



Mental Health
Foundation
Scotland

Supporting the emotional and mental health needs of people with cancer

How poor mental health, anxiety and depression can be prevented during and after cancer treatment by good support provision.

Recommendations

1. There needs to be a greater awareness by all service providers of the mental health impacts of cancer and the need to support emotional wellbeing and mental health needs
2. The right support needs to be given at the right time
3. Tailored, person-centred support needs to be offered at all stages of the cancer journey
4. There must be more collaboration and communication between service providers
5. Improve signposting for mental wellbeing services
6. Provide clearer and more co-ordinated support pathways after treatment
7. Improve the provision of support across Scotland
8. More research is needed into how best to tackle social deprivation and co-morbid health inequalities
9. More research and awareness is needed to design cancer and wellbeing support services that engage BME communities
10. Ensure all people with cancer have access to some level of tumour specific support

Contents



Executive Summary	3
Introduction	5
Methods	6
Findings: Understanding the mental health impact of cancer	8
Findings: Supporting mental health during cancer	15
Findings: Barriers to accessing support	23
Policy Recommendations	29
Conclusion	31
Bibliography	32

Executive Summary



A cancer diagnosis is a life changing and challenging experience for anyone. Whilst great progress has been made in researching cancer causes and treatments, there has been little research conducted into mental health during cancer and how best to support mental health and wellbeing.

Through interviews with people with lived experience of using cancer services and cancer support providers working in Scotland, a qualitative research study was undertaken by the Mental Health Foundation to better understand emotional and mental health during cancer. This investigation focused on the negative mental health impacts of cancer, how effective support can be delivered, the barriers to support and the unmet mental health support needs.

Throughout the cancer journey there needs to be an appreciation of the different mental health needs at each stage. Cancer brings many challenges for wellbeing with fear, isolation, loss of self-esteem and of independence all having an impact. How service providers engage with service users, before during and after treatment also has an impact, with good communication and signposting to support services an important part in promoting wellbeing. Effective support needs to be built around tailored, person-centred initiatives based on need to ensure the right support is available at the right time.

The research we conducted highlighted that the post-treatment phase is an especially volatile time for mental wellbeing, with full psychosocial impacts of cancer and treatment likely to be felt most acutely at this stage. But it is also the time when the well-managed clinical pathway of support is withdrawn. This can lead to people being unable to access support services due to lack of signposting or co-ordination between clinical and non-clinical support providers. Whilst there are many excellent support initiatives in Scotland, with work being done to improve support routes and encourage multi-agency approaches, there is still much to be done to ensure that everyone can access the support they need.

Such barriers to emotional and mental health support can often stem from the lack of collaboration between service providers, creating this absence of signposting and integrated support pathways throughout the whole cancer journey. There are also serious inequalities in service access across Scotland, with rural and deprived areas facing an unmet need in terms of service provision. Certain groups, especially men and minority groups again represent an unmet need and service provision needs to be better suited to their needs.

In order to address the unmet need in terms of service provision for mental health during cancer and to strengthen existing programmes, we make the following recommendations:



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Introduction



Receiving a cancer diagnosis is never easy. It can be a confusing and frightening period, full of uncertainty and pressure with the physical realities of both cancer and cancer treatment causing major disruptions to daily life. As with all physical health conditions, there is a psychological aspect to cancer – adjusting to the new reality of living with cancer and facing the challenges it brings can have a major impact on mental wellbeing (Naylor et al., 2016.).

However the effect that cancer has on emotional and mental health receives less attention than the effects on physical wellbeing. This is despite existing evidence on the emotional stress of living with cancer and its treatment being a major source of distress. Almost half of people with cancer identify that the emotional effects of cancer are more difficult to cope with than the physical effects (Adler, 2008)

From an initial Mental Health Foundation literature review that examined the mental health impacts of cancer, it was suggested that depression and anxiety were the two most prevalent mental

health disorders arising from cancer. Moreover the literature review identified that the mental health of people living with cancer was a significant unmet need and that there was a lack of evidence about the most effective- and available – forms of treatment and support.

This report builds upon this review to explore and better understand the emotional and mental health needs of people living with cancer in Scotland. To do this, we have looked at the whole cancer journey, from diagnosis to post-treatment support and sought to identify:

- The major negative impacts of cancer on mental health during the cancer journey
- What mental and emotional wellbeing support is currently available in Scotland
- Where there are barriers to good mental wellbeing during the cancer journey and why this is.
- Opportunities for prevention of mental health problem

Methods



The research conducted in this study comprised of interviews with people with lived experience of cancer (hereafter called service users) and with clinical and non-clinical staff who provide some form of emotional and mental health support (hereafter called support providers). We used semi-structured interviews with service providers and focus groups with service users. There were twelve interviews in total with service providers and a separate focus groups with service users. All interviewees were identified through a snowballing sampling method.

In interviews with service providers, information about the project was given and verbal consent was obtained before interview. All service providers stated that they were happy to be interviewed and for their input of information to be used in the study, so long as this was anonymous.

The service users involved in the focus groups were all given consent forms and information sheets prior to the group starting. All stated that they were happy for the meeting to be recorded by audio recorder and for their experiences, knowledge and direct quotes to be used in the research, once these had been made anonymous.

We offered service providers the option of face to face or telephone interviews which lasted up to 75 minutes. Service providers were asked to identify the major challenges to mental and emotional health during cancer, how they viewed current mental health support in cancer treatment, whether it was adequate and where they identified key areas of unmet need. Service providers were also asked to identify one or two key policy recommendations that they would make to improve mental health support along the cancer journey. Detailed notes were taken during the interviews that were then coded thematically for analysis.

During focus groups, service users were asked about topics such as their support experiences, the impact of cancer on their mental and emotional wellbeing, and what they identified as the gaps in support service provision being. In some cases, this led service users to discuss personal or sensitive information but all were aware that they were able to withdraw at any time if they felt uncomfortable. The audio files from these sessions were transcribed and coded thematically for analysis.

The two sets of data from service providers and service users were analysed separately and then combined to identify emerging trends and issues.



Marianne's Story

Marianne was diagnosed with cancer in her late forties. Her initial reaction was one of shock, grief and disbelief that this was happening - that she was ill. She had had no identifiable symptoms and her diagnosis was made via a standard screening programme. From the first moment she was called back to the doctor after her screening, her mind was whirling with emotions.

What if it is cancer? What happens next? What will I tell the kids? What will going through treatment do to me? How will we manage if I have to give up work? Is my relationship with my husband strong enough to survive this? Am I going to die?

Once her diagnosis was confirmed Marianne went straight into an unfamiliar clinical world of treatment. Surgical consultations, hospital stays, chemotherapy appointments and check-ups took over her life. She had to give up work and cancel the holiday with her family in the summer. There was too much going on with clinical appointments and she felt too unwell from the side effects of the treatment. Then, after surgery and months of chemotherapy, the clinical phase was done. She was discharged and told to come back in a month for a check-up.

The first few weeks at home were again a blur for Marianne. She had got through the treatment, she had survived and the doctors were optimistic about her future. Her family were quickly returning to how they always had been and her friends kept inviting her out. It felt as though the whole world had returned to normal, but for Marianne, everything had changed. She felt low, anxious about the future and unable to be the happy, carefree person she had been before her diagnosis. All throughout the diagnosis and treatment she had pushed on and hadn't thought much beyond just getting through it. But now that treatment had finished, she felt she had fallen off a cliff edge and didn't know why she felt so bad. There had been no mention of potentially experiencing mental wellbeing issues post treatment and she did not know where to turn for help, especially now that she was no longer in the clinical world of treatment.

Findings: Understanding the mental health impact of cancer



What are the negative effects of cancer on mental health?

The cancer journey is the pathway that encompasses a person's cancer experiences from diagnosis through survivorship, or death (Jacobs et al. 2015). No two journeys are exactly the same because no two individuals are the same. Therefore a person-centred approach to analysis and research is required. The premise of this research is to unpack what impacts mental health during the cancer journey, how good mental health support can be given, opportunities for prevention, and what the barriers or unmet needs are to providing support.

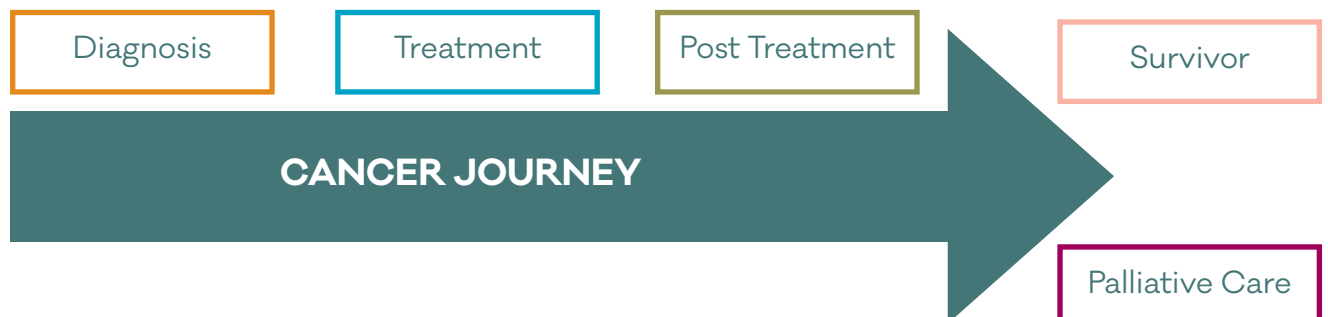
There are different impacts on emotional and mental health at different stages of the cancer journey. Rather than being looked at homogenously, emotional and mental health need to be seen as a dynamic process of change, struggle and adjustment, which should be met with an integrated, person-led support, because of the variety of pressures and challenges that cancer causes at different times and for different people.

If the emotional and mental health impacts of cancer are to be better understood, recognising that different people will experience and need different things at different times, is vital. As such, a multi-agency approach to help people with cancer identify their needs and receive corresponding support is required.

Responses to Diagnosis

When first confronted with a cancer diagnosis, the emotions that people experience can be intense. Fear, anger, grief, guilt can all collide making the initial processing of a diagnosis difficult. *"My diagnosis, I would have probably put pretty much like a grief thing. Probably anger initially and disbelief and probably a lot of negativity – not sure about what was ahead."* SUO3, 2018.

Service providers identified that emotional distress was likely to be most severe if there had been a lot of clinical investigation and uncertainty over a prolonged period of time prior to a diagnosis (SPO6, 2018). This correlates





with previous findings in the literature that distress is magnified if diagnosis has been significantly delayed as people may find it harder to accept their diagnosis (Ball et al. 2011). High rates of anxiety in the early stages of the cancer journey can be seen as especially problematic, as diagnosis and the beginning of treatment is the time when people must synthesise a lot of new information (Bawn, 2017). Anxiety can compound the ability to do this effectively and can therefore impact on people's understanding of their disease and treatment options. Ensuring that people get the right information at the right time is important but doing so in a person-centred way is also important. Service users spoke of the need to not be inundated with information about their cancer and available treatment and support in the early stages.

"I was one of these people, I didn't want too much information initially because the information would have scared me" (SUO2, 2018).

This highlights the importance of clinical staff recognising the presence of anxiety and providing information effectively and in a patient-led way where possible way and responding to needs of each individual.

Fear

Whilst great progress has been made in cancer treatment in the last 40 years, 50% of people still do not survive their disease (CRUK, 2018). Data gathered in interviews found that cancer is one of the most feared diagnoses. Many of the challenging symptoms and treatments

are understood, meaning people know what to expect and deeply fear it. Indeed, such is the fear surrounding a cancer diagnosis that one support provider identified situations where people felt relief about receiving a non-cancer terminal diagnosis, despite it being terminal, because it was not cancer (SPO7, 2018). This fear is often a major part of the anxiety experienced by cancer patients and is related to fear surrounding mortality and the impact and experience of cancer treatment.

Support providers identified that the main reasons for seeing people with high levels of anxiety was either imminent mortality or a fear of recurrence (SPO5, 2018). Fear of recurrence was likely to be especially high if diagnosis had been unexpected with few or no physical symptoms at initial diagnosis, and therefore people were uncertain if they would be able to recognise a recurrence and access timely treatment.

"That's the bit I struggle with most, being vigilant enough to notice but not paranoid to think that everything is a symptom. It's that balance because it's always in your mind...it never really leaves you." (SUO4, 2018)

Routine check-ups were highlighted by the majority of service users interviewed as being a source of acute anxiety and distress. It was stated that although follow ups were helpful, they also increased feelings of fear and anxiety.

"It's reassuring to know you're being followed up but in the weeks leading up to it and afterwards, you've got that tension again of 'is it coming back?'" (SUO3, 2018)



There is currently a move across NHS health boards to reduce routine follow ups in favour of person-led follow ups whereby people will contact clinical service if and when they feel they may have a symptom that needs investigation. This approach can be seen to be especially appropriate for people with good prognosis, precisely because it helps reduce the mental distress that routine follow up creates when there is low risk of recurrence (Nogrady, 2014).

Fear however does not have a single source and can stem from many different places. Distress in cancer is normal and whilst it is important not to pathologise all distress, the statistic that depression is three times more likely in cancer patients than the general public and up to 10% of cancer patients will develop clinical levels of depression needs acknowledgement by service providers (Smith, 2015). All of the service users interviewed in this study, identified that clinical did not discuss with them the potential for mental distress to develop as a result of a cancer diagnosis or the challenges of undergoing treatment.

"I was given a lot of information about the side effects of chemo and radiotherapy etc. but no one at any point that I can remember mentioned that cancer would have an effect on my mental health" (SUO4, 2018).

The development of mental health issues like anxiety and depression themselves, were a major source of distress for people living with cancer. Service users suggested that had it been

mentioned that their mental health could be affected, this would have been a protective factor for mental wellbeing, as it would have acted to normalise any difficulties and ease subsequent anxieties.

Loss

Living with or through cancer often means having to develop new identities and behaviours whilst losing certain previous ones (Park et al., 2009). This experience of loss can take many forms but all can have a significant impact on the likelihood of anxiety and depression.

Loss of control

Receiving a diagnosis, going through treatment and bearing the effect of symptoms and side effects can lead people to feel as though cancer has taken over their life, which can lead to feelings of loss of control and mental distress. Going through treatment often can feel like giving over control to the specialists managing the condition. One service provider identified that losing control in this way is particularly difficult for people who had a high level of control in their lives previously (SPO5, 2018). Cancer may be the first time that things have slid out of control and so they may not have previously built resilience to 'situational adversity' (Waring, 2016, p.83). This can lead to mental wellbeing suffering badly and support may be needed to help accept that some aspects of physical health outcomes are out with your control. If a person has dealt positively with previous stress and adversity, this can be a good protective factor for mental health.



Not all loss is as immediate as loss of control over daily life. But for those with incurable or life limiting cancers, grief, anxiety and depression about what is to come – or not to come – can be even more challenging. The knowledge that life is limited means that future losses are felt before they happen leading to predictive loss. This was identified by a service provider as being particularly difficult for parents who knew in advance that they would be leaving their children –

“If you’ve got young children, ten years isn’t very long” (SPO5, 2018). Anxiety over how their children would cope and who will look after them can negatively impact mental health. Even for those without children, for anyone facing potential mortality, there is grief in knowing that a life limiting condition will take away future plans and dreams. Therefore maintaining good mental health is harder in the pre-morbid stage and depression is more likely to be present (SPO5, 2018). It is imperative in these situations that there is a focus on quality of life, and that care is given in a way that counteracts existential loss by engaging people in self-managing support that gives back control as much as possible.

Loss of Identity and Self Esteem

The impacts of cancer and its treatment can severely disrupt people’s daily lives and routines. It can also disrupt their identity and sense of self. Loss – whether it is loss of hair, loss of libido, loss of routine and friends, loss from surgery – can all lead to a loss of identity. The forced adjustments that can happen and how people with cancer and their family

and friends process and adapt to these, can have a huge influence on mental wellbeing. These forced adjustments can lead to people being unable to fulfil previous roles or self-images, leading to decrease in self-esteem and feelings of depression and anxiety. Both of these impacts can have a significant effect on emotional and mental wellbeing.

How people acknowledge their appearance and how they think of themselves and their place within social structures, such as the work place or family unit, creates a person’s sense of self and if these are abruptly and forcibly altered, mental distress can ensue (Fingeret et al. 2014). One service provider highlighted the effects that surgery, especially a mastectomy or hysterectomy, could have on identity, leading to anxieties around how partners will respond and creating intimacy difficulties (SPO1, 2018). Emotional support is needed after any major treatment to allow for processing and adjustment of new normalities and to help people rebuild their self-esteem and confidence.

Being unable to fully perform previous roles – at work and at home – was also identified by service providers as a source of major distress and a potential to lead to depression, stemming from an identity crisis. This was particularly likely in someone no longer able to fulfil a role, such as a father or CEO or an active runner, that had been a large part of their identity. This sort of mental distress is highly unique and personal and needs to be supported in a person-centred way. It is important to recognise that the limitations created by cancer or cancer



treatment extend far beyond physical restriction and can erode mental wellbeing and self-esteem.

The loss of social networks during cancer because of disruption to daily life or because of relationship breakdown for various reasons can also have a major impact on self-esteem. One service provider identified that often family and friends don't know what to say to someone who has cancer, and so may stop contacting them - this can lead to feelings of low self-esteem in the individual with cancer and further compound the likelihood for mental distress and anxiety and depression to develop (SPO6, 2018).

Isolation

The causal effects of isolation and increased rates of anxiety and depression are well documented. This theme of isolation was regularly brought up during data collection by both service users and service providers, making it apparent that isolation is a common problem for people living with cancer. Being unable to work or to engage in usual activities can cause people to lose their social network, even if just temporarily. Beyond this, several service users identified that their friends and family didn't know how to relate to them after their diagnosis and this gap of understanding left them feeling isolated.

"I was the first in the group, my social group, to get cancer and it didn't really fit with the where we were all at...Didn't have anyone. I was told my local support groups weren't applicable because they were just full of old ladies...and that must have stuck in my head. It got to the point

where I was just stuck in my house, too anxious to go out." (SUO6, 2018)

A major contributor to feelings of isolation raised by service users was not being aware of the support available or what is going on in their local area and that services were fragmented, with rural areas having a service provision gap (SPO2, 2018). A lack of signposting between and within clinical and third sector organisations to appropriate support services acts to further compound this and can leave people with a sense that they have to deal with cancer and all its emotional challenge on their own. One service provider suggested that sometimes a lack of signposting may not be the only issue and that stigma, both from society and from the self, surrounding mental health can prevent people from attending services with a mental or emotional wellbeing focus (SPO2, 2018). The majority of interview participants however saw that lack of promotion of, or a lack of support services as being a the key reason for isolation in cancer.

Communication

Linked to the lack of promotion of services, a major impact on mental wellbeing that was found in both the literature and data collected was how service providers communicated. Ball et al. (2016) found that poor communication in clinical settings, especially regarding choices about treatment and care, negatively impacted on a person's wellbeing and compounded feelings of being out of control. Support providers confirmed that poor communication from clinicians increased the risk of anxiety because it



generated a lack of trust and feelings of safety and care among patients. As one support provider stated, with regards to anxiety requiring a clinical intervention:

"In my experience when things go badly wrong, it's often not the tumour but the way the health service has handled it and engaged with the patient." (SPO5, 2018)

Conversely, knowing that support is available in clinical settings and being able to talk to staff about any concerns can help reduce anxiety. Both service users and service provider emphasised that who a person comes into contact with on their cancer journey, has a huge effect on their wellbeing. A support provider stressed that if mental wellbeing can be set on a good track right at the start of the cancer journey, it is more likely to remain stable throughout (SPO5, 2018). This assumption can be demonstrated by the testimony of service user emphasising that by having a meeting with a senior surgeon before their operation and having the procedure fully explained to them, this set their mind at ease. Good communication from staff in this instance alleviated their anxiety by allowing a chance for discussion and this built trust in the clinical system.

Whilst the above discussion shows the importance of positive reinforcements and resilience from both the person and their service providers, in the case of a terminal diagnosis, a different attitude needs to be taken to avoid feeling completely out of control. Where treatment is no longer an option, people can feel very depressed and hopeless.

The rhetoric of 'fighting' and 'beating' cancer can make those with a terminal diagnosis feel even more out of control because their disease is beyond anyone's control (SPO7, 2018). This can make a terminal diagnosis very hard to accept and lead to distress. A practically and person-centred focused approach is necessary in this instance.

Physical Effect of Cancer on Mental Health

Whilst there is great variety between cancers and their treatments, many treatments can be invasive and their side effects can be challenging at the time and life changing afterwards. Side effects of cancer and treatment such as fatigue, nausea, vomiting, insomnia, hair loss, sexual dysfunction, incontinence, weight gain/loss and surgical removal of tissue not only affect the body but can also have a profound impact on mental wellbeing and act as barriers to adaptation and maintaining usual activities (Bertan et al., 2010).

Negative effects from cancer treatment can affect people's capacity to do certain things. While some of these effects are very identifiable, others are less so. The idea of cancer being a hidden disability was bought up by service users who spoke of the lack of support, and often compassion, shown by others in the aftermath of cancer. This was identified as causing emotional distress, because having had a very difficult experience, having someone fail to understand or call into question the legitimacy of this pain or suffering due to signs of ill health not being immediately visible, acted to invalidate the lived experience of the



cancer and the strength into takes to move forward. Workplaces and clinical settings in particular were identified as often offering little recognition for the fact that people may have disabilities or difficulties as a result of cancer and this had a huge impact on people's mental wellbeing.

"I may not be able to get out of the bath or put my socks on but things like that are never questioned in a clinical setting" (SU05, 2018).

Here a service user is demonstrating not only the physical impacts being ignored but also that no support, practical or emotional, is being offered by clinical service providers – despite the cause of this impairment being a clinical one. The feeling of powerlessness at not being able to do simple task was disregarded. Service users emphasised that the lack of consideration given to the mental impacts of the physical effects of cancer needs to be addressed and tailored, appropriate support given.

Cancer can also impact cognitive capacity. Cancer Related Cognitive Impairment – more informally known as 'chemo-brain' – can be an effect of chemotherapy and radiotherapy and affects memory, attention and

functioning (Pascal, 2015). Cognitive impairment can lead to people being forgetful, have difficulty following conversations or work on multiple tasks at the same time. Understandably, this can be a source of great distress to people, especially if they are unaware that this may occur. Whilst the effects are not usually permanent, they can be very debilitating and affect people's work, social life and relationships. One service provider highlighted that cognitive impairment may not always be as a result of treatment (SPO8, 2018). They emphasised that the stress, pain and challenges that cancer can cause needs to be appreciated in understanding why people may experience cognitive difficulties and these need to be addressed at source in order to tackle the issue. The Cognitive Rehabilitation Programme run by Greater Glasgow and Clyde NHS seeks to address cognitive impairment and provide support and information. During research, it was identified that because it is invisible impairment, greater awareness is needed in places such as work places, where employees suffering from its effects need to be met with understanding and reasonable adjustments made for them (SPO8, 2018).

Findings: Supporting mental health during cancer



How can effective emotional and mental health be provided during the different stages of the cancer journey?

People living with cancer need access to effective support and to get the right help at the right time. Beyond receiving the best treatments, people with cancer also need to feel that they are being treated with respect and as an individual whose voice is heard. By locating the focus of care on the 'whole person' this helps to promote a higher quality of life (WoSCAN, 2015).

There is an increasing awareness of the need for person-centred support to be available throughout the cancer journey, with a range of services – both clinical and non-clinical - and different types of support available. As well as such services being available, there needs to be good signposting to them from service providers, who should be aware of a wide range of support mechanisms and not just their own speciality. However as Purushotham et al. (2013) identified, there is still a lack of sustained research or clinical attention between mental health and cancer, leading to unmet need.

One of the main purposes of this study was to explore what support was available to people at the different stages of the cancer journey and also what support was found to be the most beneficial which is explored in the following section.

Needs Assessment

A key point that was identified by service users and service providers as enhancing person-centre care was the need for people to be able to identify what their individual needs and concerns are at the early stage of the cancer journey.

"It's very hard to know what one person is going to need and there's such an importance for assessment – the personal assessment. What one person needs, wouldn't necessarily suit another." (SUO2, 2018).

The use of the Holistic Needs Assessment (HNA) was highlighted as helpful for both service users and service providers as it can help to formulate an effective care plan for individuals by identifying areas that might need immediate or future support. The HNA can be used to ensure that attention is given to all aspects of a person's life and that each person is given the opportunity to discuss what is important or troubling to them on physical, practical, emotional, spiritual and social levels (Macmillan, 2015, NHS Lothian, 2018). Service providers in this study reiterated the point that the HNA is useful in gaining information about the whole needs of the person and subsequently allowing for effective signposting to the most appropriate form of support as necessary. They felt that the HNA should be used across all oncology sites in Scotland (SPO1, 2018, SPO4, 2018). One service provider suggested that



although it took up time initially, by routinely assessing emotional and mental health early in the cancer journey and identifying potential stressors, early intervention could prevent issues from developing into more serious problems (SPO4, 2018). This would act to save time later on and ensure that distress does not become prolonged. Conducting a HNA can also act to improve mental wellbeing and reduce anxiety. Research conducted by Snowden et al. (2014) shows that by feeling as though they are being listened too and that their concerns are being validated by effective communication with clinical staff, service users psychological outcomes can be improved and anxiety reduced.

However, one service user emphasised that the use of tools like the HNA are only effective if needs are able to be fully expressed by the support user and if the assessor has the knowledge and inclination to adequately meet these needs. This point was raised in other forms during interviews with support providers who reiterated that the HNA must not simply be a 'box ticking exercise' by support staff, but must lead to tangible, practical action.

Person Centred Support

Cancer affects multiple areas of people's lives in different ways. Some will struggle financially as a result of cancer, due to additional living or travel costs or because they are no longer able to work. For some their relationships with family may be put under pressure, or for others the side effects of treatment may impact how they can function day to day. The need for support to be person-centred

and reflect the needs and wishes of the person it is aimed at is therefore vital. This idea was reflected time and again by service users and service providers with the emphasis that 'different people need different support at different points' (SPO3, 2018).

Encouraging self-led support is an intrinsic element of person centred support. By giving people the agency to direct, identify and engage with their own needs, this can help to make people feel more in control of their lives and not passive recipients of clinical interventions (SPO2, 2018). One support provider impressed the importance of remaining engaged and leading life as normally as possible whilst living with cancer, and self-led support as a protective factor for mental wellbeing that could help prevent depression (SPO5, 2018).

Peer support

Peer support was emphasised as being a major beneficial factor of self-led support. In engaging with and exchanging knowledge and support with people going through a similar experience, both support users and providers stated that this had the capacity to build resilience, strength and promote wellbeing. One support provider impressed that peer support was particularly useful post treatment in helping people to adjust and find their new normality and that different mediums such as peer-support groups and online forums were a good way of providing meaningful and accessible support (SPO3, 2018). Recognising the diversity of people diagnosed and living with cancer is the first step to ensuring



that support reflects actual needs and that different forms of support are available to ensure that each individual is able to access the right help at the *right time* for them.

It was identified that people need to be able to recognise that services are meant for them (SPO6, 2018). Assumptions that services are meant only for a certain type of person as well

as physical distance of services from local communities can act as a barrier to people accessing support, especially in more deprived areas. Service providers identified the need for service to be distributed through communities rather than all based in one location in an area (SPO6, 2018., SPO2, 2018). Such an approach acts to legitimise that such services are for everyone and by locating them in communities; this helps

Case Study

The Macmillan @ Glasgow Libraries service states that over 60% of people using their services came to have someone to talk to and that the relaxed, non-clinical setting meant that people felt comfortable in discussing the issues that were bothering them. Having a space in which to disclose problems to trained volunteers as a non-judgemental, non-emotionally attached audience was identified as being very helpful. Fear of upsetting family members can cause some people not to disclose additional issues such as feeling depressed, because they don't want to add to their loved ones burdens or feel that their family can't quite relate to what they are going through (SUO6, 2018). As one service user said (regarding cancer):

"Sometimes when it comes to families, families don't always want to be talking about it and it's sometime easier to get support out of the family, cos you're speaking to someone who actually knows what you're talking about and sometimes that's better" (SUO2, 2018).

The range of services offered by Macmillan @ Glasgow Libraries includes advice about finance and benefits, diet, exercise and sign posting to other groups and services. This approach can be seen as useful as it acts to provide a base for the holistic needs of a person to either be met or to be signposted on, in one place. Plans to include more complimentary therapies, such as counselling and massage, as well as advice and listening services aim to make a wider range of support services available in communities.



community engagement. One service provider identified that the 'fear factor' of leaving your own community and going somewhere new, especially when already experiencing challenges, can prevent people from accessing support (SPO6, 2018). By keeping services local and in familiar settings, this ensures that people recognise that they are there for them to use and feel comfortable in engaging. A person centred approach such as this also removes economic barriers to uptake such as additional travel costs or having to take increased amounts of time off work to access services.

Levels of Support

Adopting person centred support can help to reduce emotional distress related to poor communication with clinicians about what the person affected wants. This was identified in the literature review as being a causal factor for depression and anxiety and can be defined as 'iatrogenic distress' (Ball et al., 2016). With each interaction with service providers, whether they are clinical or not clinical, being seen as an opportunity to monitor a person's mental and emotional wellbeing, this means that continual attention is being given to their mental health. This allows for any changes to emotional or mental health to be recognised and for the person to be signposted effectively to the most appropriate form of psychological support. The forms of support used to manage anxiety and depression, like everything else in person centred support, differ and need to be given according to the actual need of the service user.

During data collection, service providers identified the four levels of support that are available and impressed the importance of ensuring that people were assessed and guided to the right level of support for them.

Macmillan (2015) outlines these four levels of support as follows:

1. Level one

- All professionals should provide high quality information about cancer, treatments and available support.
- They should be able to provide day to day emotional support in an empowering way based on compassionate communication skills.

2. Level two

- The HNA should be used to identify emotional and mental health distress and clinicians need to be able to offer 'focused interventions' to help build self-care skills, help people adjust to their situation and move forward.
- Depending on the person, they may need to be referred to more specialised support

3. Level three

- In this level of support there is a need for specialist psychological support professionals to offer support through targeted interventions or counselling and therapy.

4. Level four

- At this level, mental health specialists need to be able offer complex care and support, often responding to pre-existing severe mental health problems that cancer may have exacerbated.



Universal support, levels one and two, are appropriate for the majority of people, and if support here is offered effectively, this can act to prevent anxiety and depression developing into severe, clinical conditions.

Around 65% of people with cancer access universal support as their main or only support form, whilst around 10% will need a higher level of psychological support – these statistics were verified by service providers and the literature on the subject (NICE, 2004., SPO4, 2018).

Returning to person centred support, service providers again stressed the importance of correct assessment in ensuring that people got the right support for them. One service provider spoke of how anxiety could actually be increased and mental health negatively impacted by unnecessary referrals to clinical psychological services (SPO5, 2018). It was felt that the clinical setting and the presumption by the person with cancer being referred that their referral must mean that they have a mental health problem could act to exacerbate anxiety unnecessarily. The stigma surrounding mental health was found to sometimes trigger anxiety if it was suggested that people need to access specialist mental health services (SPO4, 2018).

In ensuring that where possible self-care and community support is used as the primary support method is a cost effective approach to cancer support and will ensure high-level clinical services are not overwhelmed.

Beyond providing benefits to the person with cancer, by adopting a more

person centred and holistic approach to support, this provides avenues for co-operation to allow clinical and non-clinical support services to work together and foster multi-agency care and learning. Both person-centred care and collaborative working is reflected in the Quality Strategy for health and social care in Scotland, demonstrating the value that is placed on these issues at national policy level (Scot Gov, 2015).

Post Treatment

With more people living longer after cancer, understanding the specific needs of people in the post treatment phase of the cancer journey is imperative. Getting the right type of support is important, but only if it is given at the right time.

An overarching theme found in this research was that the biggest need for emotional and mental health support was in the period after treatment. In interviews with service providers and service users both emphasised that the post treatment phase was the most volatile time for mental health and the period where people feel the most isolated and anxious- yet receive the least support after the end of a usually carefully managed clinical phase.

“My life was in order, everything was in its place - I had cancer and everything went up in the air and when it all fell down, it didn't all fall down in the same place” (SUO4, 2018)

This finding differs to what is identified in the literature review, where several studies found depression and anxiety rates to be highest before and during



treatment and declining on completion of treatment (Watts et al. 2015).

The post-treatment phase was identified as being a particularly difficult period for allowing good mental health to flourish. The view that mental wellbeing often declines in this phase was suggested for three main reasons during interviews with service providers and focus group discussion with service users:

- A processing of the full psychosocial impact of cancer has been delayed by the rigour of and energy required to undergo treatment;
- The likelihood of mental distress developing now has not being adequately mentioned in previous stages of the cancer journey;
- An end to well managed clinical support and a lack of signposting to other forms of support leading to isolation;

Delayed Psychological Response

The pressure on people from family, friends and even themselves, to return to normal after treatment was emphasised as having a negative impact on mental health. Both service users and providers stated that feeling unable to return to previous norms could lead to anxiety and distress relating to the confusion of not being able to understand why a return to 'normal' was often not immediately possible.

"Everyone expected me just to be normal and return to what they considered my normal self and I crashed and burned." (SU06, 2018)

The fact that time is needed to adjust and to process all that has happened during treatment can leave people feeling in a different place to their friends and family, who may have been able to process the psychosocial impacts of cancer during earlier stages of the cancer journey.

Service providers identified that this can cause feelings of disconnect and depression because people feel isolated in their own processing of the full impacts of cancer. This can be explained in part by the focus up to this point for many, being on the physical illness and on practical issues rather than psychological ones. One service provider (SPO4, 2018) reiterated this point stating that in many cases, survival mode overtakes and that people may experience 'mental blinkers', whereby the psychosocial and emotional impacts of cancer are pushed to one side and not processed because of more pressing practical concerns. Often it is only once the acute phase of diagnosis and treatment have occurred, that the broader impacts on emotional and mental wellbeing can be fully realised and the anxieties and stressors are released.

Lack of discussion around mental health in general

It was raised that not only are emotional and mental health aspects of distress more likely to be expressed post treatment, but a sudden decline of mental wellbeing can itself be a source of mental distress because people are unaware that it may occur.



"A few months after treatment, I found myself in a black cloud and wondering why...had it been planted in my mind that mental health problems was a side effect or at least a possibility, it probably would have helped" (SUO4, 2018).

Service providers and service users identified that there was very little, if any, information given about the potential for depression and anxiety to develop in the aftermath of cancer treatment. This leaves people unaware that they will potentially face another struggle once treatment is over and does not prepare them to build resilience to face it. It was felt that the lack of communication by support providers about the potential for mental health problems following treatment needs to be addressed and people need to be prepared for what may lie ahead. In addition, appropriate support needs to be offered from the outset of the post treatment phase in order to prevent mental distress developing or to act quickly to prevent it worsening. Service providers suggested that reasons for not discussing the potential for depression and anxiety post treatment were that it could be unnecessarily distressing to present people with the potential of developing mental health issues when they were already going through the rigours of cancer treatment. This may be logical reasoning, but if it is the case, then co-ordinated, multi-agency support needs to be available after treatment as standard.

As one service user stated: *"It's very hard because you've reached a false summit, you're full of hope and it takes sort of the experience of that to realise what can potentially be coming along"* (SUO6, 2018).

With 50% of the service users we talked to identifying that they had reached a 'false summit' in terms of wellbeing in the aftermath of treatment, is an intrinsic part of post treatment mental health needs. It helps identify both the unmet needs in terms of service provision and in terms of signposting in the post treatment phase. The 'false summit' concept also demonstrates the lack of awareness and discussion, at all stages of the cancer journey, of the mental health impacts of cancer. People do not have adequate information or support to help them move forward whilst accessing the support that they need. There must be a wider appreciation by clinical and non-clinical staff of the mental health implication and pressures that cancer creates and this must be disseminated to cancer patients. The assumption that people will be unable to cope with hearing they may experience depression or anxiety after treatment and therefore not explaining this or providing adequate service provision to support them, is not a responsible response as it could inadvertently lead to further pain and suffering.

Service providers emphasised that the most important aspects of post treatment mental wellbeing support involved helping individuals to acknowledge that life wasn't going to be the same as it was and that it was normal to experience difficulties at this stage. Peer support, whereby support is offered from others with lived experience of cancer, was seen as particularly valuable and found to build resilience and strength (SPO3, 2018). Ensuring that people are aware of what support is available to access is also vital in the post-treatment phase. The move from the neat structure of clinical support, with



a clearly defined pathway of systematic progression, to an undefined and unstructured future was highlighted as a major cause of anxiety, depression and distress for people in the post treatment phase.

Lack of clearly defined support pathway

Moving from being part of the strictly regulated and managed clinical system, once treatment stops, service users spoke of feeling as though they had 'fallen off a cliff edge' (SUO2, 2018, SUO3, 2018). This sudden change of losing the clinical element of the cancer journey, has the effect of leaving people feeling isolated and abandoned (SPO8, 2018). Support providers engaged in this research were keenly aware of this issue and identified that people needed help to move forward and adjust to their new normality as a post-treatment individual. This adjustment was seen as a key area of need, as having got through treatment and all its challenges, many people are unable to understand why they are struggling emotionally and mentally in the weeks and months afterwards.

The Transforming Care After Treatment (TCAT) programme, is a five year project operating since 2014 and run jointly by Macmillan, the Scottish Government and Local Authorities and third sector organisations. Whilst not all 25 project operating across Scotland have a mental health component, TCAT seeks to provide support for a wide range of issues that people experience as a result of cancer or treatment, reflecting a 'whole life' approach. Programmes such as this demonstrate the awareness in Scotland to respond to and meet unmet needs in cancer support.

Further work to build an integrated pathway of support that recognises a person's ability to lead the way for their own support, and combine clinical and non-clinical support services as necessary to ensure the most appropriate and holistic support. This is being done by the West of Scotland Cancer Network (WoSCAN) in recognition of that the different levels of support that are needed to effectively meet the mental health needs of all people living with cancer can only be done through a joint effort. In keeping with the premise of person centred self led support there has been a movement to enhance co-operation between statutory clinical services and third sector organisations. The Psychological Therapies and Support Framework for People Affected by Cancer compiled by the WoSCAN was developed as part of a multi-agency, collaborative project by health boards, third sector and social care organisations. An approach like the one the Framework is trying to take is important because of the fundamental differences in terms of referral behaviours and support mechanisms between statutory clinical care and third sector and social care organisations. Something that service providers spoke of frequently in this research was the need for better co-ordination between clinical and non-clinical services in order to create better signposting and referrals for patients. People are not aware, once leaving clinical support services, of what other support exists and this needs to be addressed through better multi-agency collaboration between service providers and better engagement.

Findings: Barriers to accessing support



What are the barriers to good mental health support during and after cancer and how can these be addressed?

Having identified what some of the major mental health impacts of cancer are and how these can best be supported, it is important to also explore why support does not always work and what the barriers to good mental and emotional wellbeing support are.

Barriers to support exist for many reasons. This study has identified three main barriers to good support:

- Poor co-ordination and communication by service providers
- Poor signposting creating lack of awareness of services
- Social inequalities and a lack of equity of access of services

As with adopting a person centred approach to providing support, so too must a person centred approach be adopted in order to effectively tackle the barriers to support. In addition there needs to be a greater awareness amongst service providers as to what creates barriers to care, and a co-ordinated effort by all to work collaboratively in order to better meet the needs of people living with cancer.

Co-ordination and Communication

In cancer treatment, as one service provider identified, the health services' priority is to keep the patient alive. They reiterated that with appointment times with clinician's often only being minutes long, this short time frame meant that focus needed to be on drug dosage, physical health care and treatment – issues that would help people to survive (SPO5, 2018). Emotional and mental wellbeing is often regarded in these situations as less important and not discussed. Service providers interviewed recognised that the time barriers in clinical appointments may prevent deeper discussion about mental health – but if cancer care and support is to improve, the issues not tackled by one service provider must be tackled by another and a whole person approach taken to support and care.

A worrying development of the lack of discussion around mental wellbeing during the treatment phase is the previously mentioned trend of the decline of mental health post treatment. Not only does the lack of discussion not prepare people for the potential of mental distress after treatment, it can act to compound it. A lack of knowledge about why distress is occurring can lead people to feel worse and increase



anxiety rates. Of the service users interviewed in this study, all stated that the fact that mental health could decline after treatment had not been mentioned to them. 80% identified that, after contacting their GP whilst experiencing mental distress during this phase, their GP's response was inadequate in meeting their needs and improving mental wellbeing.

"It got to the point where I was stuck in my house, too anxious to go out, stuck on antidepressants and I had no idea what to do" (SUO6, 2018)

The service user here stated that after they had expressed their distress to their GP, the issues of anxiety, isolation and disconnect were given a medical solution – antidepressants. However this did not address the root cause of their distress and left them feeling unsure of how to proceed and of what pathways of help were open to them. A major barrier to good mental health is the lack of communication by professionals to people going through cancer, that mental distress is neither uncommon nor untreatable – but an awareness of the issue and appropriate and available solutions needs to be offered to improve mental health outcomes.

Such an example highlights the need for better communication by service providers about what the issues the person is identifying actually are, and better communication about how these issues can be addressed. GP's are the first point of contact for clinical services and often the interface between signposting for clinical and non-clinical support. It is vital that they are aware

of the mental and emotional health impacts of cancer and able to provide person centred support by having the knowledge and inclination to be able to refer people to a variety of appropriate support services.

This idea of increased co-ordination between service providers to enable better communication with service users arose multiple times during data collection. One service provider spoke of disconnect in the understanding of mental health that different oncology specialised clinicians had. They stated that the lack of standardisation of support referrals across different health care sites meant that there was a discrepancy in how people were referred to support service (SpO3, 2018). This created situations whereby some people were sent for clinical mental health interventions when community based support would have been more suitable, and vice versa. To ensure that people get the right support at the right time, greater multi-agency co-ordination and collaboration between service providers is needed to remove the barrier of poor communication.

The Psychological Therapies and Support Framework set out by WoSCAN also identifies that a fundamental barrier to support is this lack of cohesion between NHS and third sector organisations, as laid out in their key quality measure statement:

"Services should have a clearly defined pathway detailing the provision of psychological assessment and care for people with cancer, including systematic, routine monitoring of



psychological well-being and ready access to psychological therapies as appropriate.” (WoSCAN, 2017)

As such, the WoSCAN Framework seeks to address this in various ways such as standardising psychological support training by opening up NHS Education Services to third sector organisations to allow for increased access to useful resources, by a wider range of actors. (SPO9,2018).

Poor signposting and lack of awareness

Increased co-ordination between clinical and non-clinical service providers would also allow for better signposting to such services. A lack of awareness about what services and supports are available within the community and where to access them was identified as the one of biggest barriers to support by service users.

“When I had my first cancer, there was absolutely nothing for me to follow. There was no direction.” (SUO5, 2018)

One service provider spoke of how every point of contact with service providers should be an opportunity to *“deliver psychologically informed services in a non-abandoning way”* (SPO5, 2018). As discussed previously in this study, mental and emotional support needs change over time during the cancer journey. This means that people need to be continually offered support that meets their mental wellbeing needs in a way that helps them to move forward; with new service providers offering an appropriate support approach at each stage.

One service provider highlighted the importance of service providers working collaboratively to *transit* people through services according to their needs (SPO3, 2018). The onus here is seen on ensuring that people are neither abandoned nor become completely dependent on one service. But rather that, third sector and social care organisations work with more continuity to ensure people get the right support at the right time. This involves better signposting within and between third sector and social care organisations and clinical services. One support provider stated that the act of signposting services for mental health legitimises and acts to normalise feeling of emotional and mental distress in cancer, as well as increasing awareness of services. By having a more defined pathway with clear markers of services, this can reassure people. As mental health services are available, they must not be the only ones experience difficulties thus helping to reduce the stigma around feeling they are *‘not coping or not normal’* (SP11, 2018)

This is particularly important during the post treatment phase of the cancer journey, where the well-structured clinical pathway ends and people are left to return to their pre-cancer lives. As one support user said:

“I remember...being put out of the door at the end of my radiotherapy treatment and being told to get dressed and go, and then you’re left – you’re left.” (SUO4, 2018)

There needs to be a greater recognition that the cancer journey doesn’t end with discharge from clinical services. It takes time to adjust, to adapt to new



normalities and to process what cancer has done to the self – both mentally and physically and support is very likely to be needed at this stage to move forward into a new phase of life.

Self-referral is important, but outreach and intra-service referral is also vital. Service providers spoke of the necessity of going to the need, not waiting for the need to come to them (SPO4, 2018). The Macmillan @ Glasgow Libraries has tried to address this through not only being very visible in the well used public spaces of libraries, but also running outreach services in the form of pop-up information stalls in health centres, supermarkets and leisure centres. Such initiatives act to provide visible, accessible signposting to support services. Breast Cancer Care also emphasises their services for post treatment support in clinical settings. Such an approach of making people aware of support networks before they need them, allows for an increased ease of transition into post treatment support, because the awareness is there and self-referral is immediately possible.

Social inequalities and lack of access to services

Rural Inequalities

There is an inequity of service provision across Scotland - particularly outside of urban centres, there is a lack of support options and this has a potential negative impact on the 30% of the Scottish population that live in rural areas (National Records of Scotland, 2017). Both service users and service providers identified that rural areas were facing inequalities in terms of provision.

“There was one support group forty miles away on a Friday evening- but over the hills in winter, far too far. Distance, poverty, transport, you name it. These things tend to affect more rural areas” (SUO1, 2018).

The above quote highlights that obstacles to accessing support can act to further compound each other, meaning that there are multiple reasons that people are unable to get the help they need.

Because of the lack of access to services in many rural areas, one service provider raised the point that for people needing complex treatment or care, may have to leave their home and move to be near clinical sites (SPO7, 2018). This can physically isolate people as they will lose their social support network and be forced to adapt not only to the changes the cancer brings, but also to the changes moving location creates.

Whilst not appropriate for clinical support, one suggestion by a service user to improve rural support services was to combine cancer wellbeing support with support for other conditions such as heart disease, diabetes and dementia. Although rural locations may not have enough people experiencing just cancer to warrant the creation of a support group or peer-support network, by combining resources and extending the coverage of such a group, meaningful support could still be given (SUO1, 2018). Person-centred, self-management approaches such as this can help combat feelings of isolation and inequality and instead harbour a sense of community spirit and empowerment.



Deprivation

As with rural areas, it was also identified by service providers that targeted interventions were needed for the most deprived areas. There are stark health inequalities linked to deprivation, with cancer incidence rates being 31% higher in the most deprived areas compared to the least deprived and cancer mortality rates 62% higher in the most deprived area compared to the least (ISD Scotland, 2016). With only 42% of cancers being preventable (CRUK, 2018), placing blame of developing cancer on a person's lifestyle choices can create stigma and feelings of shame and mean that people are less likely to engage with services. The need for support interventions focused on prevention, health literacy, engagement with clinical services and emotional and mental health is a clear unmet need. All service providers interviewed identified that more targeted interventions were needed in Scotland to tackle health inequalities relating to socioeconomic disparity, but that it was a difficult, costly and time consuming process – one that needed a concerted multi-agency effort to be successful.

Demographic Disparity

Other demographic groups also experience worse health outcome and have a lower uptake of service engagement. Whilst men and women are as likely to get cancer – although different types vary – men are less likely to access support services. Of the service provider interviewed, who provided services for both men and women, the average percentage of male service users attending their services was between 30 and 40%. The reasons

for the lower uptake of service usage for men were suggested to be that men were less willing to admit mental or emotional stress and so engage with service providers because of feelings of shame or stigma (SPO2, 2018). Another service provider said that many of their volunteers and peer befrienders were older females. The lack of males in these roles could potentially be a barrier to male service users discussing issues causing them distress, especially ones related to bodily or sexual function (SPO7, 2018). By engaging more men as volunteers and activists in mental and emotional health support, this could help act to break down barriers of stigma.

Service providers also identified a similar trend of low service use amongst BME communities. This is reflected in the finding that more research into support initiatives that best meet the specific needs of this group is required. Service providers suggested potential reasons for lower engagement existed because of cultural barriers in discussing mental health concerns outside of the community and a lack of culturally diverse mental health support methods. Increased awareness training on responding to different cultural needs and providing different approaches of support in relation to cultural practice needs to be given for service providers. One clinical support provider also identified that language barriers could prevent the most effective support being given, with the use of interpreters, whilst necessary, potentially acting to complicate support provision (SPO4, 2018). This supports research conducted by Glasgow based organization REACH, who identified that language barriers



were particularly an issue for older BME women, who may not have had the same access to language exposure or classes (REACH, 2004). With cancer affecting older people more than any other group, ensuring that those who most need services are able to access them is imperative. Support service need to be accessible to all and provision made for everyone to be able to attend.

Resource Allocation Disparity

As well as between people and place, there can also be inequity of service provision between cancers. While all tumour types are worthy of resource allocation to help support and treat those suffering from them, some receive more resources than others. In part this may be down to the incidence of cancer rates, with the more common types such as breast cancer and bowel cancer receiving more publicity, because they affect so many people. However there is potentially an unmet need

for tumour specific support for less common, but no less distressing, tumour types. One service provider in particular highlighted that they felt that there was a discrepancy in the support for women with gynaecological and cervical cancers compared to breast cancer (SPO1, 2018). Ensuing that people experiencing any tumour type have support mechanisms in place that corresponds to the effect of both the cancer and the treatment is important not just for physical wellbeing but for mental wellbeing. People need to feel that their condition is taken seriously and value is placed on their quality of life whilst living with it. Having access to peer support from others experiencing the same type of cancer was found by service users to be hugely beneficial for mental wellbeing as this allowed the exchange of advice, knowledge and other practical and emotional support from someone with a good understanding of the issue (SOO4, 2018, SPO7, 2018).

Policy Recommendations



1. There needs to be a greater awareness by all service providers of the mental health impacts of cancer and the need to support emotional wellbeing and mental health needs

Almost half of people with cancer identify that the emotional effects of cancer are more difficult to cope with than the physical effects (Macmillan, 2006). Mental health and wellbeing needs to be recognised as a key priority area in cancer support and there needs to be more research into the causes of poor mental health, how these can be prevented, and how to promote good mental health during cancer in order to maximise the quality of life for people living with cancer.

2. The right support needs to be given at the right time

People have different mental and emotional support needs at different times during their cancer journey and it is vital that these needs are met at every stage by the most appropriate support possible. Good emotional and mental health can only flourish if the correct kind of support is offered. There needs to be an appreciation by service providers that a whole range of support options must be available and service providers need to have the knowledge and inclination to be able to effectively signpost people.

3. Tailored, person-centred support needs to be offered at all stages of the cancer journey

Everyone's experience of cancer is different - support providers should

adopt a person-centred approach to support provision that recognises the importance of the agency and engagement of the support user. This will help prevent homogenous, one size-fits-all attitudes to support provision and ensure that actual needs are being met in a compassionate and appropriate way.

4. There must be more collaboration and communication between service providers

Increased communication between clinical health and non-clinical third sector and social care organisation service providers will allow for better service collaboration and for different actors to better understand what service the other can provide. This in turn would allow for more co-ordinated support pathways to be put in place with better links between clinical and non-clinical services, meaning increased support access for support users

5. Improve signposting for mental wellbeing services

A lack of awareness about what support services are available and where to access them is one of biggest barriers to support. This must be addressed as a matter of priority. Multi-agency partnerships for service provision should be further developed to allow for better dissemination of what services are available in local areas. There should also be more outreach programmes by support service providers to increase awareness of available support.



6. Provide clearer and more co-ordinated support pathways after treatment

The post treatment phase of the cancer journey can be a 'false summit' in terms of mental and emotional wellbeing and recovery. With the loss of the neat, managed clinical support pathway and the lack of signposting to other support services, as well as having to adjust to new normalities, more preventative actions are needed to protect mental health during this phase. Current initiatives to improve post treatment mental wellbeing need to be increasingly rolled out across Scotland and the allocated resources for existing ones developed and ring-fenced.

7. Improve the provision of support across Scotland

There needs to be a concerted effort by policy makers and service providers to ensure that no one in Scotland is unable to access support because of where they live. Rural support services need to be increased and there should be more investment in online and telephone support and digital peer support communities to enable an empowered and self-led approach to support.

8. More research is needed into how best to tackle social deprivation and co-morbid health inequalities

The links between cancer, mental health and deprivation need more investigation and research. There should be a fundamental appreciation of the impacts that inequality and deprivation has on both mental and physical health and targeted interventions – with both preventative and a support aspect –

developed. Initiatives to improve health literacy, encourage early diagnosis and screening up-take in deprived areas need to be researched and developed. Resources should also be put into creating high quality services placed in the most deprived areas to remove barriers to access such as travel costs, and to help engage local communities to use such services.

9. More research and awareness is needed to design cancer and wellbeing support services that engage BME communities

There must also be more research into how to meet the mental wellbeing needs of BME community members living with cancer. More culturally aware attitudes to service provision and support should be adopted in clinical and third sector settings and targeted outreach programmes should also be developed.

10. Ensure all people with cancer have access to some level of tumour specific support

There needs to be a high quality range of services available across Scotland to offer meaningful support to people with all types of cancer. The mental health impacts that different types of cancer and subsequent treatments can create, vary and there needs to be an appreciation of this by service providers, who are in a position to be able to meet these specific needs. This is especially important in terms of peer support provision and resources need to be available to allow tumour specific peer support, both in person and online, to exist and in order for people with cancer in Scotland to find meaningful, resilience building peer networks.

Conclusion



In conclusion, we believe that the most important aspect of ensuring good emotional and mental health during cancer is that people are able to access the right support at the right time. No one should have to face the psychological impacts cancer alone - mental health needs to have more recognition amongst support providers and the impact of cancer on well-being needs more investigation and research.

For this to happen, there needs to be greater awareness of the effects of cancer on emotional and mental health through increased education and transparency by support providers. The needs of all people with cancer must be met with person-centred, effective support and there must to be a concerted effort of collaboration between support providers – both clinical and non-clinical. This would help ensure a more integrated support pathway for mental and emotional support, right through the cancer journey and ensure that there are tailored services each step of the way. Thus there must be more co-ordination between service providers for this to happen, with clinical and non-clinical actors being aware of the benefits - and limitations – of their own and the others services and being able to effectively signpost people to the most effective support. WoSCAN's work in creating better referral pathways in Scotland is progress to be welcomed and it is initiatives like this that help provide the right support at the right time.

The post treatment phase of the cancer journey has been identified as a key area of mental health support need and there must be continued, expanded efforts to ensure that people are supported in this period. Support providers must explain the 'false summit' of mental wellbeing that can occur after treatment. Well signposted support mechanisms put in place to assist people during this stage. In this vein, services need to be available throughout all of Scotland's communities. Further research needs to be done into how to make support more accessible and engaging for groups who currently have low uptake of services. More resources need to be put into online and telephone support services to enable a range of virtual peer support to be accessible. This would fill support gaps in rural areas, but should not be a replacement for improving face to face support in these areas as well.

Finally, there needs to be an effort from policy makers to give mental health the same level of consideration as physical health during cancer. There can be no health without mental health and this needs to be reflected in the level of and investment in service provision – from both clinical and non-clinical actors. People living with cancer in Scotland need to have their needs met in a holistic way, which takes account of the whole experience of cancer, including the psychological impacts.

Bibliography

- Adler NE, (2008). *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington (DC): National Academies Press (US);. 1, The Psychosocial Needs of Cancer Patients. (online) Available from: <https://www.ncbi.nlm.nih.gov/books/NBK4011/>
- Bawn, P. (2017) Research Feature. *Cancer Research UK: Fighting the feared disease*. (online) Available at: <http://researchfeatures.com/2017/04/24/cancer-research-uk-fighting-feared-disease/>
- Ball, H., Moore, S., Leary, A., (2016). A systematic literature review comparing the psychological care needs of patients with mesothelioma and advanced lung cancer. *European Journal of Oncology Nursing* 25:62–67.
- Bertan et al., (2010) Bertan FC, Castro EK. Quality of Life, Anxiety and Depressions Indicators and Sexual Satisfaction in Adult Patients with Cancer. *Rev Salud Soc.* 2010;1(2):76–88.
- CRUK, (2018). *Cancer statistics for the UK*. (online) Available at: <http://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk>
- Fingeret, M. C., Teo, I., & Epner, D. E. (2014). Managing Body Image Difficulties of Adult Cancer Patients: Lessons from Research. *Cancer*, 120(5), 633–641. (online) Available at: <http://doi.org/10.1002/cncr.28469>
- ISD Scotland, (2016). *Cancer Mortality Support* (online) Available at: <http://www.isdscotland.org/Health-Topics/Cancer/Publications/2016-10-25/2016-10-25-Cancer-Mortality-Report.pdf>
- Macmillan, (2006). *Worried sick: the emotional impact of cancer*. (online) Available at: https://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/impact_of_cancer_english.pdf
- Macmillan (2015) *Marilyn On Being A Macmillan Clinical Psychologist* (online) Available at: <https://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/newsandupdates/macvoice/winter2015/psychologicalsupport.aspx>
- Macmillan (2018). *Assessment and care planning for people with cancer*. [ebook] Macmillan, p.7. (online) Available at: <http://www.nhs.uk/borders.scot.nhs.uk/media/242997/hna-assessment-and-care-planning-booklet.pdf>
- National Records of Scotland, (2017). *Population Estimates* (online) Available at: <https://www.nrscotland.gov.uk/files//statistics/population-estimates/sape16/2016-sape.pdf>
- Naylor, C., Das, P., Ross, S., Honeyman, M., Thompson, J. and Gilbert, H. (2016). *Bringing together physical and mental health A new frontier for integrated care*. [ebook] London: The King's Fund. (online) Available at: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Bringing-together-Kings-Fund-March-2016_1.pdf
- Nogrady, B., (2014). *Patient-led follow-up safe and cost effective*. *ACS Surgery News* 18th Nov, 2014. (online) Available at: <https://www.mdedge.com/acssurgerynews/article/88821/gynecologic-cancer/patient-led-follow-safe-and-cost-effective>
- NHS Border, (2018). *Holistic needs Assessment (HNA)* (online) Available at: [http://www.nhs.uk/borders.scot.nhs.uk/patients-and-visitors/our-services/general-services/transforming-care-after-treatment-\(tcatt\)/holistic-needs-assessment-\(hna\)/](http://www.nhs.uk/borders.scot.nhs.uk/patients-and-visitors/our-services/general-services/transforming-care-after-treatment-(tcatt)/holistic-needs-assessment-(hna)/)
- NICE, 2004. *National Institute for Health and Clinical Excellence. Improving supportive and palliative care for adults with cancer*. (online) Available at: <http://www.nice.org.uk/guidance/csgsp>
- Park, C. L., Zlateva, I., & Blank, T. O. (2009). *Self-identity After Cancer: "Survivor", "Victim", "Patient", and "Person with Cancer"*. *Journal of General Internal Medicine*, 24(Supplement2), 430–435. (online) Available at: <http://doi.org/10.1007/s11606-009-0993-x>
- Purushotham, A., Bains, S., Lewison, G., Szmukler, G., Sullivan, R., 2013. *Cancer and mental health—a clinical and research unmet need*. *Annals of Oncology* 24:2274–78.
- REACH, (2017) *Mapping Exercise of Mental Health Service in Glasgow*. (online) Available at: <https://www.reachhealth.org.uk/research/Mapping-Exercise-of-Mental-Health-Service-in-Glasgow>
- Scottish Government, (2016). *Quality Strategy*. (online) Available at: <http://www.gov.scot/Topics/Health/Policy/Quality-Strategy>
- Smith, H. R. (2015). *Depression in cancer patients: Pathogenesis, implications and treatment* (Review). *Oncology Letters*, 9(4), 1509–1514. (online) Available at: <http://doi.org/10.3892/ol.2015.2944>



Snowden A, White C. (2014) Assessment and care planning for cancer survivors: a concise evidence review. Macmillan Cancer Support (online) Available at: <http://be.macmillan.org.uk/be/p-21255-assessment-and-care-planning-for-cancer-survivors-a-concise-evidence-review.aspx>

Waring, E. (2016). The Healing Virtues: Character Ethics in Psychotherapy. York University, Canada. Oxford University Press. pg83

WoSCAN (2015). Psychological Therapies and Support Framework for People Affected by Cancer. [ebook] NHS West of Scotland Cancer Network, pp.3 - 7. (online) Available at: <http://www.woscan.scot.nhs.uk/wp-content/uploads/WoSCAN-Psychological-Therapies-and-Support-Framework-v2-O-23082017.pdf>

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