Health and Wellbeing Board

30 July 2019

Joining the Dots County Durham

Amanda Healy, Director of Public Health, Durham County Council

Councillor Lucy Hovvels, Cabinet Portfolio Holder for Adult and Health Services

Electoral division(s) affected:

Countywide

Purpose of the Report

1 To update the Health and Wellbeing Board on Macmillan Joining the Dots Programme.

Executive summary

2 Macmillan Joining the Dots is a service around non-clinical needs and that it is available from the point of a diagnosis to living with/beyond or end of life/palliative care and bereavement.

3 The official launch of the service took place on the 24th January 2019 with over 90 delegates attending. 30 local voluntary, statutory and charitable services attended the launch, an opportunity for them to meet the 6 new facilitators and 3 clients who had benefitted from using the Joining the Dots service.

4 Macmillan Joining the Dots have been taking referrals since the 1st September 2018.

5 The Governance of the Programme comes from the Programme Board, chaired by the Director of Public Health, Amanda Healy, with representation from Cllr Lucy Hovvels.

6 The development of the service has been supported by a Coproduction Group, volunteers who themselves have been through a cancer journey. As the Programme moves into Phase 2, service delivery and sustainability, this group will continue to shape the service moving forward.

7 The Programme is funded by Macmillan Cancer Support and the Northern Cancer Alliance and costs a maximum of £300,000 per annum. Currently, this funding is only secure until March 2020, however, with

underspend the service is currently able to run until September 2020. The project team is looking at future funding options to extend the service beyond this time.

8 The review of wellbeing and the implementation of social prescribing provides an opportunity to expand the principles of Joining the Dots to other long-term conditions and embed in a wellbeing approach.

9 The Joining the Dots service is already ahead of the NHS Long Term Plan with regard the recommendation that by 2021, every person diagnosed with cancer will have access to personalised care including a needs assessment, care plan and health and wellbeing information and support.

Recommendations

10 Members of the Health and Wellbeing Board are recommended to:

(a) Note the contents of the report and development of the Programme since the last report.
(b) Request further updates on the service when required.
(c) Ensure partners cascade information on the service to their respective organisations and encourage employees to make referrals where relevant.
(d) Support discussions around the sustainability of the service in due course.

Background

11 Cancer is the highest cause of death in England of the under 75's. Cancer contributes significantly to the gap in life expectancy between the least and most deprived areas of County Durham. For men, cancer is the 2nd biggest contributor to the gap between the least and most deprived areas of County Durham (19.4%). For women, this is the largest contributor at 25%.

12 There are approximately 15,000 people living in County Durham living with or beyond cancer. This figure is projected to rise to 28,000 by 2030 if the population increases as anticipated.

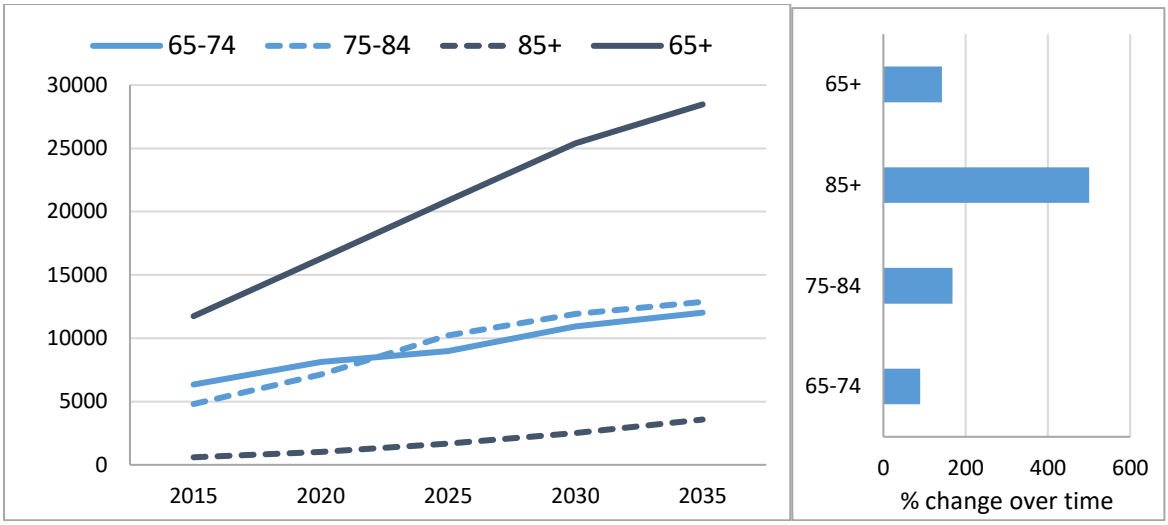

Figure 1: Predicted Cancer Prevalence by Age Group

13 Improvement in diagnosis and treatment mean that more people are likely to survive cancer than die from it. More than half of people diagnosed with cancer today are living more than 10 years. Cancer can now be considered a long-term condition.

14 The Macmillan Joining the Dots programme is part of a national Macmillan Cancer Support and local authority programme of work, one of four flagship areas. The service has been in operation since November 2015 and is an ongoing partnership primarily between Macmillan Cancer Support and Durham County Council.

15 In January 2018, following comprehensive work undertaken and an options appraisal, the Programme Board made the decision to progress with implementation of the Macmillan Joining the Dots Service through varying the Wellbeing for Life contract.

16 The Programme is governed by the Programme Board, chaired by the Director of Public Health with membership from the Portfolio Holder for Adults and Health and chair of the Health and Wellbeing Board; and has a Coproduction group which includes people who have been affected by cancer (coproduction volunteers), partners from primary and secondary care and clinical commissioning groups.

17 The Programme was established to develop a new 'social model' of support which will make sure that all people affected by cancer in County Durham have the opportunity to receive early support for their individual holistic, non-clinical needs.

18 The service began engaging clients in September 2018 with an official launch on the 24th January 2019. Over 30 prominent voluntary and statutory organisations were part of the 90 people who attended the

launch which provided attendees with an opportunity to meet the facilitators and clients that had previously benefitted from the service.

19 The Macmillan Joining the Dots Service aims to:

(a) Improve or increase the offer of support to people affected by cancer;
(b) Improve the psychological well-being of people affected by cancer;
(c) Increase the ability of people affected by cancer to live more independently;
(d) Increase skills and knowledge regarding cancer among the workforce;
(e) Improve systems and processes to support people affected by cancer;
(f) Involve people affected by cancer in continuously improving services.

Service Description

20 The key components of the Macmillan Joining the Dots County Durham Service are:

(a) The allocation of a Joining the Dots Facilitator available from the point of a cancer diagnosis and consistent throughout someone's cancer experience;
(b) Single and free access routes into the Joining the Dots service;
(c) Identification of needs (Holistic Needs Assessment/ Concern's Checklist);
(d) Facilitated access to support for identified needs;
(e) Follow up to ensure people are receiving the support that they need;
(f) A structured plan for "step-down" in the level of support;
(g) Ongoing support is available as agreed between the individual and the Facilitator and people are able to access support at any time should their circumstances change;
(h) Access to support is available and tailored to individual needs.

21 Macmillan Joining the Dots is available from cancer diagnosis to living with and beyond cancer or end of life.

22 Referral pathways have been developed between the service and Hospital Trusts (including cancer treatment centres), Clinical Commissioning leads, voluntary sector organisations, Healthwatch, Age UK, pharmacies, Macmillan Information Centres, Macmillan Durham Not Alone, cancer support groups, GPs, GP Cancer Champions, Palliative Care Teams, Clinical Nurse Specialists and Hospices, amongst others.

Pathways with other partners are still under development and existing pathways will remain under constant review and engagement.

23 Six (6) facilitators work across County Durham in three geographical areas. The North of County Durham, based at The Greenhouse, Stanley, the South West, based at the Pioneering Care Partnership in Newton Aycliffe and the East, based at Heathworks, Easington. The facilitators are aligned to “teams around the patient” (TAPs).

24 Between September 2018 and June 2019, the service engaged with 264 clients, 156 of these people have a cancer diagnosis of their own. This shows that, although in its infancy, the service is already engaging with the friends, family and carers of someone with cancer who have often not accessed support previously. It has also allowed the service to work with friends, family and carers of those who are end of life, to help prepare for their passing. This support focuses upon financial concerns, funerals, wills/probate and emotional issues. Where relationships have already been established with the carers and family, the team continue to support the carers and family following their bereavement. All clients to the service receive a personalised Macmillan Joining the Dots ring binder to store all notes regarding their interventions will all services.

25 The North of the county (Consett, Stanley, Durham, Chester-le-Street) has the highest engagement, 41%, South West (Bishop Auckland, Barnard Castle, Crook, Willington) 35%, and East (Peterlee, Easington, Seaham) at 27%. The East has been the most difficult area to engage with clients since the start of the project. Running at a reduced staff capacity has been a contributing factor to this difficulty as has the clinical buy-in. The complexities of accessing cancer treatment for people who live in this area coupled with the reduced likelihood that they will ever be seen within County Durham and Darlington Foundation Trust means that there is a greater dependence upon referrals from primary care who are further removed from cancer care pathways than secondary care providers. An additional Joining the Dots facilitator is due to be employed imminently, and additional work to engage clinical services outside of the county in line with patient flows, will help to increase support provided to people affected by cancer who live in the East of the county.

26 Over 50% of the clients seen are currently undergoing treatment (the time when reportedly people have the most support). Lower levels of engagement in the service so far is from people who have had a recent diagnosis and those who are living beyond cancer.

27 Although the service is engaging with people who have a range of cancers; breast, bowel and lung make up 60% of the cancers that are registered with the service.

28 81% engaging with the service to date are between the ages of 46-75, with 6% (17) below the age of 45 and 13% (33) above the age of 75.

29 From September 2018 to the end of Quarter 4, March 2019, just over 33% of the clients were male. Between April 2019 to June 2019, there has been a significant increase in men engaging with the service, with an equal split of men and women accessing support.

30 A significant part of the JTD service is ensuring that once facilitators have identified the holistic needs of the person affected by cancer, they signpost or refer to the most appropriate service to support the meeting of the holistic needs. Referrals from the service to welfare rights and local cancer support groups are significantly higher than to other agencies. There is, however, good evidence of referrals for support to a number of areas including transport, housing, hospices and secondary care. This has allowed the service to record specific case studies regarding their work with the service (Appendix 2 and 3).

Macmillan Local Authority Partnership (MLAP) Programme Evaluation

31 Macmillan Cancer Support have commissioned SQW to evaluate the Macmillan Local Authority Partnership (MLAP) programme across all four MLAP sites. The evaluation aims to assess the rationale and approach taken, the partnerships, Macmillan's strategic capability, and the scalability of the models being implemented. The evaluation will also share findings and learning with key stakeholders.

32 The interim reports in both October 2018 and May 2019 highlighted the success in Durham of creating an effective partnership with the NHS Foundation Trust, the success in using Coproduction as a mechanism to designing an effective service and in responding to the increasing needs of the people affected by cancer.

33 The final evaluation report is not due until March 2020. This poses some difficulties for Joining the Dots as the report will not be delivered in a timely manner to allow evidence based discussions around sustainability of the service.

Local Evaluation

34 Public Health has commissioned Teesside University to undertake the local evaluation for the Joining the Dots service, a more intensive evaluation focussing on 20 selected clients as well as individuals involved in the development and operational aspects of the service.

35 The primary aim of this evaluation is to study the person-centred outcomes of the Joining the Dots programme. The evaluation will explore with stakeholders and partner organisations their understanding of the process for the JTDs service, to assess the referral pathways to see how many clients are referred to partner organisations, to explore the barriers to referral from delivery staff and partner experiences, to gain feedback from beneficiaries of the service.

36 Ethical approval from the School of Social Sciences and Law Ethics Committee at Teesside University has been granted to undertake this study.

37 Data collection began in June 2019, a preliminary report will be provided in September 2019 with a final report due in December 2019.

Future Service Developments

Patient Activation Measure (PAMS)

38 PAMS is a patient-reported measure, providing a powerful and reliable measure of patient activation. This will allow the Joining the Dots service to prioritise people who need most support to access services to meet their identified needs. PAMS will allow the service to measure activation at a start point and at any point along the cancer journey to assess progress or challenges. This also includes the potential for joint working with the Trust with risk stratification.

Primary Care Recovery Pilot

39 For people living beyond cancer, recovery can be a very difficult time. People often feel in limbo once they have finished treatment, they are no longer engaged with services that manage their health and maybe unlikely to hear about Joining the Dots. During the patient and carer engagement work these were the people who were most likely to be living with unmet needs. Working with the Weardale Practice in Stanhope and the Macmillan GP Cancer Lead for DDES CCG, the Programme is piloting a scheme to assess the holistic needs of people affected by cancer who are living beyond treatment. The Practice is writing out to every patient that has had a diagnosis of cancer in the last 3-5 years offering the Joining the Dots service.

Pilot of Community Hubs

40 The Macmillan Joining the Dots Programme team acknowledges that for the service to be successful, it also needs to be efficient and see as many people as possible in the right place at the right time. As a result, the service is piloting “clinic” appointments in Shotley Bridge hospital

alongside the chemotherapy unit. This allows people with higher activation levels of health to attend appointments in a more central place and while they are in hospital for other appointments.

41 In the current pilot, which has been running for 7 weeks, five (5) clients have been motivated to attend weekly appointments, three of which were referred directly from the chemotherapy unit. The model being used at Shotley Bridge will be monitored closely and fully evaluated prior to determining whether to roll-out further.

Buddy System

42 Within the contract specification, the development of a Buddy System, which will see the recruitment of people affected by cancer as volunteers to support people engaged with the service once they no longer needed the more intensive support of a facilitator, was included. It has been important for the facilitators to embed into the service prior to this system being developed. The Programme team is now working with the service and other partners to plan the implementation of a buddying system.

Sustainability

43 The Programme is currently only funded until March 2020, through Macmillan Cancer Support and the Northern Cancer Alliance funding. Sustainability is a priority for the Programme. Initial discussions regarding this have taken place at the Programme Board and an options paper will be developed for the September board meeting.

Conclusion

44 As cancer is the highest cause of death in England of the under 75's. Cancer contributes significantly to the gap in life expectancy between County Durham and England. We are aware that 15,000 people living in County Durham are living with or beyond cancer, and that both diagnosis and treatment are improving. Therefore, with increased need for holistic support, Macmillan Cancer Support and Durham County Council developed a new 'social model' of care. Macmillan Joining the Dots began engaging with clients since September 2018.

45 In partnership with the Wellbeing for Life service, there has been significant development of the Joining the Dots service. The main areas of development have focussed upon developing the clinical referral pathways as this is the 'bread and butter' of the service. There has been an increase in referrals in the past two months and in the hope that this will be maintained and increased, the buddying programme and PAMS will help to help with any capacity issues.

46 Progress justifies the sustainability of the service past March 2020. Using the expertise of the coproduction team and working with current partners, identification of pathways for sustainability need to be investigated. At the Programme Board on the 4th June 2019, discussion began about how the Programme can be sustained for the future. This will culminate in an options paper being presented to the next Programme Board for decision about how we will action this.

Background papers

- None

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Appendix 1: Implications

Legal Implications

The Health & Social Care Act 2012 refers to Section 2B NHS Act 2006 which places a duty on each local authority to take such steps as it considers appropriate for improving the health of the people in its area.

Finance

Sustainability past March 2020

Consultation

No implications

Equality and Diversity / Public Sector Equality Duty

No implications

Human Rights

No implications

Crime and Disorder

No implications

Staffing

No implications

Accommodation

No implications

Risk

No implications

Procurement

No implications

Appendix 2: Case Study 1

Client came to Macmillan Joining the Dots as first point of support. The support I was able to offer included arranging transport and attending the 4 chemotherapy sessions with the client as they had no close family. I also arranged the transport for the 20 sessions at James Cook and supported by attending the follow up tests and scans. This client has become socially isolated and I have provided emotional support. I meet with the client most weeks to see how they are doing and to provide practical solutions to problems.

On referral to Macmillan Welfare Rights, the client applied for and received Attendance Allowance totalling £800. They also received a Macmillan Grant and support with clothing and fuel costs.

Having fainted at home, I contacted the GP and requested a home care assessment and contact from a Macmillan nurse. I also arranged for the client to receive a wheelchair. The client later told me that they had stopped going into the kitchen as they were scared to stand up, so the wheelchair means they can use their kitchen again and prepare basic meals.

The client's medication caused severe constipation and chronic pain. With permission from the client, I contacted the GP and requested an assessment. A change in medication led to the pain being alleviated.

This intervention was also useful for reducing the stereotype that Macmillan nurses only worked with end of life patients. Having convinced this client to work with a Macmillan nurse, this client now realises that this is not the case.

Appendix 3: Case Study 2

On referral from the Macmillan Information Centre in Bishop Auckland, I met Len with a diagnosis of prostate cancer since 2016, untreated due to conflicting heath issues. In December 2017 Len was told that the cancer had spread to his bones and he had about 6 months to live.

Len requested two items, a shower to replace his bath which he could not longer access and support with finance to get incontinence pants which he currently purchased himself.

I contacted Social Care Direct who refused an assessment of Len as he had previously been assessed by an Occupational Therapist from Livin Housing. Livin has refused making alterations and offered Len a bungalow, something he did not want.

The District Nurse assessed Ken for a continence grant which he was refused. Obviously, this was disappointing, but I applied to Wellbeing for Life for a Micro Grant to purchase some incontinence pants. This was approved, and I purchased 10 packs which I picked up from the pharmacy and delivered to Len.

After a couple of appointments, I noticed that Len was struggling with his health and maybe needed some clinical intervention from a nurse. At his previous clinical appointment, he had been told that a referral would be made to the Macmillan nurse. On investigation, it was found that this had not happened. I arranged for this to occur. Len now has an appointment booked in with a Macmillan nurse. As Len moves towards the end of his life, we are starting to look at any arrangements that need to be made with regard his will and finances as he has a partner of 37 years but is not married.