teddies/items for children of different cancer patients, from the Osbourne Trust.

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 in the ongoing pandemic when all charities have suffered a loss in income.

'Thank you for the wonderful support you have provided for the Colorectal patients this year. We are using your services more than ever before and value your expertise in guiding our patients through their often complex journeys. You are always there for both our patients and staff. The information and advice you give is invaluable. We are looking forward to working with you even more closely in the future.'

Helen Ilsley, Colorectal CNS

"Such a massive relief to share our anxieties when we felt there was nowhere else to go for specialist help. The key for me was a radio advert saying Macmillan was there for families of cancer sufferers."

Family Member, 2021

2021 Data Summary – who did we help?

The year 2021 saw a large increase in our contacts with 847 more contacts than in 2020 (where we had 3166 contacts overall), which constitutes a huge 27% increase.

Of these – 1825 contacts were at Calderdale Royal Hospital and 2188 contacts were at Huddersfield Royal Infirmary. Compared to the previous year, the contacts at Calderdale increased by 311 in 2021 and in Huddersfield by 536 contacts. These figures demonstrate a slightly higher accessing of the service at HRI which has been the case for the last few years, and clearly demonstrate the ongoing need to deliver the service out of the two hospital sites and maintain permanent staff members in each place.

3171 contacts were from people who had used the service in the past and the remaining 842 were with people new to the service. In Calderdale and Huddersfield there were 3,112 patients diagnosed with cancer for the first time or with a recurrence in 2021. This means that the Macmillan Information Service supported 27% of all newly diagnosed patients in 2021, which is a slight decrease of 2% from last year. This also means that 73% of all newly diagnosed patients are not accessing the support of the Macmillan Information Service, and so ongoing efforts need to be made in 2022 to encourage further referrals and signposting to our service.

From November 2020 and throughout 2021, we ran a project with the breast team where we trialled the systematic referral of all of the newly diagnosed breast patients to our service. Feedback from the clinical team was that this worked well in terms of supporting the personalised needs to the patients and the benefits of us referring back to the breast team if there were clinical concerns. Since this project we have seen a greater uptake of breast patients at all of our education sessions and support groups. In 2022, we aim to trial the systematic referral of another tumour group to our service, to increase uptake and offer our support. Ideally, if we had more staff, we would welcome a systematic referral of all newly diagnosed patients to our service.

The following charts use data taken from our **4013 direct contacts** with people affected by cancer, in the year 2021.

Gender

Our figures show a marked increase in the number of men who have accessed support from our service in 2021. Historically, the ratio of men to women contacting the service, has been roughly 30%:70% for the last few years but in 2021, 43% of our contacts were with men, which is excellent.

	2020	**2021**
Men	30%	43%
Women	69%	56.5%
Prefer not to say	1%	0.5%

Ethnic Groups

Our ethnicity figures show a small change in 2021, with slightly more Asian and Black African/Caribbean people accessing the service than in the last two years, which is pleasing. In terms of supporting people from Black African/Caribbean communities - our contacts were higher than the population statistics - 2.9% compared to a population of 1.9% in Kirklees and 0.4% in Calderdale. However the data continues to show a discrepancy in our contacts compared to population statistics for local Asian communities – so our contacts were 3.6% (which is an increase on recent years) but the population figure is 8.3% in Calderdale and 14.8% in Kirklees. This shows that fewer Asian people are accessing the service than are representative in the populations of Calderdale and Huddersfield.

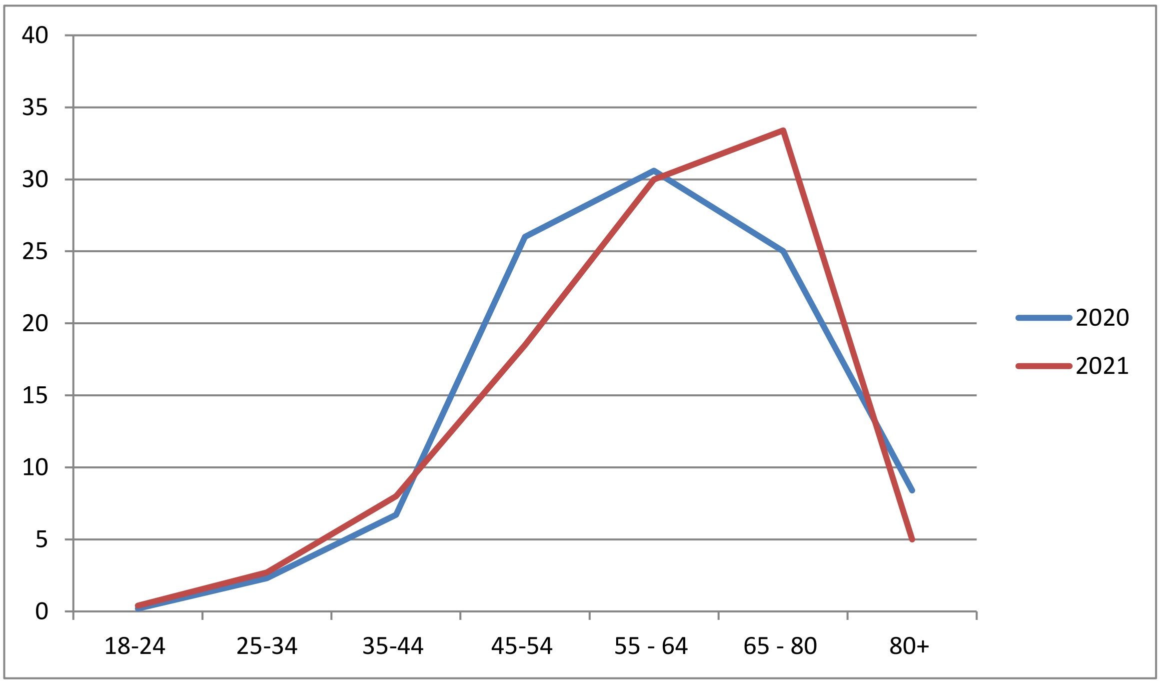
	2019	2020	2021
White British	91%	94%	91%
Asian/Asian British	3.3%	2.4%	3.6%
Black African/ Black Caribbean	1.1%	1.1%	2.9%
Other White	0.8%	0.7%	0.2%
Not asked/other	3.8%	1.8%	2.3%

In 2021 we began working more closely on a BAME project in Kirklees, took part a cancer collaborative project with NHSE looking at health inequalities, and made further connections in Calderdale. The pandemic has hampered our plans to offer outreach in mosques and other faith buildings to raise awareness of our service, but we hope to develop this further in 2022, as this remains a priority.

Age Brackets

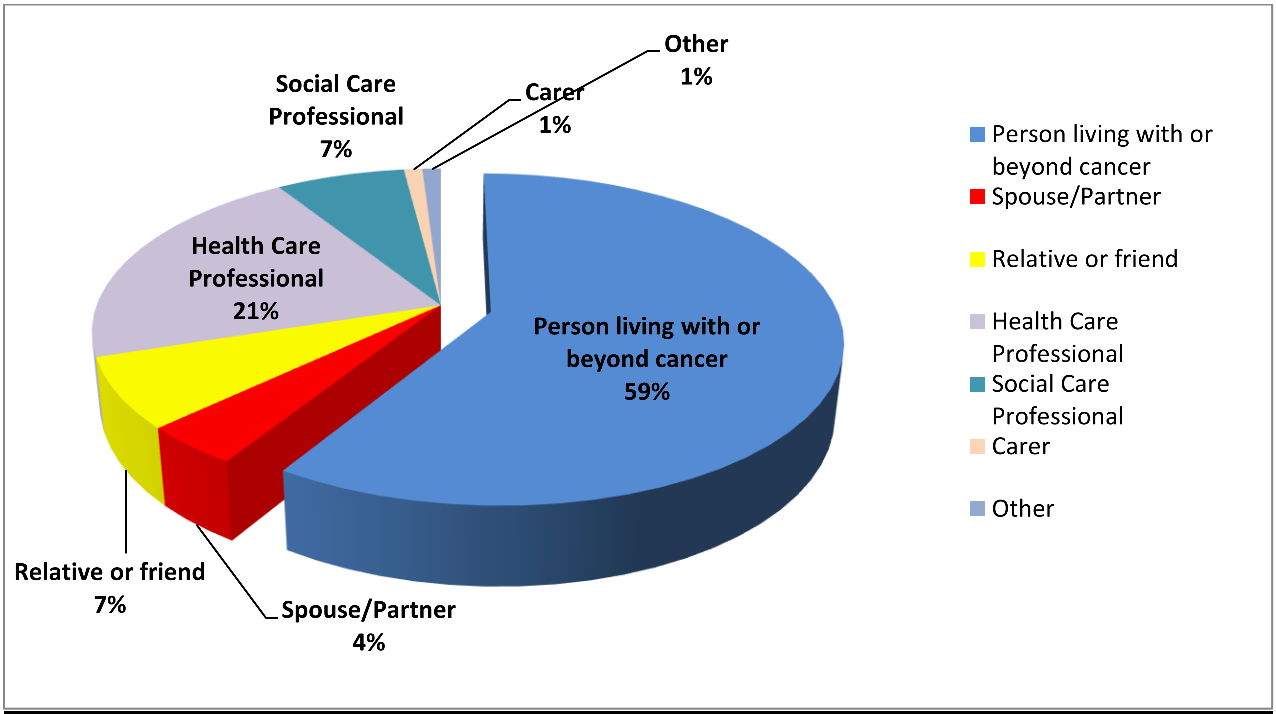
Last year the most common age group of patients we supported was 55-64 years. In 2021, our most common age group is slightly older at 65-80 years. In terms of highest to lowest percentages of age groups these are – 65-80 years (33.4%), 55-64 years (30%), 45-54 years (18.5%), 35-44 years (8%), 80+ years (5%), 25-34 years (2.7%), 18-24 years (0.4%). For 2% of our contacts, the age of the person was unknown.

The chart below compares age figures for 2020 and 2021, showing an increase in supporting a slightly older population in 2021.



Who were our contacts?

59% of our contacts were with people who currently have or previously had, a cancer diagnosis, which is an increase of 14% since 2020. We had fewer contacts with family members in 2021, probably due to relatives not being allowed to attend hospital appointments with patients a lot of the time, due to the pandemic. All other figures were similar to 2020.

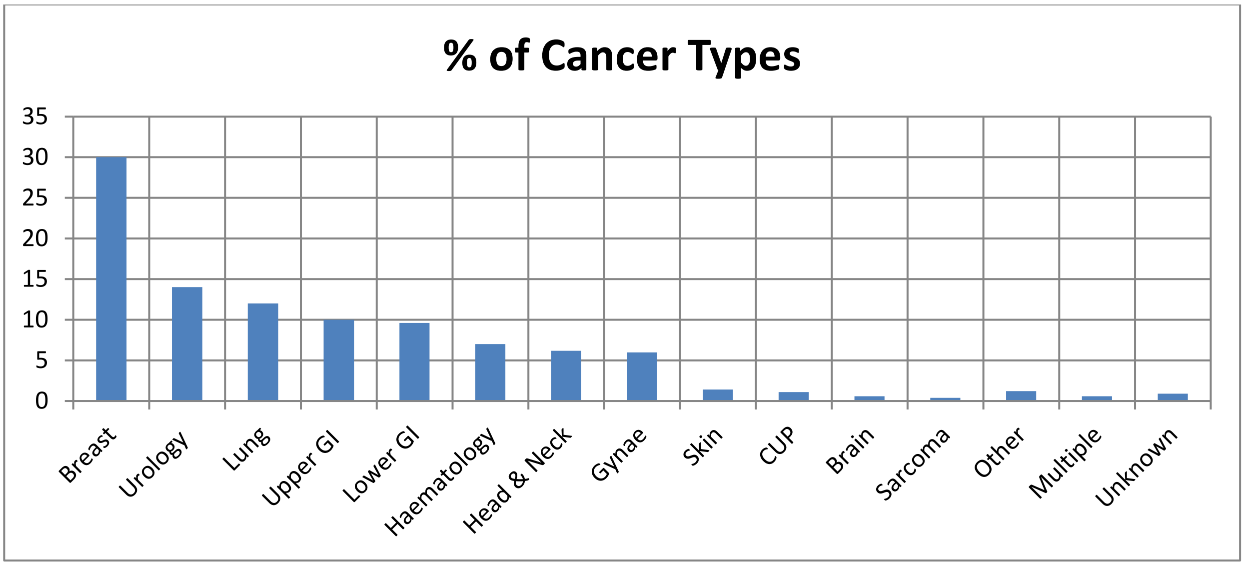


> **"You have always been available, ready and willing to listen and support without question or judgement."**
>
> **Patient, 2021**

> **"Your team gave me the tools to handle my situation."**
>
> **Patient, 2021**

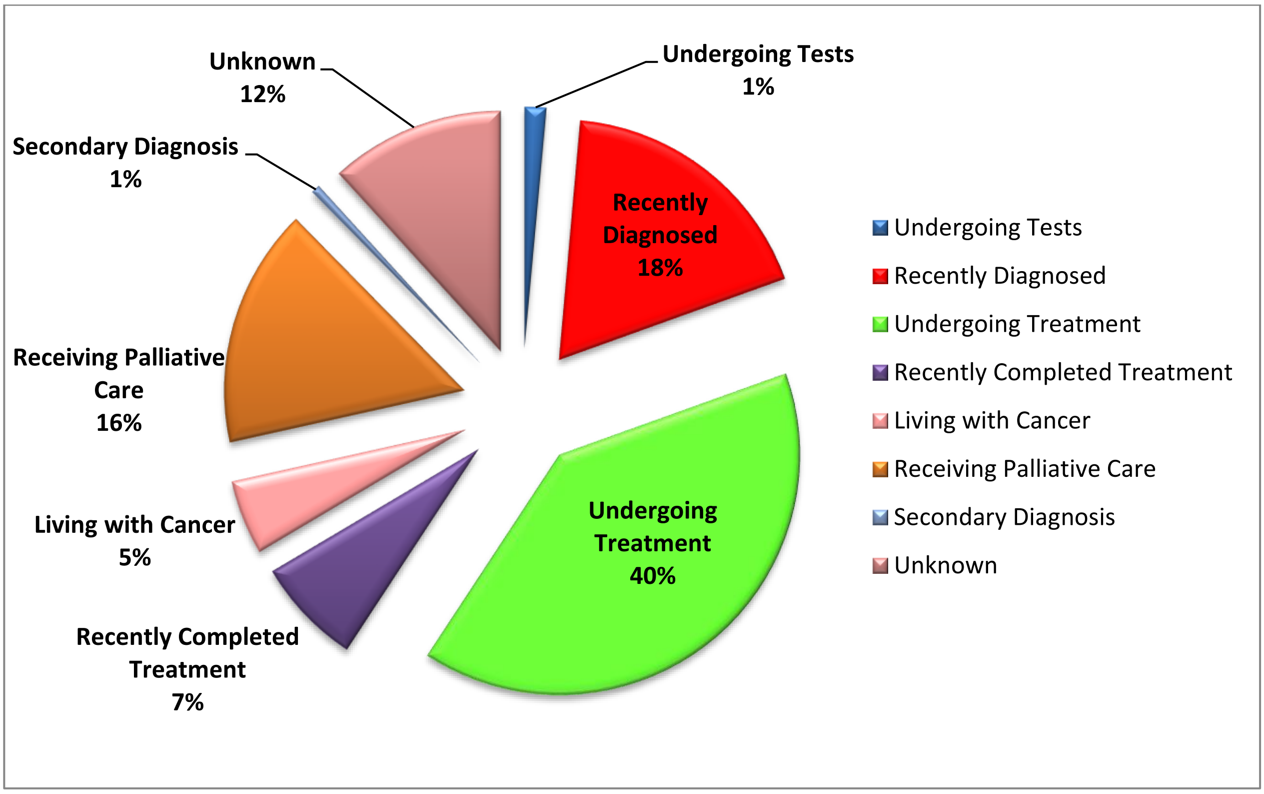
What cancer diagnosis did people have?

Breast cancer patients were again the most common people who our service had contact with during the year, and figures increased to a huge 30% of all our contacts in 2021, compared to 19% in 2020 and 10% in 2019. This is due to the ongoing breast project whereby the breast team send all newly diagnosed patients to our service for support. The next largest groups of patients to access our service were urology, then lung, upper GI and lower GI. As well as breast patients, in 2021, we also saw an increased percentage of urology, haematology and upper GI patients, but a reduced percentage of lung, lower GI and head and neck cancer patients than in 2020.



What was the stage of the cancer pathway?

As in previous years, we were most commonly contacted by people undergoing treatment, which is to be expected in a hospital context (40%). This year we had an increase in contacts with people who had recently completed treatment (7.2% compared to 3.9% in 2020) and in people receiving palliative care (16% compared to 13.4%). There was a slight drop in contacts with people who were recently diagnosed (18% of contacts compared to 19% last year).



‘Working with the Macmillan Cancer Information Service has been integral to some of the development of providing Prehabilitation support to our cancer patients.

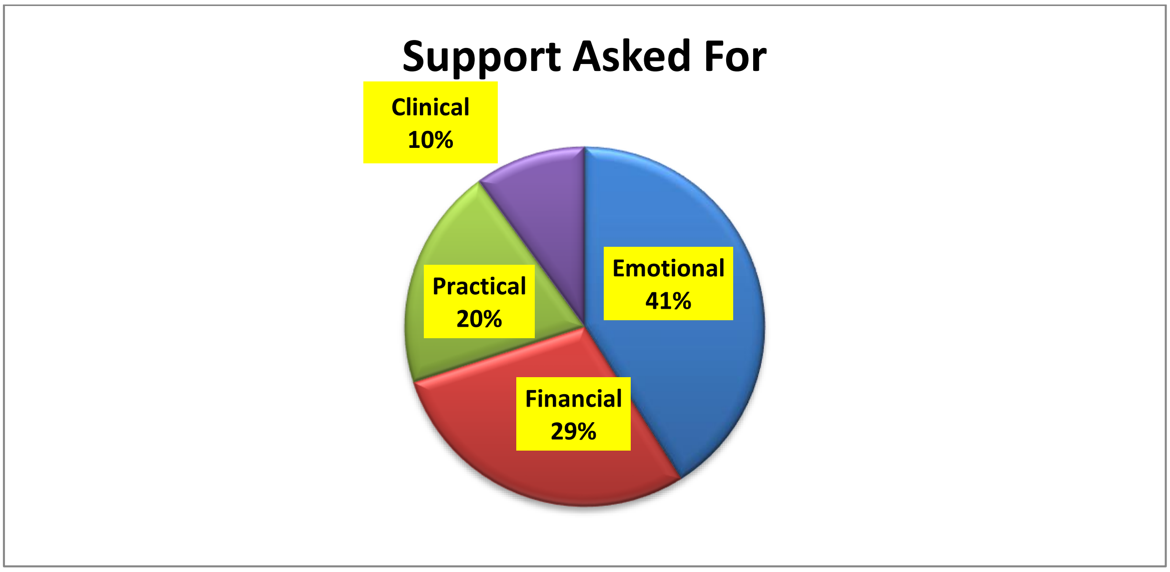
Over this past year it has been a privilege to be involved with the team and obtain national recognition at the Macmillan Professionals Awards. The support provided, co-designed and developed with patients has continued to grow over the past year and this is down to the amazing work the team do and their ability to go above and beyond when required.

The team not only consists of professionals but patients themselves and this adds to their ability to support more people in the right way. I really look forward to continuing to work together over the forthcoming year to develop more support for our patients.’

Nicky Hill, Prehabilitation Lead

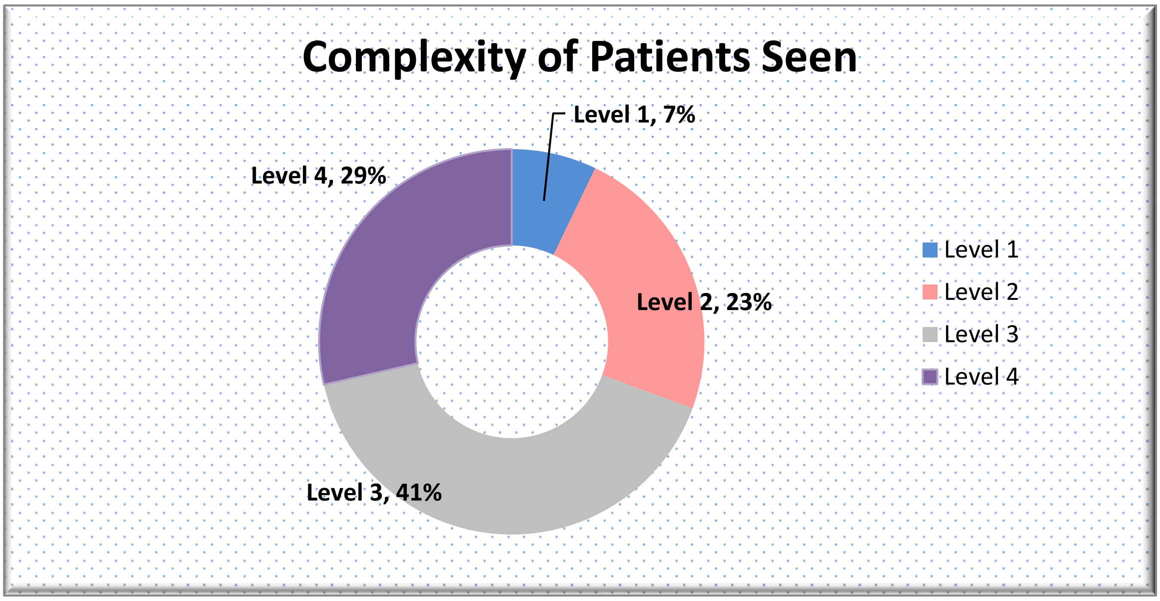
What support did people ask for?

In 2021, the most significant difference in what kind of support people needed, was a huge increase in emotional support, which went up to 41% of all contacts, compared to 25% in 2020. This is likely to be due to the ongoing pandemic which exacerbated the emotional stress people were experiencing as well as facing cancer. Financial support was the second most frequent request for help, with large numbers of patients asking for financial support, advice and onward referral to our benefits advisors. We had fewer requests for practical help than in 2021, though requests for carer support and Blue Badges were high.



How complex were our contacts?

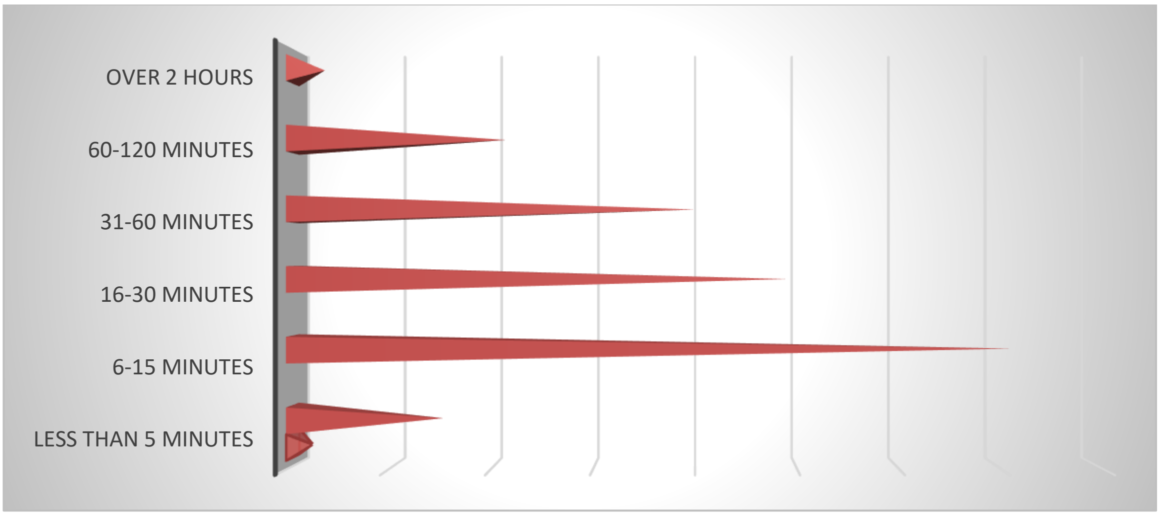
According to Macmillan data collection, our contacts with patients are graded in terms of the level of support required and complexity of each case. In 2021, Macmillan introduced a Level 0 whereby patients took an information leaflet without any contact with a team member (2% of our contacts). Level 1 contacts tend to be those queries easily answered such as paying in a donation; level 2 contacts may require some information and emotional support; level 3 may require onward referral to other organisations, and may return on a regular basis for ongoing emotional and other support; level 4 are the most complex cases where people need much liaison, various referrals and ongoing, varied support.



In 2021 we had a marked reduction in level 1 and 2 cases (L1 – 18% in 2020 compared to 7% in 2021; L2 – 35% in 2020 to 23% in 2021). We saw a marked increase in both level 3 and 4 cases, with level 3s rising from 27% up to 40% in 2021 and level 4s from 20% up to 28%. This is indicative of the increased number of people being diagnosed late with cancer in the pandemic and therefore presenting with more complex needs, necessitating various referrals and different types of support for individual patients.

How long were our contacts?

Our most frequent length of time for contacts was between 6 and 15 minutes, followed by contacts of 16 – 30 minutes. Significantly, we had many more contacts which were over one hour in length in 2021 compared to previous years, with 12.2% of contacts being over an hour in 2021 compared to 6.2% in 2020. This confirms the increase in more complex patients at levels 3 and 4, who need lengthier conversations and more time for support.



> **"As soon as I asked a question, I received not only the answer but so much compassion and heartfelt concern."**
>
> **Patient, 2021**

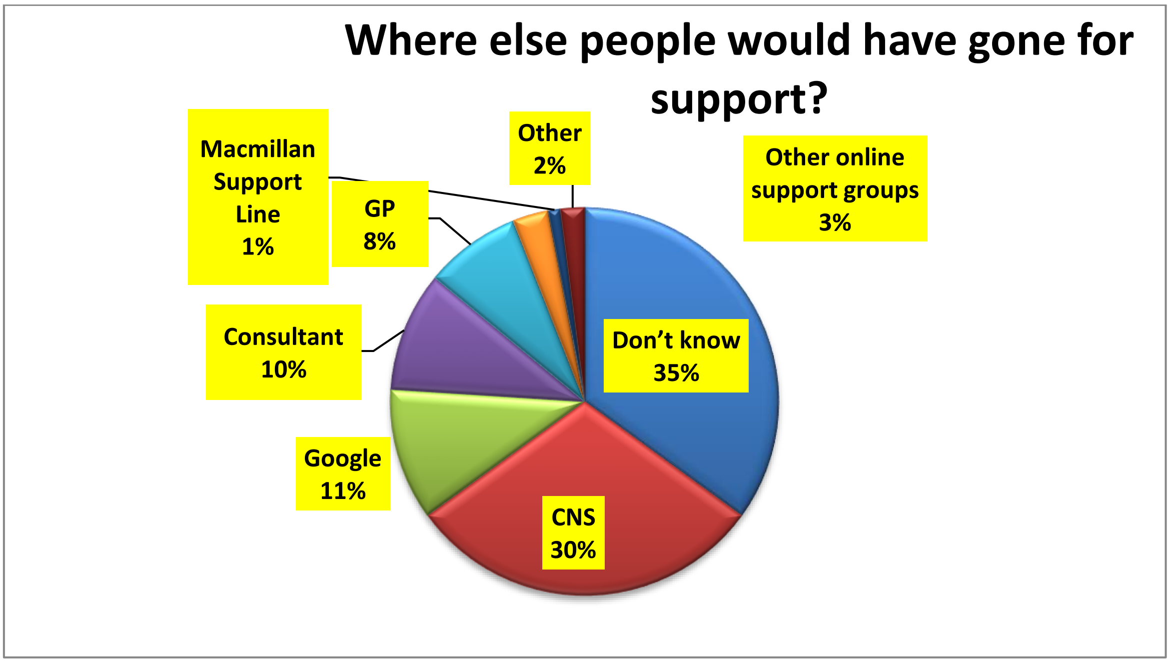
Patient Feedback

In 2021, 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:

- 95% said they would recommend the service to someone else and 4% said they were not sure.
- 95% said that they felt listened to and understood.
- 79% of patients and carers said that contact with our service had specifically helped to reduce their anxiety. (18% 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.' Some people felt that the room on Greenlea at HRI was not visible enough saying it 'is very hidden away', 'HRI could do with a more visible area and larger area to meet the needs and requirements of visitors', 'HRI Greenlea Unit is quite hard to find and very tiny but you make the best of the space.' Comments were positive about the information pod in the entrance of HRI to increase visibility and promote the service.

As part of our feedback, we asked patients where they would have gone if they had not accessed support from our service. The majority of patients said they did not know where else they would have gone for support and 48% said another health professional such as their CNS, consultant or GP. These figures provide evidence that having contact with our service saves time and reduces pressure on the clinical teams, as noted in the professional feedback throughout this report.



The only negative comments we received were around our education programmes and support groups being online in 2021 and people struggling with technology/IT skills. We are aware this presents an issue for patients and have devised a First Steps DVD and sent written information in the post regarding our programmes, as well as offering phone calls. Sadly, the ongoing pandemic prevented us being able to offer face to face support and education sessions. One person also commented that we should be open seven days a week.

Numerous comments and quotes were given to us from patients and family members about the support provided by the service in 2021, 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 feel the staff are dedicated in helping patients with a variety of problems/enquiries and are prepared to go the extra distance to get them the help they need."

"I am just so grateful for my local Macmillan team in Huddersfield, Helen, Mandy, Holly and Kajal. They make our virtual meetings fun and always have time for everyone."

"The service is of a high quality and I seriously cannot fault it."

“You have been great and helped me realise I'm not on my own, especially with the covid pandemic and medical appointments being delayed which adds to anxiety. 100% excellent service.”

“You have been extremely helpful and caring every time I have approached your service.”

“Mandy, I'm writing to say thank you for attending the meeting with me on Tuesday. Thank you for making the time to be with me. It was a great help. I was a nervous wreck as you probably noticed! I also feel much happier and positive after the meeting on Tuesday. Without Mandy requesting this check-up I don't think that appointment would have happened. Having you there with me enabled me to focus on what I had to do. You and the team have my eternal gratitude. I often feel that I've been in someone else's bad dream these last 12 months or so. Stumbling about blind in darkness always on the back foot. Now I can see what's on the horizon and some of what has passed by. Thank you.”

“The friendliness and expertise is important and much appreciated at these difficult times.”

“I feel as if the Macmillan Information Service is there if I need it and that is a massive reassurance.”

“It's just nice if people who want to can get involved sometimes as it does help take your mind of working and I think you deserve more recognition.”

“I am so grateful for this service as due to my illness has been helping me and contacting me making sure I'm getting the right help … so so grateful.”

“All staff very caring & understanding, could not have wished for better attention!”

“You are doing a fantastic job and always respond quickly, thank you.”

“The service that you provide is so special, I am very lucky that even though I have had bowel cancer, things have gone very well, but as an organisation you have always been there to turn to. Thanks to you all.”

“You gave me tools to help me cope with upset and emotional distress.”

“Your team listened to my concerns and forwarded my problems to Health Professionals.”

“Personally, I couldn't have managed last year without your support.”

“You are a fantastic organisation and just thank you to you all for the work you do.”

“I appreciated the early stage introduction to your service and opportunity to sign up to the newsletter.”

“You have supported me with regular email updates of virtual meetings taking place, introduced me to other support networks, referred me to other services that have helped me e.g. mental health, benefits etc, introduced me to a whole new set of friends, helped me when I lost my Macmillan friend to cancer and helped me enjoy the simple things in life like meeting people virtually for a quiz, sing or just a chat and a cuppa.”

“We have lots of communications via email and the team are really quick to respond to questions etc. I know you are always there on the phone should I need you and this is so nice to know - thank you.”

“Good information was provided in different formats (verbal face to face chats, leaflets and telephone). Always sympathetic and understanding, always kind and supportive. Help wasn't just about cancer but always things relating to my cancer. The support groups with other cancer patients were also excellent. The MacMillan team worked well together to provide an excellent service when it was most needed and it's good that it continues to be available after treatment has ended.”

“Your staff are fantastic, very caring & understanding.”

“Thank you Mandy for listening last week, after our conversation it gave me chance to reflect and not be too hard on myself, a lot of the time I feel like I address my issues in a bubble which sometimes makes them bigger than they actually are, but by speaking about them to you last week, I realise a lot of them are worries that are for the future or upsets that are in the past, maybe even grieving for the old me. I was doing nothing for the present mode, the one I can control and enjoy. Since speaking to you I have been taking time for myself and even managed to find the confidence to bake! One step at a time. I know I will have a few wobbles, but if I focus on the 'now' I can cope with life and bit by bit in the coming days and years, mould a bit of the old me back into the mixture, but only when I am ready.”

“I was really cheered up by our conversation yesterday, so thank you. Helen, you had me laughing through tears at times. Thank you for all that you do, you must have such a positive impact on so many people's lives.”

“I feel you are already constantly improving your service for cancer patients to access help they need. It is an excellent service and I felt fully cared for and supported.”

“The service works incredibly well and I can’t think of any improvements.”

“It would be good to see your team on the wards.”

"You listened, got the right contacts for supporting me, and support was brilliant when I was scared and worried, you got me to the right people."

"I felt that you were always there at my side if I needed you. Even though I am now in remission and don't get involved much, it's reassuring to know I can always count on yourselves."

"A great team - always listening and willing to help."

"You were excellent and acted quickly when we were desperate."

"It was lovely to receive the initial call from Holly introducing the service and what is available. Holly explained things in the right way and left it all with me. It's reassuring to know the service is there as and when you need it."

"I found the Nurse Specialists difficult to approach so I don't know what I would have done without your team - thank you so much."

"I think you provide a very good service and am grateful for support and information I received. The online information is extremely useful as well."

"I was kept informed and face to face discussions were more helpful with support staff than the consultant."

"During COVID in 2020 I was diagnosed with cancer and the zoom calls (replacing the meeting) and the emails, newsletters etc were just amazing and so supportive and full of information."

"I received help very quickly and it came from all different directions within your service. The positive happy environment made me feel less worried."

"I have received tremendous support from MacMillan particularly Mandy & Helen, as a cancer patient seeking help & advice from my HR team regarding a concern of having to go back to a public facing role. Upon speaking with Mandy initially then Helen, they have tried to reach some rationale with HR & OH which would aid my return to a safe working environment. I sincere thank them for their valiant efforts on my behalf."

"I haven't used your services directly this last year but I really value the newsletters and the constant feeling of support from you. My treatment is hopefully finished but knowing the endless support is there is so reassuring and I'm sure there are many people who truly value the service - thank you."

"I would just like to say how much I appreciate being kept in the loop of things going on. I find it really useful and although thankfully I have not had to ask for your help a great deal, it is a comfort to know this service is available. And when I have needed some information, somebody from the team has always been there to help. I cannot stress enough how much this service is vital for somewhere to turn to if help is needed. If this service was not available it would, I am sure, be very detrimental to all patients suffering from various forms of cancer. I can only say many, many thanks."

Professional's Feedback

A key part of our work involves liaising and working closely with health professionals across our NHS trust and in the community. Our role is to work in collaboration to provide the best possible care to patients, with our holistic support complementing the clinical support given by our colleagues. We attend specialist forum team meetings, steering group meetings, trust cancer board meetings and some joint outpatient appointments with other staff, as well as some external meetings. We also answer cancer information and support queries from staff and volunteers across the hospital sites, as well as externally. We asked our clinical staff across the trust, as well as some community staff we work with, about the value of our Macmillan Cancer Information Service to them and their patients in 2021 and were given the following feedback:

'As always, the Macmillan information and support service is one of the excellent service providers in CHFT. All the staff are brilliant and offer excellent support to patients and are very approachable. The service has set up very high standards and have initiated cancer support services and been a role model for other trusts. They have various initiatives to integrate patients and clinicians and do not delay in offering support when requested. The Macmillan cancer support service is a great asset to the Oncology unit in CHFT.' Dr Deivasikamani Ramanujam, Medical Oncology Consultant

"I often hear from cancer patients referred to me by your service, how helpful your service has been." Eileen Murray, Macmillan Benefits Advisor, 2021

"You offer an amazing array of services both in person and now online. I wish every Macmillan Centre offered the same. It's a pleasure to refer people to your service. I wish you could accept patients from other areas."

Jill Long, Yorkshire Cancer Community, 2021

'Over the past year I have found the Macmillan team invaluable in their help and support for my patients. The Covid lockdown has meant that more patients are having remote medical appointments, and the additional face-to-face and remote support that the Macmillan team have been providing has really meant that my patients have felt much more supported over the past year. As always, the ongoing help and practical support with things such as travel insurance has also been exceptionally useful.'

Dr Nick Brown, Medical Oncology Consultant

‘We could not continue the high level of care that our patients receive without the help and support that we get from the Macmillan cancer support service. It means that the chemotherapy nurses can concentrate on the safe delivery of treatment in the knowledge that the emotional, financial and psychological needs for the patient are being met. We have found that when needs are met properly the patient generally experiences a much better outcome. The time that this would add on the chemotherapy nurses day would be colossal. The fact that we can usually speak to someone in the team immediately to initiate or chase up various referrals gives the patient greater confidence in our delivery of a safe and robust service. All the staff in the team are amazing and helpful and always have the best interests of the patient and their family and this shines through all the time. Helen, Mandy and all the team plus their volunteers are amazing people and the care and compassion that is shown to all the patients regardless of disease age etc is a credit to the hospital. Thank you seems not enough.’ Bernie Beith, Senior Chemotherapy Sister

‘This is a comprehensive and empathic service, going the extra mile for patients and their families, happy to support both patients and medical team.’

Dr Uschi Hofmann, Medical Oncology Consultant

‘I feel that the Macmillan cancer information team are an extremely valuable resource for both patients and the CNS team. The upper GI/ HPB patients often have a poor prognosis or long pathways. I have had a few patients that the Macmillan information team have supported greatly. This is from helping out with benefits, providing a listening ear, signposting to support groups etc. They work extremely hard to support patients throughout their cancer pathways, really helping rebuild their lives or give them a sense of security. From a CNS point of view, the Macmillan information team are always happy to help me and take pressure of my role where possible with my ever expending caseload. They always find the answers to my questions or queries. A very much valued team in my eyes - thank you Helen and the team.’

Rebecca Macmillan, Upper GI Specialist CNS

‘At Calderdale and Huddersfield NHS Trust we have a brilliant Macmillan Information support team. As a CNS I find that I use them often they are always so helpful and friendly they can't do enough to help. I think they are an asset to this Trust. I know my patients really appreciate their input to as they help my patients in many different ways. They run educational and support events for our patients such as the First steps programme, thinking ahead programme, IHOPE programme and health and well being events for our patients. I really don't know what we would do without them.’

Miriam Slade, Urology Cancer Nurse Specialist

‘I was at a multi-site specialty meeting today and it was noted by several colleagues, that your service had been invaluable for providing financial, practical and emotional support. This was especially highlighted in areas where, due to unforeseen circumstances, a patient had struggled to contact their CNS team. Could you please let your team know that they are all appreciated and keep up the amazing work that you all do.' Anthony Thomas, Palliative Care CNS

Our Development Plans for 2022

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

1. **Continuing to offer high quality, personalised information and support according to the patient/carers need.** As part of the NHS long term plan and CHFT cancer strategy, we aim to continue to deliver personalised, tailored support based around whatever matters to patients. We aim to support the implementation of more Care Plans produced by our clinical colleagues following their Holistic Needs Assessments, as well as to again potentially look to offer HNAs/Care Plans from the information centre, possibly at the end of treatment. The aim of our service is to be a cancer hub where patients can receive high quality information and support, but then be signposted to ongoing support outside the hospital context.

2. **Increasing patient attendance at the various Patient Education Programmes – virtually and face to face.**
   We have been proud to have run our various education and support programmes online for patients over the last year, though attendance has been disappointing. This may have been due to virtual fatigue in the pandemic and so we will look to deliver a return to face-to-face sessions for some of our programmes, to hopefully increase uptake. We are committed to continuing to offer and develop First Steps, Thinking Ahead, iHOPE and end of treatment Health and Wellbeing Events, and to develop new initiatives such as 'Body Matters' to support patients with often hidden difficulties in dealing with the impact of cancer on sex, intimacy and body image. We will continue to work with our trust colleagues to encourage important conversations around the education programmes rather than just giving a leaflet. We will also work closely with the West Yorkshire and Harrogate Cancer Alliance to increase uptake of the Thinking Ahead Programme across the three trusts, as well as potentially new trusts coming on board in 2022.

3. **Further promotion of the service – especially for newly diagnosed patients.**
   This year saw more contacts with our service than ever before, but the percentage of newly diagnosed patients in our trust that we supported, has reduced from 29% to 25%. As a charity, Macmillan are keen to be offering support from the point of diagnosis, which we fully endorse in our CHFT service. Because attendance at First Steps continues to be low, many patients still only learn about our service during or as they complete treatment, thus missing out on vital support that could have been available to them much earlier. We therefore need to increase the promotion of our service in the trust and community and look at news ways of doing this, to make

more newly diagnosed patients aware of our service in case they would like to access it. We hope that continued working with the new rapid diagnostic service, prehab lead, and new personalised community support lead, will support this in 2021.

4. **Reviewing uptake of our service in different tumour groups**
   In 2020 and 2021, we have seen the success of the breast project, whereby our service has had contact with every newly diagnosed breast patient. This has mainly been a conversation with one of our support workers to introduce the service, discuss the education programmes and encourage sign up to the newsletter. Such initial contact makes patients aware that the service is there to support them at any point throughout their cancer journey and as a result, we have seen an increased uptake of our support groups, education programmes and accessing of emotional support in breast patients. Ideally we would like to offer a consistent referral and phonecall for every newly diagnosed patient in the trust, but with four staff and an already busy workload, we would struggle with capacity . In 2021, we would therefore like to look at other tumour groups where uptake of our service and education programmes is low, and offer a project with the colorectal team first, and potentially the lung team later in 2021.

5. **Look to potentially offer support on the hospital wards**
   We know from other trusts that information and support rounds on hospital inpatient wards enhances patient experience. The feedback from the Cancer Patient Experience Survey for our trust also highlights that more emotional and practical support is potentially needed for our cancer patients on the inpatient wards. We would therefore like to trial offering information and support rounds on ward 12 at HRI and potentially other wards in both hospitals (as capacity allows), to see what the demand and impact of this would be. We also need to connect more with discharge staff and matrons on the wards to make them aware of our service and support we can offer.

6. **Continued patient engagement and co-design**
   Our Cancer Patient Focus Group and patient reps have been instrumental in the co-design of our virtual education programmes during the pandemic and their feedback gives us ongoing areas for development, such as the introduction of a Body Matters group following patient feedback around a lack of support relating to sex, intimacy and body image after cancer. The Cancer Patient Focus Group and patient rep suggestions, will be fedback to the Trust Cancer Board and will remain a key part of listening to the patient voice and implementing recommendations in 2022 and beyond.

7. **Supporting the return of the volunteers**
   As a service, we have greatly missed our dedicated team of volunteers during the last year and are looking forward to them hopefully returning in 2022 as restrictions continue to ease. Thankfully we have been able to keep in touch virtually and some

volunteers have been able to offer patient support calls and help with online support groups and education sessions. In 2022, we plan to support a return to duty for our Information Service and Headstrong volunteers – easing the transition and supporting the team as much as possible. We also plan to grow our patient rep volunteer team – increasing the number of patient reps who can support other patients and represent the patient voice at various meetings in the trust and externally. We would also like to recruit new volunteers to help with Headstrong and other roles.

8. **Closer working with GPs and community services across Calderdale and Huddersfield.**
   Throughout 2021 we have sent out our newsletter to every GP practice in Calderdale in Huddersfield, as well as flyers for our service and our various education programmes. We have had occasional referrals from GPs but feel that a lot of GP practices still do not know about our service and how we can support patients following their Cancer Care Reviews. In 2022, we need to look for opportunities to give talks and training to GP practice staff/practice managers, cancer link workers and social prescribing link workers in the community and primary care to establish stronger links and raise awareness and referrals.

9. **Hard to Reach Communities.**
   Our 2021 statistics show that we are not reaching sufficient patients from ethnic minority groups, so it is essential for us to continue to look at ways to link with various communities in 2022. We will continue to work with the trust cancer team to address inequalities, particularly through the BAME Kirklees network, NHS improvement collaborative work and by linking with faith and community leaders, groups and settings.

10. **Maintain and develop the high quality service provided** by the CHFT Macmillan Information and Support Service team, as demonstrated in this report. Good enough is never good enough, and we will continue to be the absolute best we can be to support our patients and their families, whatever it takes.

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

17.5.2022

Appendix One – Additional Patient Feedback in 2021:

Personally, I couldn't have managed last year without your support.

You talked to me, asked me how I could be helped. I was offered a telephone buddy, which I found very helpful.

Very useful meetings (unfortunately on Zoom) with Macmillan team and fellow cancer patients.

The staff are all so amazing especially had more contact with Helen who is so so lovely and kind. Important to have staff who are empathetic and you then feel listened to - thank you so much.

You helped me with counselling, the iHope Course, coffee and virtual walk meetings, Christmas singalongs, advice, car parking, love and support.

Helen explained everything very clearly and was very empathetic. It was a bit like talking to a daughter.

Always there at the end of the phone and very helpful indeed plus always sending out the monthly bulletins.

You supported with a very needed grant, being a listening ear, sorting out possible benefits, obtaining a 'Blue Badge.'

Although I haven't used any services throughout this past year as a volunteer; I'd like to say that the 'virtual' services you have continued to offer for the wider community has been fantastic. There's been lots of online/social media content of which I've been more than delighted to share! Keep up the fantastic work team and hope to be alongside side you with our health walk before too long!

Her many, many friends and that includes you all, have been amazing and very supportive of K during her illness and we will forever be grateful. I cannot express enough our thanks, for all that you have done for K. You have held her hand through the very bad days and helped her carry on. She accepted her fate with grace, but with great determination to carry on as best she could. We are forever in your debt. (Patient's brother)

You couldn't have done any better for me, you are all lovely.

You are all very caring & professional. I think you doing a fantastic service.

My only suggestion is just keep being wonderful!

I dont feel virtual coffee mornings and group chats were helpful to me, but face to face support would have been welcomed

Thank you very much for encouraging me to attend and look after myself I found attending virtual courses difficult due to work pattern

She spoke very fondly about you all and loved to bake for you to show how much she appreciated everything you did for her. K really looked forward to seeing you guys, the banter between you made her tough days bearable. Keep doing such a fantastic job because we saw what a difference you make to very poorly people and thank you from the bottom of our hearts.

Thank you so much for all you have done for my dad, and for how quickly you've been able to do it. Our family appreciate it so much.

Your team offered emotional support, practical and financial help. Macmillan's welfare really helped to guide me in what to claim financially when my wages were going to be reduced.

I had peace of mind knowing that you were there if I had needed you.

I felt safe and listen to. Feel that I can contact you if I have any queries.

Helen was helpful and charming. Her and the team are good listeners, patient and empathetic.

The team gave urgent help and advice for family and our daughter suffering mentally from the effects of her 15 yr fight against brain cancer.

Thanks for bring on the end of the phone. You arranged things on zoom, which I did appreciate even if I couldn't get to the meetings very often.

I would like to express my thanks for all the hard work and dedication that your organisation brings to us cancer sufferers. I was diagnosed with bowel cancer just over three years ago and underwent chemo and radiotherapy followed by surgery following which I now have a permanent stoma. Whilst I may not attend many meetings and online get togethers I know that you are always there should I or my family need help, it feels so reassuring to have you there. I receive my newsletter every month and look forward to see what is going on. Thanks again for your care and concern.

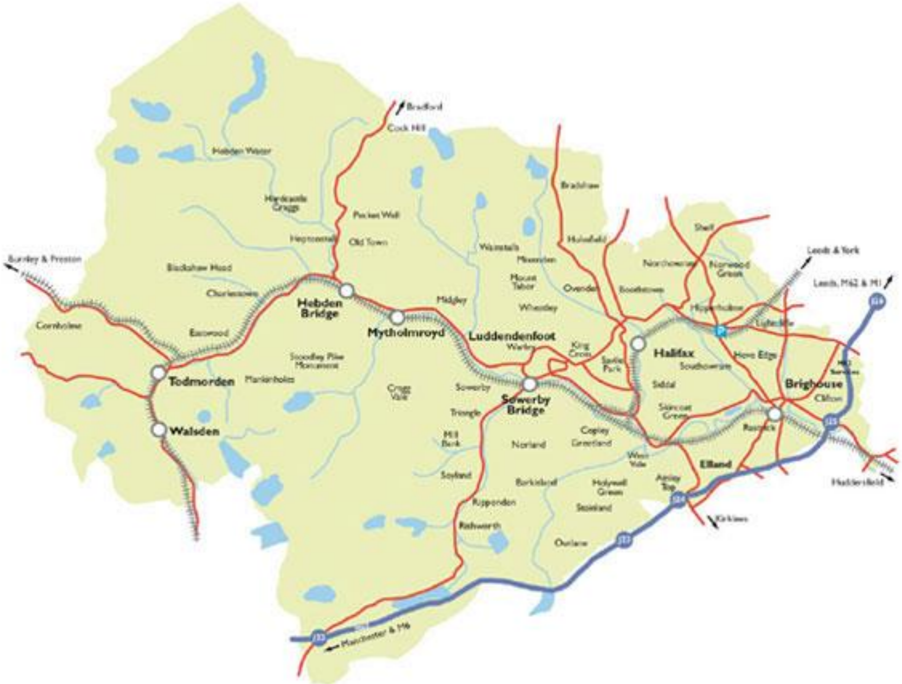
I would just like say a big thank you to all the doctors nurses and the support staff that includes Macmillan staff, that has help and support me with both my operations and treatment over the past three years, every department in the hospital that I have received treatment from have always being polite and inform me about the treatment I was receiving, even during the pandemic they have being fantastic. thank you all again.

Appendix Two – The Demographic Population in Kirklees and Calderdale:

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

Calderdale

Calderdale comprises of the main towns of Brighouse, Elland, Halifax, Hebden Bridge, Sowerby Bridge and Todmorden. Calderdale is one of the smallest districts in England in terms of population, but one of the largest in terms of area as it covers 140 square miles. The district is served by NHS Calderdale Clinical Commissioning Group. In June 2020 the Office for National Statistics ONS published its 2018 mid-year population estimates, which indicated that there are 209,500 210,100 people living in Calderdale which is an increase of approximately 6,200 people since the 2011 Census.



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The largest ethnic group in Calderdale is White British (89.7%), as recorded in June 2020. The second largest ethnic group is Asian /Asian British (8.3%) of which the majority (6.8%) are Pakistani.

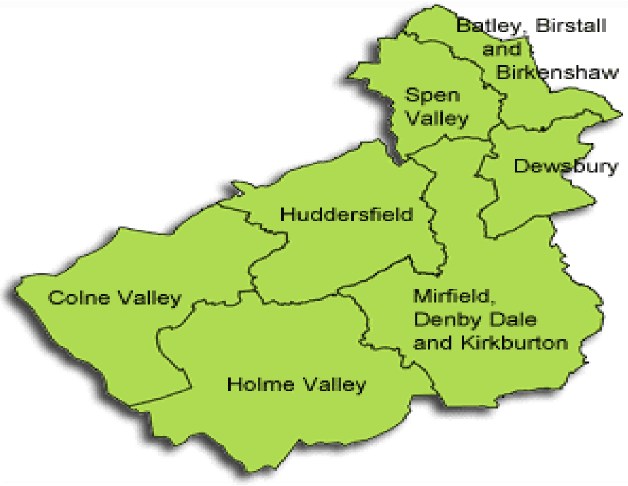
Source - https://www.calderdale.gov.uk/v2/residents/health-and-social-care/joint-strategic-needs-assessment/calderdale-demographic-information

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

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

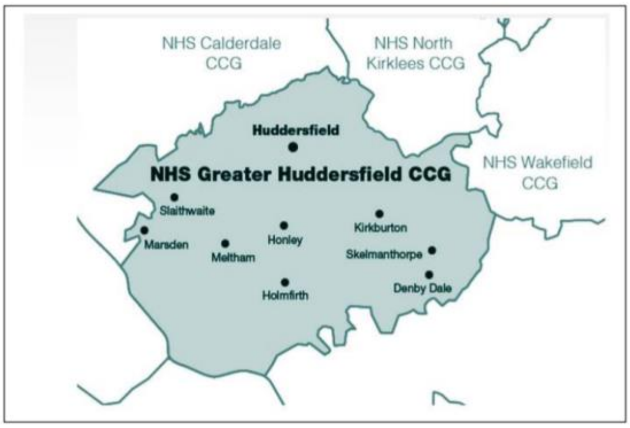
Kirklees

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

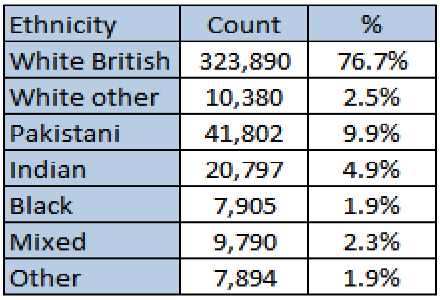


Source - http://isleworth.blogspot.co.uk/2016/01/districts-of-west-yorkshire.html

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

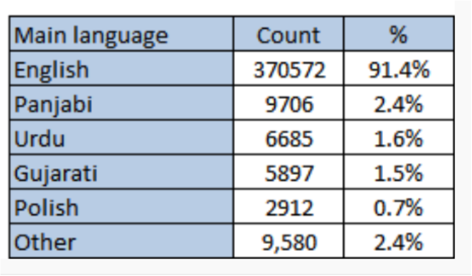


Kirklees is an ethnically diverse population, as illustrated in the table below.



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

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



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

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

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

Cancer remains the most common cause of death in under 75s in the Greater Huddersfield area and more people die from lung cancer than from any other type of cancer. Rates of new breast, prostate and bowel cancer diagnoses are higher in our area than in the Kirklees average.
Source: https://www.greaterhuddersfieldccg.nhs.uk/local-health/