1. **MIDLOTHIAN**

Midlothian is a small local authority area adjoining Edinburgh’s southern boundary, framed by the Pentland Hills in the West and the Moorfoot Hills in the South. Most of Midlothian’s population resides in or around the main towns of Penicuik, Bonnyrigg, Loanhead, Dalkeith, Newtownrange and Gorebridge. Midlothian’s traditional industries were coal mining, papermaking, textile milling and farming of which only agriculture remains. Parts of Midlothian have seen increasing levels of economic deprivation with associated social and health issues, which worsened because of the economic downturn that began in 2009. It is well recognised that people who live in deprived areas are often more likely to have one or more long-term conditions including cancer. However, even though it is predicted that there will be an increased number of people diagnosed with cancer in the future, there is also an increasing number of people surviving and living with the effects of cancer and associated treatments.

2. **SUPPORTING PEOPLE WITH LONG TERM CONDITIONS**

The importance of supporting people with long-term conditions to live well is one of Midlothian Health & Social Care Partnership’s key priorities. This is in recognition of the growing numbers of people with such conditions; the heavy reliance they have on primary and acute health services; and the potential there is to bring about significant improvements in their quality of life. Strengthening self-management; developing peer support; and addressing issues related to inequalities such as income and employment are some of the measures we are seeking to take to assist people live well with their condition(s). The Partnership is committed to a holistic approach, based on the “House of Care” framework, for people with long term conditions generally including people recovering from or living with cancer.

3. **PEOPLE WITH CANCER IN MIDLOTHIAN**

There are approximately 500 new people (above the national average) diagnosed with cancer every year in Midlothian while there are some 2140 patients with cancer on the local GP registers (QAF March 2014). Given the wider impact of the illness on patients’ families a significant proportion of the Midlothian population are affected by cancer. It is clear that as part of the local strategic commissioning process much greater priority needs to be given to addressing their needs adopting a holistic approach. Evidence from Macmillan Rich Picture Series; views of local senior health and social care managers and frontline staff and feedback from people recovering from cancer after treatment emphasised the importance of local support, following discharge from the Cancer Centre. Support and advice on issues such as exercise, income, employment and anxiety were highlighted as was the value of peer support.

4. **MIDLOTHIAN’S INTEREST IN THE TCAT PROGRAMME**

In making application to become a TCAT test site, we were aware from the outset that the size of Midlothian would prohibit a stand-alone support service for people with cancer. Nevertheless, we viewed our involvement as an excellent opportunity to improve our understanding of the needs of people with cancer and to explore ways in which we might build our local capacity within mainstream services. In the longer term our objective was to sustain this capacity, whether in primary care, libraries or leisure
Midlothian Health and Social Care Partnership

centres, whilst developing a generic approach to proactively providing person-centred support to people with any long term health condition including cancer.

5. **OUTLINE OF SERVICE**

In June 2016, we launched the Midlothian’s **Living Well after Treatment** Project to ensure everyone affected by cancer in Midlothian had the opportunity to access practical, emotional and financial support. The initial objectives were to

- Develop a comprehensive understanding of the needs of local people living in Midlothian with a cancer diagnosis.
- Establish a person-centred pathway/support service where people can highlight their concerns and discuss what matters most to them.
- Provide easy access to advice and information on physical activity, healthy eating, income maximisation and employment.
- Create information hubs within libraries for people to access in hard to reach areas of Midlothian.
- Create a local advisory/peer support group.

6. **SPECIFIC SERVICES**

6.1 **Holistic Needs Assessment:** The project worker encouraged people who were referred to the service to consider what their main concerns were through the completion of a Holistic Needs Assessment (HNA). This then formed the basis of a more in depth discussion about the issues that “mattered to them”.

6.2 **Information:** Macmillan provide a wealth of information on a wide range of issues relevant to people who have had cancer and associated treatments. There are good information directories about services available in Midlothian, which were likely to be of interest to people with a long-term condition such as cancer. We worked with the Council Library Service to make all of this information more accessible to people with cancer.

6.3 **Exercise and Diet:** Six members of the Council Leisure Service members undertook exercise training in cancer rehabilitation to provide safe and effective programs to people during and after cancer. Funding was provided to have some dedicated time of the Council’s physical activity coordinator to support TCAT throughout the project, conduct HNAs with people in Midlothian and train other instructors to offer people HNAs.

6.4 **Specialist Occupational Therapy:** Alongside a Project Worker, a part-time Occupational Therapist provided home-based appointments for people unable to travel. Services included assessment for adaptations in homes to help people live well and independently.

6.5 **Income Maximisation:** Although the specialist Income Maximisation Officer post was not part of the TCAT Project the service was partially funded by Macmillan with a clear expectation that the two services would work very closely together in supporting people with cancer.
6.6 Employment: Close links were established with the specialist employment service based in the Edinburgh Cancer Centre. This included the offer of outreach support to people in Midlothian who were experiencing challenges in either retaining their current employment or moving to a more suitable job following their treatment for cancer.

6.7 Complementary Therapies: One of the most common concerns expressed through the HNAs was that of ongoing pain. We negotiated with the IRIS Cancer Partnership for the local provision of massage therapy.

7. WIDER IMPACT ON MAINSTREAM SERVICES

The higher profile that the TCAT Project gave to people living with cancer, directly influenced the local GPs to apply successfully to undertake the Quality Toolkit for Cancer in Primary Care. Similarly, the Wellbeing Service, introduced to eight GP Practices to support people with long-term health conditions and complex social problems, was made available to people with cancer. Macmillan is providing training for the Wellbeing practitioners to enhance their work with people with cancer.

8. INVOLVEMENT OF SERVICE USERS

The Midlothian project recruited one of the largest TCAT user involvement groups in Scotland. This group has been involved in:

- Planning and implementation of the official service launch.
- Sharing views and experiences to identify gaps and shape new cancer support services in Midlothian.
- Highlighting where it is easiest for people to access resources and attend appointments.
- Presenting at a national conference designed to promote the evolution of user involvement into influencing processes locally and nationally.
- Creating marketing materials and disseminating these across the region to promote the service to people affected by cancer.
- Leading discussion on a number of topics pertinent to people who have undergone treatment: primary care / access to GP, physical activity, employment support, health and wellbeing.

9. WHO USED THE SERVICE

The original intention as captured in the project title was to support people after treatment helping them to live well. However we gradually relaxed this in response to feedback from service users who felt that planning for the changes in their circumstances should be possible at an earlier stage.

The most common age group for people referred to the service was 50-59 yrs - people of working age and who may still have child care responsibilities. One in four people lived alone which reflects the position in the general population.
10. **SERVICE USER CONCERNS**

During the period of the pilot project 94 people were referred for individual support including a Holistic Needs Assessment. The feedback about the HNA process was positive enabling people to think in a structured way about the issues which were of concern to them. Most people referred were concerned about a range of issues, the average number being 10. The most common concerns were

- **Tired/exhausted or fatigued.**
- **Worry, fear or anxiety.**
- **Sleeping problems/nightmares.**
- **Exercise / activity.**
- **Memory / concentration.**
- **Sadness or depression.**

Pain also featured quite often and in response to this, we were able to arrange the provision of complementary therapies.

11. **SERVICES PROVIDED**

The service operated between July 2016 and November 2017. During this time

- 94 people received one to one support
- 100 people received complementary therapies
- 6 Leisure staff completed training in safe exercise for people with cancer
£1.5m of benefits were generated by the specialist Welfare Rights Officer
18 people received specialist Occupational Therapy services

12. IMPACT

The feedback from service users was very positive with people reporting their needs were either fully or partially met as a result of the TCAT Service.

What difference has the Midlothian Living Well after Treatment Project made?

This was reflected in their mental wellbeing scores which showed significant improvement. The mean difference of 10.7 between first and last appointments brought users’ scores in line with the Scottish population mean.

Alongside these measurable improvements, the service received many direct compliments.

Examples of comments by service users included:

_The biggest success of this project has been its ability to make us, as patients feel important and listened to. The psychological effects have been immense with all of us feeling better about ourselves and our relatives have also noticed the difference._

_“The vast array of help which has been suggested to me including massage therapies and wellbeing support. This has led on to very positive activities which are helping me move on from the problems left by my cancer treatment.”_

_“Being able to speak to someone who was reassuring, a good listener, and gave me the information and confidence to move on in the right direction.”_

13. **EVALUATION**

The evidence above confirms the benefits to people having access to support to manage a range of new challenges which arose as a result of cancer or the impact of treatment(s). The support systems varied. While not directly part of the TCAT Project the value of a dedicated income maximisation service cannot be overstated. The provision of a complementary therapy service has proved extremely popular over a short space of time. For some people the greatest source of support was from others experiencing the same journey. Membership of the Advisory Group was highly valued by those who became involved.

In relation to the original objectives of the project

- **Develop a comprehensive understanding of the needs of local people living in Midlothian with a cancer diagnosis**: The needs expressed were consistent with the national findings of Macmillan’s own research. The specific finding was the value placed on having a locally accessible support service. However achievement of the objective was limited by the relatively low take up of the service

- **Establish a person-centred pathway/ support service where people can highlight their concerns and discuss what matters most to them**: This was achieved through the project and has been maintained by transfer to the Wellbeing Service – soon to be available in all GP Practices

- **Provide easy access to advice and information on physical activity, healthy eating, income maximisation and employment**: Advice continues to be available through Midlothian Active Choices and the Welfare Rights Service. The employment project is based in the Cancer Centre and therefore has a low local profile.

- **Create information hubs within libraries for people to access in hard to reach areas of Midlothian**: The library service continues to be very willing and able to act as information hubs but is dependent upon on a coordinated approach to maintaining up to date information. This has not been possible since the end of the TCAT project

- **Create a local advisory / peer support group**: A local group was successfully established; the loss of the project officer post and TCAT Project Group will inevitably have affected its activity levels.
The biggest challenge that we faced throughout the project was encouraging people to use the service. Publicity, partnership working with GPs and the regular presence of the Project Worker in the Edinburgh Cancer Centre had a limited impact on take up of the one to one service. Perhaps with more time word of mouth would have helped along with more regular referrals as a result of the application by GPs of the Macmillan Quality Framework.

Looking ahead we are exploring options to continue to reach out to people with cancer to offer them support to live well following treatment wherever possible:

1. The Midlothian Partnership remains committed to improving support to people with long term health conditions. The Wellbeing Service, which has been piloted in GP Practices over the past two years will now be more formally commissioned and provided in all 12 Practices. The service offers flexible support to people with complex health and social issues in their lives. The current team have received training from Macmillan on working with people with cancer and this will be made explicit in the commissioning requirements for the new service.

2. The four Health and Care Partnerships in Lothians have agreed to adopt the Improving the Cancer Journey approach successfully implemented elsewhere in Scotland. Midlothian is leading this work on behalf of the four Partnerships. One of the most interesting components of this approach is the automatic notification to service users upon diagnosis that a support service is available. This system would hopefully enable us to increase uptake in Midlothian.

3. The importance of improving self-management, using technology where appropriate, is a growing dimension to our delivery of health and social care services in Midlothian. We have recognised the particular value of Peer Support and funds have been made available to expand the provision of such support. For some people this may best be provided in a way which is condition specific; the Advisory Group was a good example of this working effectively. However, we also received feedback from some people who attended Living Well Groups, that they wished to address their concerns but had no desire to spend a lot of time specifically with other people with cancer.

None of these are mutually exclusively and we will explore how best to build on existing services through the design of our local approach to Improving the Cancer Journey. These services include the GPs continuing commitment to the application of the Quality Cancer Framework; the continuing work of the specialist Welfare Rights Officer; the continuing specialist advice on safe exercise available in Council Leisure Centres and the holistic support available in GP Practices through the Wellbeing Service.

Tom Welsh
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12th April 2018