





Live Well with Cancer

Tameside Locality Report



Programme Lead: Michelle Leach Senior Responsible Officer: Claire O'Rourke



December 2023





Executive Summary

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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 Tameside 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 July and September 2023 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 Tameside could be.

Introduction

Made up of 10 boroughs and two cities, <u>Greater Manchester</u> 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 NHC England » Core20PLUS5 (adults) – an approach to reducing healthcare inequalities

en equality-objectives-1.pdf (gmintegratedcare.org.uk)





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The Borough of Tameside lies to the East of Greater Manchester. Tameside shares borders with Oldham, Manchester, Stockport and the Derbyshire Borough of High Peak where residents may travel to access health and wellbeing information and support (HWBIS) and vice versa. Tameside has a population of 231,073 (2021 census). The borough's population is equal to approximately 9.1% of Greater Manchester's population.

Tameside is ranked as the 28th most deprived of 317 Local Authority districts in England, and the 5th most deprived in Greater Manchester. In terms of ethnicity Tameside is predominantly White, which makes up 90.9% of the population. 6.65% of the population are Asian; 1.4% are Mixed; 0.08% Black; and 0.2% of the population are other ethnicities⁵.

Live Well with Cancer - Tameside

Working with communities in Tameside, 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 Tameside 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.

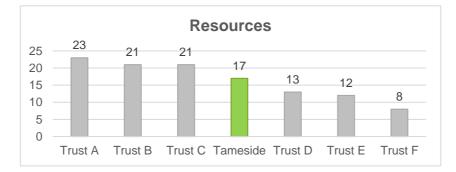
Services were asked about the types of resource offered relating to the following areas:		
Pre-treatment	Psychological Impact	Finance
Health Promotion	Complementary	Work
Patient Activation	Therapies	
Recurrence	Late Effects	







In Tameside, responses were received from 3 clinical services: Breast Care, Gynaecology, HPB & Rare Cancer and two support services: the Cancer Care Coordinator Team and the Macmillan Centre.



Services identified on average 17 resources each which is average for the GM footprint.

Tameside is unique in GM for having a close-knit team of Cancer Care Coordinators who work across all specialities to provide personalised care to people with cancer. Many services rely on this team to deliver all aspects of personalised care that people require. This can explain why the level of knowledge of supportive resources within service teams is somewhat lower than it is in other trusts.

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 Survey⁷:

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 6.

3 out of 5 services stated that they provide support to carers and family of people with cancer.

Appetite problems	
Bowel problems	
Breathing difficulties	
Fatigue/sleep difficulties	

Late effects/treatment toxicity Sexual difficulties Musculoskeletal problems Nausea/vomiting Nutrition Pain Psychological impact

Conclusion

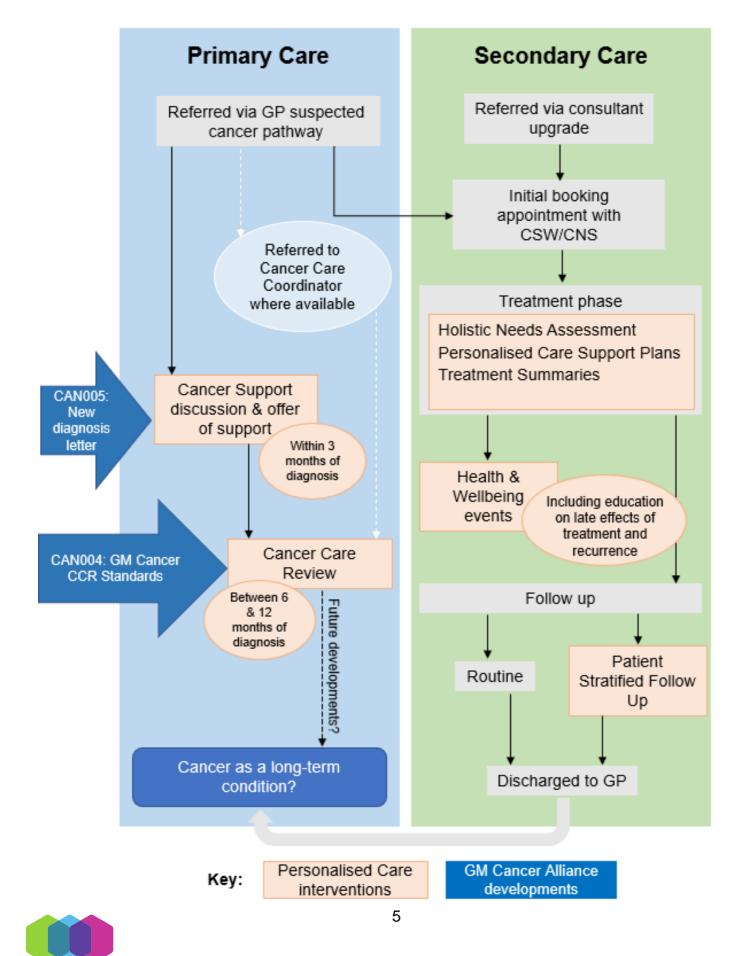
The data gathered from this exercise has supported the work of the Live Well With programme by identifying local resources in the Tameside area who work to support people with cancer. Whilst not all services responded to the survey and some responses were of limited value due to lack of completeness,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







The Patient Pathway (Diagram 1)









Interventions & Resources

The steps below show what health and wellbeing information, and support are offered in Tameside mapped against the patient pathway a summary of this is available in an infographic format (app 5.).



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

You can see detailed descriptions of these in the Tameside Macmillan Unit Directory (App I.) which includes well over 200 sources of support both non cancer and cancer specific. 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 **Tameside'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 Social Prescribing can be made by health care professionals via EMIS or directly via Elemental, they can also take self-referrals via their Action Together website: <u>actiontogether.org.uk</u>. If you are unsure whether a person is suitable for Social Prescribing, you can email socialprescribing@actiontogether.org.uk before making the referral to check suitability.



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 <u>Having a Holistic Needs Assessment | Macmillan Cancer Support</u>.

The Greater Manchester Cancer Alliance Personalised Care Team are working with Tameside and Glossop Integrated Care NHS Foundation Trust 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 Tameside this is usually via the **Macmillan Cancer Information and Support Service (MCISS)** who then deliver health and wellbeing advice and support as part of their services but also refer and signpost on. Details of how to contact the centre are here <u>Macmillan Unit :: Tameside and Glossop</u> Integrated Care (tamesideandglossopicft.nhs.uk). Nursing Teams and Cancer Care Co-ordinators/Support Workers can also refer directly into services via the Elemental Portal to some services such as social prescribing. These actions/ referrals can promote changes to daily routines and take part in 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.⁸

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).

The Local Picture

Tameside has a dedicated talking therapies service, providing expedited and specialist psychological support to individuals with cancer. Referrals can be made via the **Macmillan Centre**, direct or via a member of staff with the Trust and triaged via MDT. There are also lots of other options for support listed in appendix 1.

If access to support outside of the Tameside 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 Dimbleby Cancer Fund charity and you can access it here <u>Homepage | Cancer Care Map</u>.

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

⁸ Cardy P. Worried Sick: The emotional impact of cancer. Macmillan Cancer Support. 2006.









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 <u>GM Cancer Alliance Personalised Care Programme - FutureNHS Collaboration Platform</u>. 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 the 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-effective⁹. 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.

⁹ https://www.england.nhs.uk/wp-content/uploads/2020/04/cancer-stratified-follow-up-handbook-v1-march-2020.pdf









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

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scans and are a good opportunity to discuss any questions they may have with a health professional.

It is important that any 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.

The Local Picture

In Tameside every patient will be invited to attend a cancer health & wellbeing event which runs on the 3rd Tuesday of every month at the **Tameside Health & Wellbeing College** (App 2). These health and well-being events can be a good way to meet people in a similar situation. They usually provide the following sessions:

- Macmillan Information & Support Centre Services local services, such as support groups and local physical activity groups.
- The HOPE (help to overcome problems effectively) course designed to support you after cancer and run by trained facilitators with lived experience.
- Wig fitting, hats and head scarfs
- Skin care and make up sessions.
- Lived experience group
- Emotional effects and how to get help if you need it
- Live Active Tai Chi sessions
- Claiming benefits and other financial support
- Getting back to work or education
- Volunteering & Social Prescribing

The Trust also offer a free art class run by the cancer care co-ordinators which runs monthly for people affected by any cancer type with an interest in art. This can be booked by phoning 0161 922 5959/5644 or asking the CNS for more information.

Tumour specific **health and wellbeing events** are also offered and will offer more tailored advice. Details of these are normally provided by a clinical nurse specialist or cancer care co-ordinator as patients near the end of their treatment. Please see the following tumour specific information and support currently available, this will be updated regularly.





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MACMILLAN CANCER SUPPORT



Hepato-biliary (HPB)

There is a support group at the **Maggie's Centre** in Manchester which nurses from Stockport and Tameside attend to provide advice and support to patients. This monthly support group is open to anyone in Greater Manchester who has had a HPB cancer diagnosis. To register for attendance please email <u>manchester@maggies.org</u> with the name and contact number, and they will send a link to join.

Advanced Cancer Care

The Advanced Cancer Nurses hold a **monthly support group** for patients with long term care needs. This is invite only and more information will be provided by the advanced care nurse team.

Upper Gastro-intestinal (GI)

The Upper GI Nursing will be resurrecting a **monthly meeting** which was held previously this will become available in early 2024. Details will be available from the clinical nurse specialist or cancer care co-ordinator.

Lung/Respiratory

The Lung respiratory team are looking to launch a **support group** in 2024. Details will be available from the clinical nurse specialist or cancer care co-ordinator once available.

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's¹⁰ <u>https://youtu.be/QtRngmw-5tc?si=rYwsxGAVKYBYheMT</u>

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.

¹⁰ 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 treatment¹¹.

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 expedited talking therapies service in Tameside 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 Macmillan¹² 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

The Tameside Macmillan Centre can help with practical and emotional support (App1).

There is also a team of **Macmillan Community Nurses** - (Specialist Community Palliative care team) you can contact them by phone 0161 669 4848 or email tga-tr.tamesidemacmillan@nhs.net. (See App 3 For referral forms).

Willow Wood Hospice is an adult Hospice providing specialist palliative care for patients with life limiting illnesses, both cancer and non-cancer diagnosis and a member of the GM Hospice Provider Collaborative working in partnership to deliver hospice services. Any Healthcare Professional can refer into their service such as: GPs, Macmillan Nurses, Hospital Teams and Professionals, District Nurses, Long Term Condition Teams self-referrals are also accepted for their wellbeing services. Further details and referral form can be found here <u>How to refer – Willow Wood Hospice</u>

¹² Internal insight based on in-depth interviews with people living with treatable but not curable cancer and healthcare professionals supporting those affected



¹¹ PowerPoint Presentation (macmillan.org.uk)







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

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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

The Live Active Team in Tameside have a GP referral service which aims to improve health and wellbeing, by working with clients to become more active within their day-to-day life. People can also self-refer using the email link below, or for any questions please contact one of the team: 0161 366 4860 / liveactive@activetameside.com. More information can also be found on the website Live Active Active Active Tameside

Stakeholder event

As part of the Live Well with Cancer work we undertook in Tameside we held a Stakeholder Engagement Event at the end of September 2023. Multiple stakeholders from across the health and social care system including patient representatives attended the event. More information and the presentations from the day are available here <u>Personalised Care - Greater Manchester Cancer (gmcancer.org.uk)</u>.

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 Tameside, what could we achieve in the next 12 months and what may stand in the way of delivering these changes. The results from these discussions are detailed in appendix 4.

Next steps

Since the event we have had further meetings and agreed the deliverables below with the Lead Cancer Nurse & Macmillan Cancer Centre Manager at Tameside and Glossop Integrated Care NHS Foundation Trust (T&G FT):

- Ongoing provision of multi-stakeholder Live Well with Cancer Steering Group sustained by T&GFT with annual face to face meeting supported by the cancer alliance
- Outreach holistic needs clinic delivered to patients closer to home at The Bureau in Glossop
- Educational Event to be held for staff at the end of January 2024
- Ongoing cancer education in the hospital with ward cancer champions programme in development

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 Tameside and beyond.









Appendices

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