Living with a mental health condition and cancer

Macmillan Mental Health Cancer Care Research Lead, Sarah Jane Ashcroft, explores the experiences of people living with a mental health condition and affected by cancer.

People with a serious, long-term mental illness face startling health inequalities. On average, they die 15 to 20 years earlier than the general population and two-thirds of these deaths are due to preventable physical illnesses\(^1\). They also have lower cancer survival rates\(^2\) and are less likely to be still alive four to five years after diagnosis.

Against this background, Macmillan carried out a two-year action research project in partnership with Middlesbrough and Stockton Mind. Our aim was to explore the experiences of people who have both a mental health condition and cancer in Teesside.

Project outline

Our project was made up of three distinct phases:

- desktop research
- information gathering
- developing recommendations.

Patients, carers and professionals in cancer and mental health services shared their stories in semi-structured interviews, focus groups and workshops.

Challenges across the cancer pathway

We analysed the information collected and found examples of good practice, where mental health and cancer staff worked collaboratively. At the same time, we identified the following challenges across the cancer pathway:

- **Cancer prevention:** People with a serious mental illness are less likely to receive routine cancer screening. 91.8% of mental health staff told us that they did not routinely question these patients about cancer screening during their annual physical health check. This group may also be at higher risk of developing cancer due to poor lifestyle choices, such as smoking, insufficient exercise and a diet lacking fruit and vegetables.

- **Accessing primary care:** The evidence suggests that people living with a serious mental health condition may be less likely to access primary care. There are problems of ‘diagnostic overshadowing’, where a patient’s mental illness may overshadow their physical symptoms and result in a late cancer diagnosis.

- **Accessing secondary care:** People with a mental health condition may experience stigma and isolate themselves from health services. As a result, their cancer may not be diagnosed until a late stage when it is more likely to have spread. They may have difficulties in understanding a cancer diagnosis or committing to treatment, but with the right support can access secondary care to achieve good outcomes.

- **Living with and beyond cancer:** Some patients shared the detrimental impact that living with the consequences of cancer treatment had on their mental health. Others described how their cancer diagnosis had a life-changing effect, prompting recovery in their mental health and enabling them to connect better with others.
• **Palliative care and end of life:** There were examples of people with mental health problems and terminal cancer being supported to die in a place of their choosing. However, some people are still dying in places that are not their preferred choice.

• **Impact on carers:** When a person with a mental illness is diagnosed with cancer, the impact on their carers can be significant. All the carers who shared their stories said that they felt unacknowledged and unsupported.

**Next steps**
We have drawn up the following recommendations and action plan:

• **Information sharing:** People must be supported to share information about their mental health needs, take up cancer screening and increase their knowledge of cancer and the risks. We propose designing a hospital passport-type document for use in the cancer pathway. Another proposal is to include cancer screening questions during patients’ annual physical health check within mental health services.

• **Professional knowledge:** The gap between mental and physical health services must be reduced, with improved communication and signposting between services. We plan to deliver a cancer awareness module for mental health staff and a basic mental health training programme for cancer staff. We will also explore the potential for a specialist mental health post in cancer services.

• **Patient information:** People must be given accessible information about managing their mental health condition when affected by cancer. We will produce content for a new booklet on this important topic and a new online cancer awareness course available through the local mental health trust.

• **Lack of support for carers:** We propose including information about local carer support organisations in the hospital passport-type document. We also recommend further research into the need for specialist peer support groups.

We hope that our recommendations will help to improve the experiences of people living with a mental health condition and affected by cancer and address their carers’ support needs. Our two-year project shows that developing integrated approaches to mental and physical healthcare must continue to be a priority.

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Developing a specialist psychology survivorship group

Dr Rachael Edge, Senior Clinical Psychologist, outlines a Macmillan specialist psychology survivorship project.

The Cancer and Palliative Care Psychology service at Gloucestershire Hospitals NHS Foundation Trust recently developed a specialist psychology cancer survivorship group. Macmillan funded this project.

The team had seen an increase in referrals for those who were struggling psychologically after completing their cancer treatment. They hoped that offering a psychology group for these people would reduce growing service waiting times and create a sense of normalisation and camaraderie.

The clinical psychologist running the project was supported by:

• an assistant psychologist working one day a week
• administration staff
• the service manager
• a placement student working with the service.

Developing the group
A steering group, consisting of Macmillan and hospital colleagues and a user representative, was formed to develop the specialist psychology cancer survivorship group.

The psychology group was based on an acceptance and commitment therapy (ACT) model (see diagram on opposite page). ACT is a form of cognitive behavioural therapy, which helps people to find new ways of responding to difficult thoughts, feelings and sensations. It also helps people connect with, and take steps towards, the things that really matter to them in life. This is often termed ‘psychological flexibility’.

ACT has benefits for people with cancer at various stages of their treatment. Improved mood, psychological flexibility and quality of life have been reported. ACT groups for those living with and beyond cancer have resulted in positive outcomes and feedback.

Delivering the sessions
The group programme was delivered twice during the year-long project. Each group programme consisted of four sessions, with every session lasting two and a half hours. This included group discussions, psychoeducation, and experiential and written exercises.

Attendees spent time understanding how their minds responded to difficult situations, and how this affected what they did or did not do. They practised ways of observing and accepting their thoughts and feelings, and explored how they could stay connected to their personal values.

Outcomes and feedback
About one-third of people who were eligible for the survivorship psychology group attended.

Around 40% of those invited to participate did not wish to join a group. A small number booked a place, but changed their mind at the last minute. The group size was therefore smaller than anticipated (6 to 7 people).
Some attrition is expected in group interventions. In future the service will aim to book 12 people for each group, with the expectation that around 10 will attend.

Attendees completed an outcome measures questionnaire and provided valuable feedback. Outcome measures showed improvements in mood, wellbeing, functioning, acceptance, confidence, understanding and level of distress.

Feedback confirmed the value of the group and the ACT model. One attendee said, ‘I would really like to thank you for offering me this programme. I’m not saying it helped me to forget about my experience with cancer and my fears and worries, but it has certainly helped me to manage the fear better.’

Another person said, ‘The tools we were given were invaluable with helping to move forward and validate/acknowledge the difficult path that survivorship can be.’

Waiting times for all patients referred to the service were lower during the group project, even though referral numbers were higher over this period. However, this may have been due to the additional psychology time created by the project. An extra two clinics were held each week: a group clinic and an individual clinic, which was mainly used to assess and prepare people for the group.

Looking to the future
The service now has all the materials it needs to offer more groups in future, including delivery protocols, handouts, presentation slides and evaluation packs. They can be adapted for pathways other than survivorship, and the service is keen to consider how a group may help people with a secondary cancer.

Limited staffing within the service will be a major challenge in running future groups. However, calculations suggest that if at least 10 people attend a group, this is a more effective use of time than holding individual sessions for those people. The service hopes to offer the group again in the new year and to continue evaluating the impact.

Acceptance and Commitment Therapy (ACT) model

Open up
- Make room for thoughts and feelings - allow them to come and go
- Step back and notice, rather than being ‘in it’

Do what matters
- Work out what’s important and meaningful (Values)
- Use values as a guide to meaningful action

Be present
- Come back to here and now when our mind pulls us away
- Strengthen our resilient sense of self

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Psychological therapy in cancer and palliative care

Macmillan Consultant Clinical Psychologist, Dr Rachael Brastock, discusses the challenges facing her psychological support service in Dorset.

Psychological therapy in cancer and palliative care services might take place in a quiet, dedicated therapy room. More often, however, it is delivered by a bed on a noisy ward or in between visits from friends, family and the dog in a person’s home! The most important thing is that this support is available at the right time to those who need it.

Challenges in the service
I work in Dorset, which is a county with:

• a higher than average percentage of people aged 65 and over
• a high rate of cancer incidence
• very little specialist psychologist support available for people with cancer or a palliative diagnosis.

When I started mapping services in Dorset in 2015, there was only myself and one other clinical psychologist in the county providing this specialist input. Neither of us was on a permanent contract, and we both worked part-time for a total of just 30 hours per week between us. This is disappointing when you consider that, to provide an equitable and accessible service across Dorset, we would need an absolute minimum of five full-time psychologists.

The need for psychological support
There has long been an expectation that every cancer service will have access to clinical psychology expertise. Neglecting psychological problems exacerbates illness and increases health costs. When psychological support is included in cancer care pathways, this can achieve savings for services of up to 20%. Not everyone with cancer or a terminal illness needs to see a psychologist, but 10% of people experience significant psychological distress.

Although the healthcare professionals that I work with recognise the need for psychological support, there is only limited money available. When measured against other resources, a clinical or counselling psychologist is often not seen as a core element or necessity. After all, it is far easier to quantify the impact of a nurse, doctor or hospital bed than a reduction in psychological pain during the weeks before death.

Yet, when we attend to both a person’s medical and psychological needs, we can achieve far more. A patient recently described it to me like this: ‘Sand without water makes a perfectly fine beach, but when put together you can build castles.’

Constraints on our service
In my current post, I have been privileged to work with a wide range of people who have cancer or a palliative diagnosis. I also provide support for family members, who are experiencing significant psychological difficulties. However, the number of individuals that I have been able to help has been limited. There is simply not the workforce capacity in Dorset to meet the needs of all those who would benefit from this high level of specialist intervention.
Time for teaching, clinical supervision and consultation is equally necessary. These activities are fundamental in a psychologist’s role and bring considerable advantages for the wider workforce. Personal benefits can be seen in feedback from training. One colleague said, ‘I feel much more confident to ask patients questions about how they are psychologically.’ There are further benefits at an organisational level as clinical supervision can contribute to breaking cycles of stress and burnout in medical professionals.

Despite all the benefits, research evidence, national recommendations and guidance, together with the local data and feedback, we have yet to see change in Dorset. I have not yet been able to secure funding to continue this post beyond March 2020. My one other psychologist colleague has now retired, and it is not yet certain that she will be replaced.

**Hope for the future**

I have been supported in my work by a wonderful steering group comprised of representatives from Macmillan, the Dorset NHS Foundation Trusts, local hospices and the Dorset Clinical Commissioning Group. We are now finalising a business case, which sets out the need for more specialist psychologist posts in the county. I remain hopeful and determined because I know that psychological support is vital.

Including psychological care in cancer care pathways can achieve:

**Savings of up to 20%**

Further information

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Award-winning clinical psychology cancer service

Macmillan Clinical Psychologist Dr Sanchia Biswas on integrating psychological care into cancer services in Nottinghamshire.

The Clinical Psychology Cancer Service at King’s Mill Hospital in Nottinghamshire provides psychological care for people with all cancer types.

Sustaining integration has been at the forefront of our service since it was set up in 2014. We wanted to build strong working relationships with multidisciplinary cancer teams, and local commissioners, to embed psychological provision successfully. In 2018, we were delighted to win a Macmillan Integration Excellence Award in recognition of this work.

Our service is based on the NICE guidance for Improving Supportive and Palliative Care for Adults with Cancer (2004). This emphasises the importance of healthcare staff routinely screening patients for symptoms of psychological distress.

NICE recommends a four-level model of professional psychological assessment and intervention. Professional psychological support at Levels 1 and 2 should, in the first instance, be provided by health and social care professionals directly responsible for the care of people with cancer. At levels 3 and 4, more severe psychological distress should be managed by a variety of psychological specialists, including counsellors and clinical and health psychologists.

Below, I have outlined how our service meets these four levels of care within oncology.

At level 1, we provide self-help resources, information for patients and stories from people with cancer through the Clinical Psychology Cancer Service website (www.sfh-tr.nhs.uk/index.php/clinical-psychology-cancer-service). This covers everything from coping with anxiety to body image and has had more than 10,000 hits since it was set up in 2015. We also run a patient-led self-help and wellbeing group, and deliver staff training for primary care health professionals in communication skills.

At level 2, we provide a psychological knowledge and skills training package for cancer multidisciplinary team (MDT) staff from diverse professions across the East Midlands. We have also integrated this training into other areas of physical health, such as gastroenterology, and delivered train the trainer sessions to other psychologists in the region. Evaluation of our level 2 training has shown significant improvements in staff confidence to assess and manage mild symptoms of psychological distress.

At level 3, we have worked hard to address the challenges of sustaining a seamless pathway for psychological wellbeing with external providers. We have now successfully integrated our service with local IAPT (Improving Access to Psychological Therapies) services in the community – so we are able to directly refer people with mild to moderate psychological distress.

At level 4, our clinical psychologists work with people who have more complex cancer-related psychological needs, through an established psychological pathway within MDTs. We provide direct psychological therapies for people living with cancer and their families and carers.
Studies show that providing psychological therapies can reduce workloads and save health and social care services money by:

- preventing mild psychological problems escalating into more severe ones
- improving self-management and reducing the demand for GP appointments and hospital admissions
- improving adherence to medical advice, therefore improving health outcomes.

**Going with the Flo**

As well as training staff to identify patients who would benefit from individual and group therapy, the team has developed innovative psychological support initiatives. This includes a text support relapse prevention package called 'Flo', which helps patients monitor and self-manage emotional difficulties outside of service hours.

Flo is a simple telehealth system that uses text messages to help people manage their own health and wellbeing. We applied it to a mindfulness-based cognitive therapy group for cancer patients to check in with them between sessions and send tailored messages of support and encouragement. Patient feedback highlighted that Flo served as a useful reminder to do mindfulness exercises and helped them to feel a personal connection. We also found that people using Flo were eight times more likely to complete the mindfulness group programme and reported greater improvement in symptoms of depression. It has the potential to be a very cost-effective intervention.

**Next steps**

We continue to expand our influence and reach where we can. Examples include our contribution to new guidelines around prophylactic mastectomy, and new plans to test video therapy for people who live far away or who are too fatigued or unwell to travel to the hospital.

The ethos of our service is perhaps best represented in a powerful and moving video created by Consultant Clinical Psychologist Dr Jo Tedstone, formerly the Lead for Physical Health and Clinical Lead for the Back Pain Unit. She was diagnosed with terminal bowel cancer in March 2018 and kindly agreed to share how her background in physical health psychology had impacted her experience with cancer. You can watch the video at [bit.ly/3050fgJ](bit.ly/3050fgJ).

Jo sadly passed away on 28 June 2019. She was extremely passionate about sharing her experiences and psychological knowledge with the hope that it would help others affected by cancer.
Creating a psychological therapy service for people with cancer

Psychotherapist Jack Southward on a new partnership enabling people with cancer to access psychological support in a familiar setting.

Tameside and Glossop Healthy Minds is an Improving Access to Psychological Therapies (IAPT) service offering assessment and psychological treatment for people experiencing mild to moderate mental health difficulties. In early 2018, we set up a partnership with the Tameside and Glossop Macmillan Unit at Tameside Hospital to provide psychological support to people with cancer and their family members through a specialist pathway.

Psychological distress can be a significant and ongoing difficulty for people with cancer. More than half (54%) of cancer survivors still experience at least one psychological issue 10 years after treatment. There is clearly a need for timely psychological intervention, and the majority of referrals to the specialist pathway are offered an assessment within two weeks. Most people are offered treatment the following week, if appropriate.

Historically, ‘counselling’ has been used as an umbrella term for all types of talking therapies. However, the majority of treatment accessed has been evidence-based low intensity cognitive behavioural therapy, with a focus on coping strategies to address negative thinking, behavioural changes and avoidance. This has shown to be particularly useful in addressing cancer-related anxiety and depression. From the start of the partnership, the focus was to prevent mild psychological problems from worsening and developing into more severe and enduring mental health difficulties, which would then most likely be addressed in community mental health services.

Through the partnership, we have been able to tailor psychological support in a setting familiar to the person with cancer. As the sessions are held at the Macmillan unit, sessions can fit around, and often alongside, cancer treatment and check-up appointments, as well as complementary therapies. This has led to comparatively low cancellation and non-attendance rates, further improving clinical outcomes.

My colleagues Sinead Gavin and Sophie Whittaker, both Psychological Wellbeing Practitioners, have continued and further improved the service. We now offer two clinics per week in addition to a drop-in session. An increased presence on the unit has also improved communication between Healthy Minds and Macmillan professionals.

Timely and appropriate psychological and emotional support has been shown to have an overwhelmingly positive impact on people who have accessed the service. We have been able to create a small but well-defined clinical pathway, providing NICE-approved psychological treatment without any additional funding. We are incredibly proud of this achievement.

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Resources

National Institute for Health and Care Excellence (2004). *Improving supportive and palliative care for adults with cancer.* This guideline covers best practice in developing and delivering cancer services for adults, including recommendations on psychological support services. Available at: [www.nice.org.uk/guidance/csg4](http://www.nice.org.uk/guidance/csg4) (accessed July 2019)

*How are you feeling? The emotional effects of cancer.* This Macmillan booklet for people affected by cancer includes information about the main emotions that many people with cancer have, and tips for coping with these feelings. Available at: [be.macmillan.org.uk/be/p-24918-how-are-you-feeling-the-emotional-effects-of-cancer.aspx](http://be.macmillan.org.uk/be/p-24918-how-are-you-feeling-the-emotional-effects-of-cancer.aspx)

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11. See ref. 8.
13. See ref. 9.
15. See ref. 9.
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