

Live Well with Cancer

Rochdale Locality Report



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Executive Summary

In May 2021 Mayor Andy Burnham pledged in his manifesto to create a *holistic, specific* “Live Well with Cancer” programme in Greater Manchester. The premise of this pledge is that everyone who has received a cancer diagnosis deserves high quality care that addresses their wider health and wellbeing needs. However, there is no consistent way across Greater Manchester for someone newly diagnosed to find out about support available and for all their needs to be assessed. In response to the manifesto commitment, Greater Manchester Cancer, Greater Manchester Integrated Care, Greater Manchester Combined Authority and Macmillan Cancer Support, have come together to create the *Greater Manchester Live Well with Cancer Programme*. This programme aims to join up the different forms of care and support already available, or in development, across Greater Manchester. This will be done using an iterative approach across each locality producing a report for each of these boroughs which will feed into a final finding and evaluation document covering the whole of Greater Manchester.

This report will explore the discoveries made when we worked with key stakeholders in Rochdale to scope out what it would take to build a ‘Live Well with Cancer’ offer. Through working together via 1:1 meetings, service provider visits, steering groups and culminating in a stakeholder engagement event between August and March 2024 a picture of what is already in place, how it would be possible to build on this & what a great Live Well with Cancer (LWWC) offer in Rochdale could be.

Introduction

Made up of 10 boroughs and two cities, [Greater Manchester](#) covers an area of 493 square miles. It is the second largest urban area in the United Kingdom, after Greater London¹. The population of Greater Manchester according to the 2021 Census was 2,867,769. The population growth rate in Greater Manchester between 2011 and 2021 was 6.9% (185,241 more residents), higher than both England (6.6%) and the North West (5.2%).² Statistics also show that the population increases across virtually all ethnic minority groups have been a big factor in the growth of Greater Manchester’s total population. In 2021, there were some 281,000 more residents from Asian, Black, Mixed and ‘Other’ populations in Greater Manchester than in 2011, an increase of 51.9%.

The Health and Care Act 2022 introduced a range of Integrated Care Board (ICB) obligations in relation to health inequalities, which should underpin everything we do. To help guide action, NHS England has developed an approach – ‘Core20PLUS5’ – that focuses on reducing inequalities by targeting efforts at the most deprived 20% of the national population³. By working with our colleagues in the Greater Manchester Integrated Care Partnership we will ensure that we align with their proposed Equality Objectives and associated actions aligned to this approach⁴.

The boroughs of Greater Manchester are incredibly diverse with health and social care delivered by different providers, by utilising a place-based approach to the scoping, mapping and engagement process that redefines services and places individuals, families, communities at its heart we can understand the offer for people affected by cancer and any gaps that need to be addressed. By working with partners across the health and social care system including the VCSE and user led/community organisations we can ensure the right care and support is offered to the population of Greater Manchester. This programme aims to become a blueprint for extending and embedding systematic, proactive holistic support for other health conditions beyond cancer.

¹ [Manchester Population 2023 – UK Population Data](#)

² [230514_population_final.pdf \(greatermanchester-ca.gov.uk\)](#)

³ [NHS England » Core20PLUS5 \(adults\) – an approach to reducing healthcare inequalities](#)

⁴ [item/equality-objectives-1.pdf \(gmintegratedcare.org.uk\)](#)



Rochdale Locality

Rochdale is a borough in the north of Greater Manchester, comprising of Heywood, Middleton, Milnrow and Newhey, Littleborough, and Wardle. Rochdale shares borders with Oldham and Bury where residents may travel to access health and wellbeing information and support (HWBIS). Rochdale has a population of 223,800 (2021 census).

Rochdale is ranked as the 17th most deprived of 317 Local Authority districts in England. In terms of ethnicity Rochdale 74 per cent white, 19 per cent Asian, 4 per cent black, 2 per cent mixed and 2 per cent other ethnicities.⁵

Live Well with Cancer - Rochdale

Working with communities in Rochdale, the aim is to deliver personalised cancer care, providing people with access to care and support that meets their varied and individual needs. Support needs to start from the moment of diagnosis – so that people can live as full, healthy, and active lives as possible.

Building on Rochdale services and systems already in place across our health, community and neighbourhood settings, the programme focuses on how we can knit those excellent services together around people affected by cancer. It will amplify the great offers already available, identifying where there may be gaps particularly for minority groups, and shaping this understanding into a clear offer for people living with cancer in Greater Manchester. With 1 in 2 of us now being affected by cancer there has never been a more important time to explore what care and support is available.⁶

Results from HWBIS survey (highlights)

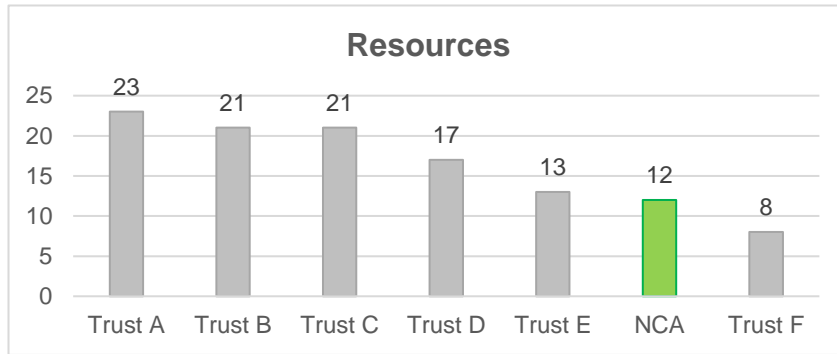
Between January and March 2023, cancer services across GM were asked to complete a survey of their Health and Wellbeing offer, including support offered ‘in house’ and details of where patients are referred for support with specific needs.

The survey is based on a self-assessment checklist which was co-produced by the NHS England National Cancer Team and Cancer Alliances, along with Alliance partners, patient and public voices representation and first circulated in GM in 2020/21.

Services were asked about the types of resource offered relating to the following areas:		
Pre-treatment	Psychological Impact	Finance
Health Promotion	Complementary	Work
Patient Activation	Therapies	
Recurrence	Late Effects	

It is difficult to understand the picture for Rochdale as the survey results identified were for the Northern Care Alliance footprint which spans Rochdale, Oldham, Bury and Salford localities. responses were received from 15 clinical services⁷, and the Macmillan Cancer Information and Support Centre.

Services identified on average 12 resources each which is just below average for the GM footprint.



Quality of Life & Carer Support

Services were asked about their offer for carers and family of people with cancer, and with respect to the 11 areas of focus in the Cancer Quality of Life Survey⁸:

- | | | |
|----------------------------|---------------------------------|----------------------|
| Appetite problems | Late effects/treatment toxicity | Nutrition |
| Bowel problems | Sexual difficulties | Pain |
| Breathing difficulties | Musculoskeletal problems | Psychological impact |
| Fatigue/sleep difficulties | Nausea/vomiting | |

Services reported offering support within their own service for an average of 2 of these problems, and referring to other resources for an average of 5.

6 out of 13 services stated that they provide support to carers and family of people with cancer.

Conclusion

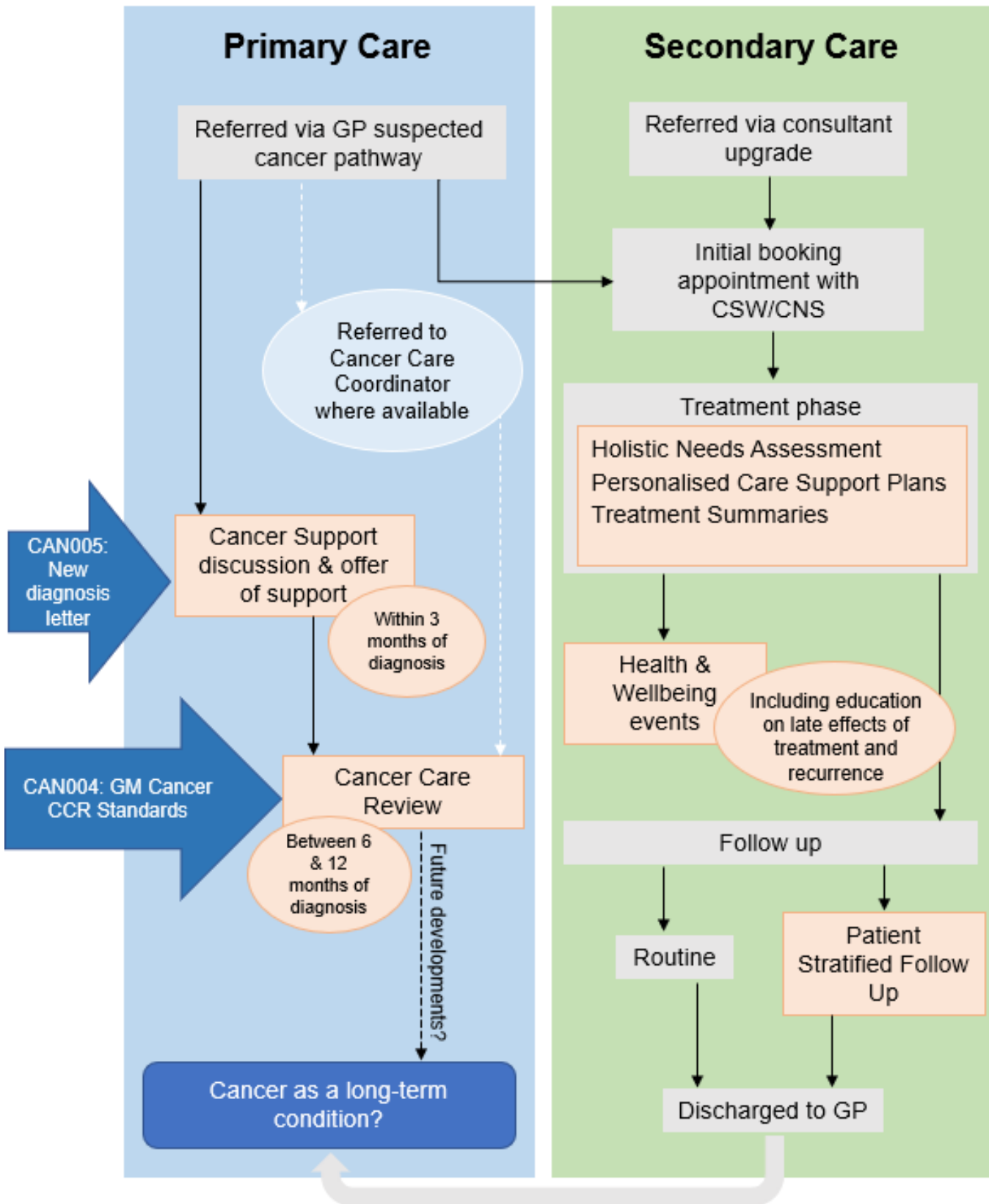
The data gathered from this exercise has supported the work of the Live Well With programme by identifying local resources in the Rochdale area who work to support people with cancer. Whilst not all services responded to the survey and some responses were of limited value due to lack of completeness, the process has provided the LWWC workstream with a solid foundation to work from.

⁷ Including two acute services and the chemotherapy service which have been excluded from the analysis as the contact they have with patients addresses a specific, sometimes short-term, need and is therefore rarely holistic in its nature. This is reflected in their responses, with many areas of HWB being reported as not applicable to, or supported by, their service.

⁸ <http://www.cancerqol.england.nhs.uk/>



The Patient Pathway (Diagram 1)



Interventions & Resources

The steps below show what health and wellbeing information, and support are offered in Rochdale mapped against the patient pathway a summary of this is available in an infographic format (app 4.).



Point of referral

The time between referral and a confirmed diagnosis can often be fraught with worry and uncertainty. There are multiple sources of support available prior to a cancer diagnosis including financial, work and career, peer, family & carer, homelessness, minority group support, children/teenage & young adults, older people, social isolation, and psychological support.

The Local Picture

Whilst Rochdale doesn't have its own Macmillan Information and Support Centre the people from this locality can tap into the **Macmillan Team based at the Royal Oldham Hospital**. You can see descriptions of the information and support they provide in the Oldham, Bury, Heywood, Middleton & Rochdale Macmillan Unit Directory (App I.) which includes over 60 sources of support both non cancer and cancer specific – local and national provisions. Criteria for referral and the pathway in can be accessed by utilising the contact details included.

This also may be a good time to tap into **Rochdale's Social Prescribing** team. They work with people to help them make new connections in their community. They listen to people to find out what's important to them, what changes they would like to make in their lives, and help identify the best ways to achieve those changes. Their strengths-based approach helps reduce use of GP surgeries, calls to 111 and 999, visits to A&E and avoidable emergency hospital admissions, reducing crisis management of care support by connecting people to people, places and community groups and activities local to them. Referrals to a Social Prescribing Link Worker can be made by your GP surgery.

Rochdale residents who are facing pressure on their household budgets due to the increase in the cost of living, food and energy bills can also access help via the council's **Cost of Living** web pages which are here: [Cost of living – Rochdale Borough Council](#). Residents can also call the Cost of Living Helpline on 01706 923685. This has a social prescribing element to it and they'll refer/signpost residents to appropriate support depending on what issues they are facing (App 2). The Bond Board also offer a **Tenants' Advocacy Service (TAS)** which aims to prevent homelessness by offering specialist, legal housing advice alongside holistic support for low income, private renting tenants in Rochdale see more information on the website here [Home - The Bond Board](#) They also offer fortnightly coffee mornings and do home visits and office appointments.





Booking appointment

Around this time patients should routinely be offered a holistic needs assessment (HNA). A HNA is an assessment and discussion that may be had with a patient with someone from their healthcare team, more information about these can be found here [Having a Holistic Needs Assessment | Macmillan Cancer Support](#).

The Greater Manchester Cancer Alliance Personalised Care Team are working with the local hospitals to improve the uptake and quality of HNA's and personalised care support plans (PCSP) which are produced as a result of these assessments. The timing of a HNA will be dependent on the pathway/tumour group as not all will be offered one early in the pathway. Ideas and actions from the PCSP are followed up with referrals.

The Local Picture

In Rochdale this is usually via the Cancer Nurse Specialist or Cancer Support Worker. The Nursing Teams and Cancer Care Co-ordinators/Support Workers will often refer patients to the Macmillan Centre (App I) or to the Oldham Maggie's Centre [Maggie's Oldham | Maggie's \(maggies.org\)](#) who will support a patient or loved ones affected by cancer regardless of their postcode. These organisations may make suggestions for referrals to community, activity or faith based groups and these actions/referrals can promote changes to daily routines and encourage proactive healing to reduce readmissions and promote long-term wellbeing.

There may also be a referral to **Prehab4Cancer** which is a free exercise nutrition and wellbeing scheme designed to help people with a recent diagnosis of cancer prepare for, and cope better with their treatment. Prehab4 Cancer is currently available for people who are over 18 years of age, registered with a Greater Manchester GP and are going to have curative treatment for:

- Colorectal Cancer (surgical treatment)
- Lung Cancer (surgery, radiotherapy or chemotherapy)
- Upper Gastrointestinal Cancer (surgery, radiotherapy or chemotherapy)

More information is available here [Who is it for? – Prehab4Cancer](#)



Treatment

During the treatment phase patients and their family/loved ones are often focussed on attending appointments and receiving treatment. Their life is largely dictated to them by the patient pathway for their cancer type. In some tumour groups another HNA may be offered at this time and the support offered can change as a result of this. For example 50% of patients experience significant psychological distress during and after treatment. It is also not just cancer patients who suffer psychologically. 67% of carers experience anxiety and 42% experience depression. Of these over three quarters do not receive any support.⁹

The patient should receive a phone call from the GP practice to have a discussion about support available within 3 months of diagnosis (diagram 1 CANOO5).

⁹ Cardy P. Worried Sick: The emotional impact of cancer. Macmillan Cancer Support. 2006.



The Local Picture

NHS Heywood, Middleton and Rochdale Talking Therapies provide psychological therapies to help people who are feeling distressed by difficult events in their lives as well as people with common mental health difficulties. They can be accessed via telephone 01706 619 020, via the GP, or fill in the online referral form [NHS Heywood, Middleton and Rochdale Talking Therapies - The Big Life group](#). Maggies Oldham also offer emotional support and there are lots of other options for support listed in appendix 1.

If access to support outside of the Rochdale area is required, perhaps closer to family and friends who may be caring for a patient then they can search using the **Cancer Care Map** which is a simple, online resource that aims to help people find cancer support services in their local area wherever they are in the UK. Cancer Care Map is run by The Richard Dimpleby Cancer Fund charity and you can access it here [Homepage | Cancer Care Map](#).

Greater Manchester Cancer Alliance is currently working with Cancer Care Map to produce a more bespoke offering for Greater Manchester.

End of Treatment



At the end of each episode of treatment i.e., surgery, chemotherapy, radiotherapy etc the patient should receive a treatment summary and then an end of treatment summary at the end of all primary treatments detailing all of the interventions and care given.

The treatment summary tells the patient, GP and other health professionals in the community what treatment has been given, what the patient needs might be, what ongoing support may be required including late effects of treatment, who to contact at the hospital if there are any questions or concerns. It also helps the patient understand their cancer and gives them the choice to share it with other professionals if necessary. Treatment summaries also help the GP to do a Cancer Care Review.

The Local Picture

In Greater Manchester the tumour specific pathway boards have co-produced a number of treatment summaries so that a standardised document is provided wherever they live and whichever Hospital they attend. The personalised care team will maintain a spreadsheet of signed off letters for all specialties with review dates. These can be accessed on the NHS futures pages which is a centralised portal here [GM Cancer Alliance Personalised Care Programme - FutureNHS Collaboration Platform](#). There is also work being done to increase the number and consistency of treatment summaries provided with all of the hospitals across Greater Manchester. These numbers are recorded on the Cancer Outcome and Services Data set (COSD) and the personalised care team present these figures regularly at the Personalised Care Programme Board so progress can be monitored.



If appropriate, information will be provided about patient follow up including where a patient may be on a personalised stratified follow up pathway (PSFU). PSFU is an effective way of adapting care to the needs of patients after cancer treatment, to ensure that we are providing world class services. PSFU pathways are tailored to individual needs, offers huge benefits to patients and the NHS. Stratified follow up improves patient experience and quality of life for people following treatment for cancer, as well as making services more efficient and cost-effective¹⁰. Having a Personalised Stratified Follow Up (PSFU) pathway means patients know that when they complete primary treatment they will be offered:

- Information about signs and symptoms to look out for which could suggest their cancer has recurred or progressed.
- Rapid access back to their cancer team, including telephone advice and support, if they are worried about any symptoms, including possible side effects of treatment.
- Regular surveillance scans or tests (depending on cancer type), with quicker and easier access to results so that any anxiety is kept to a minimum.
- Personalised care and support planning and support for self-management, to help them to improve their health and wellbeing in the long term.

Patients having the remote monitoring option within PSFU will not have to travel back to hospital simply to be given scan/test results that show no causes for concern.



Follow up

After cancer treatment, patients will have follow-up care from their healthcare team to make sure everything is going well and find out if they have any concerns. They may be on a PSFU pathway as mentioned above or may have face to face follow up appointments at the hospital. These appointments may include blood tests, X-rays or scans and are a good opportunity to discuss any questions they may have with a health professional.

It is important that any clinical concerns that arise between appointments are raised with the hospital team. They will find details of how to access the team in the treatment summary which is a letter sent to them at the end of each episode of treatment.



Health & Wellbeing

Health and wellbeing information and support includes the provision of accessible information about emotional support, coping with side effects, financial advice, getting back to work and making healthy lifestyle choices. This support will be available before, during and after cancer treatment although a patient's needs may change during this time.

¹⁰ <https://www.england.nhs.uk/wp-content/uploads/2020/04/cancer-stratified-follow-up-handbook-v1-march-2020.pdf>



The Local Picture

In Rochdale there are currently no offers of generic or tumour specific **health and wellbeing events**. However, the Northern Care Alliance do provide a schedule of tumour specific health and wellbeing events in surrounding areas and these will offer more tailored advice (App 3). Details of these may change and more up to date are normally provided by a clinical nurse specialist or cancer care co-ordinator as patients near the end of their treatment. Social Prescribing services can offer personalised support with specific needs and signpost to services in the community as mentioned in section 1.

Rochdale and District Mind ([Rochdale Mind – For better mental health](#)) offers a number of services to support mental wellbeing, including support groups, counselling services and gentle physical activities. There are also two Wellbeing cafes in Middleton and Rochdale where individuals can find emotional support on a drop in basis.

Our Rochdale (www.ourrochdale.org.uk) provides a comprehensive database of local support for health and wellbeing needs. Rochdale Borough Council has also developed a digital resource which signposts to applications which support Health & Wellbeing for use on phones and tablets. This can be accessed here: <https://ourrochdale.orchahealth.com/en-GB>

Please also see other forms of support currently available across Greater Manchester (App 4) this will be updated regularly by the Oldham Macmillan Information and Support Centre which supports the Rochdale locality.

Discharge to primary care



After cancer treatment has finished patients will be discharged from the hospital back to care with the GP practice (primary care). They should receive an appointment with a member of the GP Practice for a cancer care review (diagram 1 - CAN004). The Cancer Care Review (CCR) is a conversation between a patient and their GP or Practice Nurse about their cancer journey. It is an opportunity for

patients to talk about their cancer experience and concerns, understand what support is available in their community and receive the information they need to begin supported self-management if appropriate.

Please access this link for more information about CCR's¹¹ <https://youtu.be/QtRngmw-5tc?si=rYwsxGAVKYBYheMT>

The Local Picture

In Greater Manchester we are currently undertaking work to understand the quality of CCRs and develop a plan of education and support to improve this.

¹¹ [Cancer Care Review \(CCR\) - Northern Cancer Alliance Northern Cancer Alliance](#)





Late effects of cancer & treatment

All cancer treatments are different and affect people in different ways. It is estimated around one in four (25%) people with cancer are living with the long-term consequences of cancer or its treatment¹².

Most people have some side effects during treatment. But some people also have late effects of treatment. Late effects are side effects that:

- Begin during or shortly after treatment and do not go away within 6 months – they can become permanent and are sometimes called long-term effects
- Do not affect you during treatment but begin months or even years after your treatment ends.

Cancer doctors or nurses can tell patients whether they are likely to have any late effects from treatment and these will also be detailed in the treatment summary. This may also include emotional and psychological effects and patients can access the talking therapies service in Rochdale for help with this as detailed in section 3.



Non-curative cancer

Some people will have treatable but not curable cancer from the moment they are diagnosed, while others will progress to having treatable but not curable cancer if their cancer continues to spread or comes back. Research by Macmillan¹³ shows that people with treatable but not curable cancer often need a great deal of emotional, physical and financial support. Most will face a prolonged and complicated treatment pathway involving repeated tests, procedures, medications and hospital appointments. Many face uncertainty every day and have specific needs that can change over time.

The Local Picture

Springhill Hospice provide an integrated palliative and end of life care service for patients within Heywood, Middleton and Rochdale area. They aim to focus on quality of life, promoting the physical, psychological and spiritual wellbeing of those individuals deemed to be in the last 12 months of life. Referral form and further information can be found on their website [Home | Springhill Hospice](#) or you can call them 01706 649920 for more information on their extensive services.

The Hospice also has a **Specialist Community Palliative Care Team** which can be contacted on 01706 752360.

The **Oldham Macmillan Centre** can help with practical and emotional support (App1) as can the **Oldham Maggies Centre**.

¹² [PowerPoint Presentation \(macmillan.org.uk\)](#)

¹³ Internal insight based on in-depth interviews with people living with treatable but not curable cancer and healthcare professionals supporting those affected





Moving on

Many people affected by cancer feel they had lots of information and support during their illness, once treatment stopped, they entered a whole new world— one filled with new questions. It is important to remember that the sources of information and support available to them through the treatment phase are still able to help. It may be that they now feel more interested in accessing the social prescribing team mentioned in section 1 or continue the work they have undertaken with exercise professionals to look at positive changes to diet and exercise to keep them as healthy as possible for the future.

The Local Picture

Your Trust Rochdale Health & Fitness membership - Your Trust (yourtrustrochdale.co.uk) are a charity working in the heart of Rochdale borough, they offer support to encourage as many people as possible to **live active**, creative, happy and **healthy** lives. They offer a number of different memberships and can offer discounts for people in receipt of means tested benefits or match any of the criteria detailed [here](#). They also have a GP exercise referral service. The Exercise Referral Scheme is intended for people who:

- Are over 16.
- Have a recurring illness or chronic medical condition

The aim is to improve health and wellbeing, by working with clients to become more active within their day-to-day life. Please talk to your GP, practice nurse or health adviser for a referral. You can also be referred by specialist NHS services and local public health services.

Stakeholder event

As part of the Live Well with Cancer work undertaken we held a Stakeholder Engagement Event in October 2023. Multiple stakeholders from across the health and social care system including patient representatives attended the event. On the day there were presentations from some of the service providers but more importantly table discussions about what would excellent care for people affected by cancer look like in Rochdale, what could we achieve in the next 12 months and what may stand in the way of delivering these changes.

Next steps






Since the event we have had further meetings and agreed the deliverables below with the Transformation and Delivery Manager (HMR Locality), Personalised Care Lead Nurse (NCA), Macmillan Cancer Centre Managers(NCA) & Senior Public Health Specialist:

- Primary Care Resources/Education in collaboration with secondary care
- Staff Inductions provided by MCISS centres across all sectors

The personalised care team within the Greater Manchester Cancer Alliance will continue to engage with the stakeholders and offer advice and support to aid continuous improvement to the lives of people affected by cancer in Rochdale and beyond.



Appendices

-  MCISS - about our service - for people af
 Resource List - 2023 (002).pdf
-  CostofLiving-ToolKit_A4_Trifold_Digital_AR
-  Health and wellbeing calendar 2024 NCA.pd
-  Support Groups 2023 .pdf

