



why...

25th Anniversary

we hear you

Providing emotional support to patients, families, friends and carers who have been touched by cancer or a life threatening condition.

Living beyond cancer: using patient experience to shape counselling services – a review 2018

When you ask **why...** we hear you.

we hear you

01373 455 255 wehearyou.org.uk

Interviewer: And can I ask, why did you decide to take part?

Lucy: well you kind of think you had your cancer and you're OK now you're a survivor – because that's what everyone calls you – but I don't think there is any data connected to how you feel after you've had the cancer, **I don't think there is enough on how long it would take after it to be completely free of whatever type of cancer you had.** So I thought I would agree to an interview.

Beth: I just think that I er want to read something or know something that someone is in the same boat. **I want to hear something else other than someone who has done wonderful things.** You don't know that someone who is walking down the street what battle they've been through. And there are people who are beating much bigger battles than what I had some of them have it back time and time again some have it terminal and they just get on with it.

Josie: Why I agreed to take part, that's a difficult one, but. I think it was because I think it's important that not all cancer patients be bombarded with facts and figures from a health care worker without also being privy to the human side... **To be able to talk to other cancer patients or survivors would have been a great help and comfort** and I think that's what I wanted to get across.

Lola: I have got quite a big loyalty to WHY. I think they're great. I think it's an area that is massively lacking and so overlooked and I think that's terrible. What was it? *CHARITY* did a thing a couple of years ago where they said "It's not just the illness it's everything else" and I still don't think this has caught on. I just wanted to do what I can, **for there to be a benefit of being ill.** Yeah. I don't know. I just thought "well I can do that. It might be of use."

We Hear You

We Hear You provides emotional support through free professional counselling services to anyone who has been affected by cancer or other life threatening conditions. We support children, young people and adults across Bath and North East Somerset, Somerset and Wiltshire.

The data in this report was collected and analysed by Heather Still as part of her MSc Health Psychology degree at the University of Bath.

Authors: Heather Still and Melissa Hillier

Published by: We Hear You, Frome Town Hall,

Christchurch Street West, Frome, Somerset, BA11 1EB

e: info@wehearyou.org.uk

t: **01373 455255**

w: wehearyou.org.uk

Registered Charity Number: 1156001

Published date: May 2019

Acknowledgements

We would like to thank all those that took the time to speak to our researcher about their experience of cancer and of using the We Hear You counselling service: without your input this report would not have been possible.



Contents

1.	Foreword	4
2.	Executive summary	5
3.	Introduction	6
4.	Methodology	8
	• Data collection	
	• Procedure	
	• Questionnaires	
5.	Results	11
	• Interview analysis	
	• Key findings	
6.	Recommendations	24
	• Service impact	
7.	Summary and conclusions	25
8.	References	27

Foreword

We Hear You (WHY) is a charity that uniquely supports children, young people and adults across Bath and North East Somerset, Somerset and Wiltshire, at any point in their cancer experience. WHY provides free professional counselling services from diagnosis through treatment and into the phase termed 'living with and beyond' cancer. WHY also supports those with a palliative diagnosis and offers bereavement support, working closely with other organisations to provide the best care possible. WHY's service is delivered by experienced therapists through one-to-one, group and online counselling.

For cancer patients who are living with and beyond their disease, the certainties once taken for granted can often feel absent and whilst the physical effects of treatment and cancer can, in some cases, be gone, the mental and psychological effects often remain. 45% of patients say that the psychological effects of cancer can be harder to cope with than the physical ones and have longer lasting effects³². With the population of those living with cancer set to double from two million to four million³ in the next 12 years⁴, this large cohort of people are developing their own set of needs. As a leading

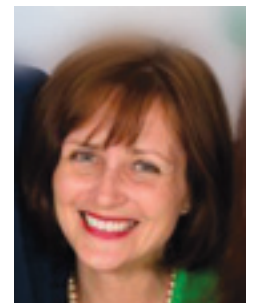
cancer charity dedicated to meeting people's emotional needs, working across B&NES, Somerset and Wiltshire, WHY is here to ensure that patients and families can access the support and services they need, when they need them and that this access is open to all, not linked to ability to pay.

WHY supports many people affected by cancer and we wanted to find out more about those we support who are living with cancer. This will enable us to feed into the wider national debate on research for living with and beyond cancer (www.ncri.org.uk/lwbc/) and also help the charity to enhance and develop the services it offers. WHY also wanted to understand more about what other studies had been undertaken to understand the impact on those living with and beyond cancer, their families and friends.

Advances in modern medicine mean cancer is a disease that some people live with for many years. Over half of people diagnosed with cancer today will live for 10 years or more and during that time WHY helps people come to terms with their new lives and to support them through the many ups and downs that living with a life-threatening condition can cause.



Anne Montague,
Chair



Melissa Hillier,
Director

What came through strongly in this research was that those we spoke to welcomed the counselling they had received and in many cases found it to be a lifeline and a mechanism for helping them to live with their cancer and/or the uncertainties of whether or not cancer could return. People were more than willing to discuss their experiences, wanting to help others, and share what had happened to them, whilst also wanting to give something back to a charity they felt had supported them.

We are extremely grateful to everyone who took part in interviews and surveys and we are also tremendously thankful to Heather Still, who undertook this work with great diligence, care and compassion.

Anne Montague, Chair

Melissa Hillier, Director

Executive summary

This report looks into understanding the experiences of living beyond cancer, and how counselling can complement these experiences. This research was carried out with We Hear You and the University of Bath between April and August 2018.

There were two aims of this research.

1. To explore the unique experiences of living beyond cancer.
2. To gain a further understanding of the impact of counselling to those living beyond cancer.

The research used a mixed methods approach, using the quantitative data to present an overview of living beyond cancer experiences, with qualitative data going deeper into certain aspects of the lived experience. Questionnaires were handed out or circulated online. Interviews were conducted at WHY either face-to-face or via telephone with those who have had experience with counselling. These interviews took place between May and July 2018. Six people took part in the interviews, whilst 29 participants took part in the questionnaire.

Five main themes emerged:

1. The relationship towards the survivor narrative.
2. Body disassociation.
3. The construct of altruism.
4. Personal relationships.
5. The need for counselling.

Key recommendations

1. There needs to be more good quality, exploratory research to build the evidence base looking into the effectiveness of cancer counselling.
2. An effective referral route between primary health care and WHY is needed during the end of cancer treatment.
3. Client advocacy is needed to help form future services or promote current ones, research or strategy.
4. There is a need for further insight and awareness campaigns, in particular around areas such as
 - 'Normality' after cancer, and
 - Recognition that a cancer diagnosis is not an isolated event in an individual's life.

Overall the research showed that counselling had a positive impact on participants' lives. Participants who used WHY expressed a desire to contribute more to helping the service. Without the option of counselling being available, there was a concern that their mental wellbeing would have suffered as a result.

The aim of this research was to explore the unique needs and considerations of those living with and beyond cancer, an area of cancer care that is uniquely supported by WHY in the areas it covers.

Introduction

The definition of living beyond cancer is seen as finishing most or all of prescribed medical treatment and may in some circumstances mean that the person is not entirely cancer free¹.

This definition is within a United Kingdom context, as definitions of living beyond cancer vary globally². The current number of those living beyond cancer in the United Kingdom stands at two million³, and it is predicted that by 2030 this will double to four million⁴.

Living beyond cancer paints a complex picture. Initial isolation during the last day of treatment or the last appointment by the oncologist team is common despite the commonly held assumption of this event overall being celebratory as it signifies an 'end' to cancer. For many a regular routine will have developed, which often gives people something very tangible to focus on. Friends and family will support people whilst treatment is ongoing but many find that once treatment stops, their social support is withdrawn, along with the ending of the now-familiar routine of hospital appointments. This can lead to a general sense of isolation and loneliness.

Regret about taking conventional cancer treatment is thought to

- **Around two million are living with cancer in 2019 and the number is predicted to rise to four million by 2030**
- **The risk of depression in people living with and beyond cancer is thought to be greatly exacerbated by poor handling of the transition into outpatient care.**
- **The value of counselling in the treatment of mild to moderate depression is recognised in NICE guidelines, however most counselling for people with cancer is provided by third sector or community organisations, rather than within the NHS.**
- **30% of those with cancer seek out and participate in complementary therapies, including counselling.**

be common amongst those living beyond cancer⁵. The side effects of treatment are potentially long lasting and can disrupt lifestyle, such as medication adherence and adjusting exercise routines to match different levels of endurance following cancer treatment⁶.

As a result, depression is thought to be quite high in this population. Cortisol levels - known to affect mood - are lowered as a result of the cancer treatment received by many cancer patients⁷. It is thought that depression is more likely to materialise within the living beyond cancer population if transition into outpatient care is handled poorly⁸. Fatigue and other physical complications brought on by cancer and its treatment can continue for a long period of time afterwards.

It has been noted that those who are living beyond cancer with these symptoms feel like they are 'using up their illness quota'⁹.

A fear that the cancer will return is reported⁶, as well as fear that the cancer returning will be worse and more unmanageable¹⁰. Moderate to severe levels of fear of reoccurrence usually result in those living beyond cancer automatically scanning the body for 'symptoms' and having difficulty planning for the future¹¹.

Due to the physical toll cancer treatment can have, returning to work may be a daunting prospect⁴. This does not mean returning to work is an inherently negative experience. For many who were in previous employment, returning to work is believed to be a vital part of establishing a routine



that benefits themselves and their families¹². A literature review into return to work initiatives¹³ found that those who faced such ongoing physical or psychological issues were vulnerable to feelings of inadequacy, further compounded by damaging reactions from others viewing those who have had cancer as less able, weaker or incapable of performing work-related duties. There is evidence to suggest that these assumptions towards cancer patients are held by some cancer care professionals during this returning to work transition¹⁴.

In younger participants in particular, the desire to work harder or to create a new career path was found¹³, although this was only viable if individuals were financially able to do so. In a UK context, those entitled to the lowest welfare benefits were most likely to return to work at earlier stages of remission where their health was still fragile, creating a higher risk of further physical and psychological health issues¹⁵, demonstrating that necessity sometimes overrides preference as the primary reason to return to work.

Post-traumatic growth – where a traumatic experience triggers positive self-change¹⁶ has been attributed to those finding a meaning of cancer. Resilience, selflessness and altruism are cited as examples of post-traumatic growth that had contributed to a meaning of cancer¹⁷.

Nearly 90% of those living with cancer remarked that their largest need since cancer treatment had ended was social based support, such as counselling¹⁸.

Whilst counselling is in NICE guidelines for mild to moderate depression³¹ and is offered by the NHS through their IAPT (improving access to psychological therapies) services, much of the counselling offered to those affected by cancer is done through community organisations, outside of NHS funding and often alongside other forms of therapies and support such as acupuncture, hypnosis and massage.

30% of those with cancer actively participate in complementary therapy¹⁹. It is not known what percentage of people living beyond cancer seek alternative treatment, including counselling.

Patients often seek counselling through their own research, since healthcare professionals may not be aware of counselling facilities outside of larger national counselling operations¹⁹. This demonstrates patient-led need for care that is outside what the NHS is able to provide.

Counselling could be explored as an appropriate and valuable option for the living beyond cancer population. It has been suggested that counselling can help individuals, couples or families who are struggling to find dialogue or to articulate complex emotions²⁰. The role of counselling in the experiences of those living beyond cancer however is limited.

One study explored the experiences of breast cancer survivors in a counselling context by interviewing eight women¹⁷. These interviews unearthed areas that have not received much attention within the literature, such as feelings of betrayal of the body. Participants felt strongly that they valued counselling more than biological or psychoeducational support once cancer treatment ended.

Methodology

Six participants were recruited through WHY's network, who had been classed as 'in remission' for a minimum of 18 months. A minimum of 18 months was chosen as the majority of literature focuses on the first six to 12 months after remission, whilst larger scale studies tend to look at five years after remission²¹, therefore we wanted to strike a balance between the two, taking into account our budget and time. We extended to 18 months to see if there were any different experiences of those who have been in remission longer than one year. The small sample scale is due in part to the time limitations on this project and because the charity had a limited amount of funding for large recruitment campaigns. Despite this, this allows a greater scope for theme findings in participants' experiences²². All of the participants who went through the interview process were female. There were two expressions of interests for interview who were male, but they did not materialise into interviews. 12 participants left their details and were contacted, only six completed the consent form and arranged a time and date for the interview within the time frame.

Recruitment was carried out through two strands. The first method was through meeting with the team counsellors at We Hear You. The counsellors would then investigate their current counselling

clients for the agreed criteria for potential to be participants, with the survey passed on to clients this way. Contact details of an email address for potential interviews were passed on to the researcher. Five surveys were captured this way.

Secondly, participants were recruited through We Hear You's social media. A brief overview of the study followed by the inclusion criteria were displayed. Those who took part in the survey were able to leave their email address at the end securely on the SurveyMonkey platform. This allowed a further reach of participants, who may be part of the We Hear You social media but may not have been a client there.

Once the researcher had participant contact details, participants were sent a participant information sheet where the interview and participant expectations were explained in more detail. Consent forms were given and signed by participants before they filled out the survey and attended the interview.

Face to face and telephone interviews were conducted. Three were done face-to-face at the We Hear You head office, whilst the other three were conducted via telephone. Consent forms were then sent out to telephone participants. The researcher conducted the telephone

conversations in the We Hear You counselling rooms for privacy.

Interviews were audio-recorded and lasted between 32 minutes and one hour. Participants then discussed with the researcher the reasons why they wished to take part, and this was followed by a conversation about previous research on the theme of living beyond cancer. Those who lived in the Frome vicinity were offered specific living with and beyond cancer groups, as part of a pilot project WHY was currently running. Interviews took place during June and July 2018, and were transcribed through a private laptop using Microsoft Office.

Pseudonyms were created with participants using a baby name generator. Pseudonyms were used for anonymity of places and hospital names. Relations of the participant were removed to protect the participant's identity (Data Protection Act, 1998). Ethical approval was granted by the University of Bath's ethics committee, following British Psychological Standards. Counselling services were offered.

Unfortunately, the response rate for the questionnaires was poor and not enough responses were collected for statistical analysis. Despite this, results were collected to examine the experiences for those who took part that may influence the further shaping of services in WHY.

Data collection and analysis plan

This research uses mixed methods, using both qualitative and quantitative methods, with the overall aim to broaden the understanding of the experiences of living beyond cancer. Mixed methods takes both perspectives in data collection, creating a larger data pool²³.

Questionnaire data:

A validated questionnaire called the Impact of Cancer Version 2²² was used to assess the everyday impact of living beyond cancer. The original version was based on qualitative interviews from those with five years minimum of non-specific cancer remission, it is an 81-item measurement. Version 2 was focused specifically on females with breast cancer and narrowed down to 51 questions. For this study, it was shortened further to 37 items after concerns of length. Items relating to relationships and partners were removed in an attempt to highlight the individual impact of living with and beyond cancer. American-related questions around insurance were also removed. Impact of Cancer version 2 is a Likert scaling system ranging between 1 to 5, from strongly disagree to strongly agree.

The Impact of Cancer Version 2 scale assesses positive and negative domains of living beyond cancer:

Negative:

- Worry
- Life interferences
- Appearance
- Body changes

Positive:

- Health awareness
- Positive self-evaluation
- Altruism
- Meaning of cancer

Interview data:

The interview structure focused again on the scales and subscales of the Impact of Cancer version 2, but mixed this in with feedback from We Hear You placement supervisors. A question about finances was added to the schedule as well as a focus on social support based on anecdotal evidence of the clinical manager's experiences of counselling clients living beyond cancer. This totalled nine questions, plus an icebreaker question asking about the history of participant's previous cancer. The interview was semi-structured, meaning that there was a set of questions but allowed flexibility and the opportunity for participants to change direction of interviews.





Interview schedule:

Icebreaker: Tell me a bit about your cancer, your diagnosis and how long it has been since you were given the all clear.

Social support (based on placement experiences of 'using up the goodwill of others'):

1. Do you talk about your cancer or how your cancer has affected you to your friends and loved ones nowadays?
(If unable) How do you feel when you try to talk about the impact of cancer with others?
2. Were you able to talk more freely about your cancer whilst you were having treatment?
3. Has the way people treat you changed in comparison to having cancer treatment?

Worry, life interferences, health awareness:

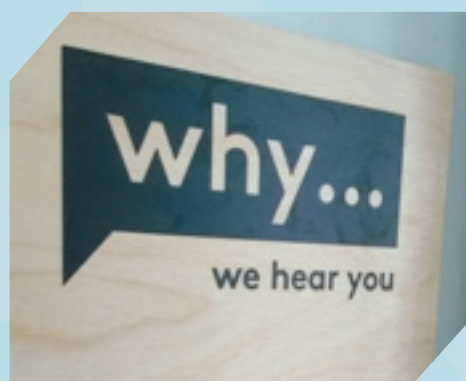
4. Do you worry about your cancer coming back?
(prompts, how often/ frequent, any particular triggers such as health appointments?)
5. Has this impacted you in your life currently?

Self-evaluation, altruism:

6. Does having cancer define who you are as a person now?
7. Do you feel like having cancer has changed how you are towards yourself and others?
8. Do you consider yourself to be a cancer survivor?
9. Could you tell me a little bit about your finances during cancer?
- were finances ever an issue after cancer? OR: Do finances continue to be an issue after cancer?

Results

Pseudonym	Age	Cancer type	Year of diagnosis	Year of remission
Lola	38	Breast	2012	2012
Josie	55	Breast	2009	2010
Emily	41	Cervical-adenocarcinoma	2012	2013
Beth	58	Throat	2012	2012
Sue	51	Breast	2013	2017
Lucy	65	Breast	2004	2004



Theme 1:

Fighter. Survivor. Strong. Fighter. Survivor. Wrong.

Subthemes: Survivor concept; Silenced by my normality.

Survivor concept

There was a varying degree of identification towards the term 'cancer survivor'. A strong affinity to this term came from Josie, who revealed a pink breast cancer tattoo hidden beneath bracelets on her right wrist, inked with the word 'survivor' over the top of the ribbon. Josie's definition of survivor was one of pragmatism, there was no idealised concept of who she should be as a survivor.

A more middling view of whether participants viewed themselves as a 'cancer survivor' came from Lucy, Sue and Lola. Lucy, who was treated 14 years ago, wonders whether she has been one of those people treated unnecessarily, and this alters her perception of herself. Meanwhile Sue was not quite finished with her treatment, whilst Lola had a strong fear of her cancer returning, meaning their cancer status was more present than others. To them, the definition of survivor was someone who survived, yet it was still incomplete. As a result, there was discomfort in what a survivor stood for.

It's not a wonderful thing to have had cancer and got through it it's just what happened to me. – JOSIE.



I don't really think of myself as a survivor except when you come across someone who has had a recent diagnosis then you do feel like you should say "yes I have gone through [it] and lots and lots of people come out of it the other side" - LUCY

Achieving a 'cancer survivor' ideal as portrayed by the media was difficult.

I wouldn't ever say "I'm a cancer survivor" ...I say I had cancer. And then I whisper "it might come back". That's what I say. – LOLA

I suppose I am. But I'm not sure what I make of that expression. I mean I read about it, you come across it a lot. I'm not sure. I dunno – SUE



Drawing on Sue's comment about reading about cancer survivorship, it was interesting to note that identity could be shaped through what participants heard or read through the media.

All the participants had a universal idea of how a cancer survivor is portrayed in the media. For some, achieving this ideal was difficult although there was an expectation for some that this ideal was how they should be.

In an attempt to embody this narrative, interviewees, including Beth, would participate in health behaviour they did not engage with previously.

I read a book...by a woman who had breast cancer she did have quite a life-changing erm it did change her attitude towards a lot of things so that is one of the reasons why I expected to be the same. But no. I'm just normal. Same old. -EMILY

I hadn't thought about it at all until I heard about it on the radio, "are people being treated unnecessarily" and I thought "oh well maybe I was one of those people" but I hadn't thought about it before that... I don't really think of myself as a survivor - LUCY



Despite Beth demonstrating exercise behaviour, she is comparing her running efforts to the often discussed cancer survivor concept, reinforcing her perceived lacking as she does not embody the concepts 'above and beyond' definition.

On the other hand, Lucy engaged in running as her health awareness increased since having cancer. The exercise was for her personal wellbeing, which contrasts to Beth's attempt to embody a survivor concept.

I get tired an awful lot so when I run for a week I have to take a week off to recoup all my energy and I don't run particularly far. But even that, I'd read something about a 65-year-old woman who had cancer and started running and I'm like "but I couldn't physically do it!" but I feel guilty for even being tired because there are so many other people doing this - BETH

I probably did do more exercise than I did do before. And that exercise thing has stood me in good stead. It was really good for me, especially when my husband got diagnosed and then he died, so it was very good for me. It's good for you mentally and physically. - LUCY

They don't know what happened to this woman in the article do they? What's gonna happen in five years, are they gonna follow her up? It's made me wearier to advertorial type things, or people with their stories on social media." - LOLA



The uncommitted stance Lola gave towards the cancer survivor definition follows through with her weariness towards the cancer survivor concept, especially towards the materials she reads about cancer survivorship on the internet.

On the other hand, Josie dismissed the cancer survivor notion in its entirety, since she defined her own version of cancer survivorship.

[after cancer] I didn't come out the hospital following a macrobiotic diet or anything like that...nah. Sod that. I didn't have that moment of going to see the whole world, or be a Buddhist, I was the same person I was before I just been through something that other people have also been through. Yeah [it] didn't change me at all like that" - JOSIE.

Her dismissal demonstrated that this narrative is still active with the living beyond cancer community, even to those who do not wish to be associated with it. In Josie's case, it is an active rejection as she controls her own survival definition.

Silenced by my normality

The cancer survivor concept contributed to a view that normality after cancer was deficient, and not what you 'should' be feeling. The normality was thought of as 'not being written about'. The mundane is being missed when literature is overly focused on the positive (life-transforming experiences, spiritual enlightenment) or overly negative experiences (depression, mental illness). This was further entrenched with participants mentioning 'I don't know if anyone else thinks like this.'

"You never seen the people who just quietly, just quietly go on...you see something in the newspapers or the TV and it's just massive, just massive achievements. But normality is not seen as an achievement, so I almost feel embarrassed by it."

**INT: Because you're normal?
Yes. Yes that's it. - BETH**

The massive achievement is not achieving normality after cancer but doing something 'amazing' or out of the ordinary. When this narrative cannot be achieved, the fault lies within participants' own perceived failings.

Emily speaks of not hearing about normality after cancer. The construct of normality after cancer has been filtered out in the media that the participants read, narrowing the perspectives of life after cancer.

In an attempt to be 'normal', one participant took up running. Running was her attempt at emulating the survivorship narrative, rather than to improve her fitness. This suggests that health behaviours intended to improve quality of life outcome may manifest deeper feelings of low self-worth, that may need to be explored further.

The lack of knowledge of experience demonstrates the need to not only research further but to highlight the normality that lies within the day-to-day experiences of living beyond cancer.



You go to find out people's experiences of cancer [online] that is what you find and it is written by people who have turned their life around...people whose lives have gone back to normal don't particularly write about it... there is a perception that having had cancer makes you a better person because you suddenly appreciate your life a lot more and you want to do something with it, but actually it isn't how I am and I expect most people feel like that but you just don't hear about it. – EMILY

I read these articles about these women who have gone on to do some fantastic things and I think "well why hasn't that gone and happened to my brain?" why is my brain "I just got to look after my little family" why is my brain not telling me to climb a mountain? I'm almost embarrassed. – BETH



Disassociation and its effects on relationships

D'ya know what I thought? I thought "this isn't real". I don't know if others think this...it's actually not happening to you...[husband] thought I was going to die. And I just thought at that point I didn't think I was gonna die I just thought I was really unwell.

He said this to me a long time afterwards, it took him a long time to say this to me – BETH.

Everyone's like "Ohhhh that's so terrible oh you poor thing" I hate that ...You don't know what it's like unless you've been there, you know you can imagine but you can't put yourself in people's shoes because it's such an out of body experience almost it's really weird experience – JOSIE

Participants spoke of disassociation between the body and mind during the cancer treatment

It impacted on relations during treatment as the perception of the experience differed, although the full effect of this was not realised until living beyond cancer.



There is a difficulty in articulating the cancer experience whilst living beyond cancer. Josie reflected on this after describing her support network repeating that she was 'strong' and 'brave', she understood that the experience of cancer was so detached it was difficult to perceive, and therefore explain to others.


For Lola, this out of body experience has continued after cancer, she refers to her body as 'it'.

I feel quite detached... I can't read it. What it should feel like or... - LOLA

Strong feelings of a bodily betrayal resonate with Lola's narrative.

I ignore my body quite a lot I think, which is an active tuning out of what it's up to. And I think there's a definite level of anger or irritation or frustration that my body is sort of naughty, did something it shouldn't. My body did something naughty. Did something it shouldn't...I feel a bit betrayed by it. -LOLA

Essentially, as she sees her body has failed her, she ignores her body as a punishment, and when she is in pain she ignores this in a way to make her body suffer.



“You don’t know what it’s like unless you’ve been there”

Theme 3:

Theme Three: Self help books for others.

Subthemes: Empathy chooses me; the advocate.

Empathy chooses me

Participants described themselves as generally more empathetic than they were before cancer.

“I think I’m a much more empathetic person, I think I always was, but I have a lot more insight” – LOLA

However, participants were not actively looking for occasions to practise their empathy, instead empathetic actions tended to be more opportunistic. For example, beyond cancer, there was an increase of others asking participants for help on behalf of someone else. There were differences in the impact it has on participants.

If people are like “well what was that like” or “what was the treatment like” I’d talk about it because at the end of the day it gives them information if it ever happens to them... It doesn’t worry me to talk about it it’s not [a] part of my life I want to forget – JOSIE

There are a couple of people who know of someone going through something similar. Er they asked if I minded if I spoke to them about it and I don’t mind I am more than happy to do that – SUE

[others say] “oh my friend has got something” ... and I go “yeah sure if she wants to talk about it that’s fine” but actually I don’t really want to because if it was someone I know I would definitely help them through it but I don’t want to spread my energy thin on someone...I don’t need to do that. – LOLA

“I think I care about people more now, but not in a medical sense but in a people sense” – JOSIE

The advocate

Emily is active on social media. Whilst receiving cancer treatment, she updated her story on a blog. Beyond cancer, she noticed that her audience were not as sympathetic towards her as it was assumed she is 'over' cancer.

I stopped talking about it [on the blog] so much because I got maybe two or three comments going with things like "you haven't got cancer anymore you're cured."

...INT: But you weren't finished talking about it then?

No. I don't think I was. – EMILY

It means it is one of these triggers that means I will never be free of it. – EMILY

Emily took to activism to continue her story. She informs her audience about the HPV vaccine, reminding people of her experiences of cancer. This activism legitimises her thoughts about her memories. It repackages her intrusive memories into something productive with purpose, though consequently it keeps her thinking about the more negative aspects of her narrative.

If it wasn't for helping other people, I would rather never have to think about it again. But I can't not. ...I might as well make the best of it so if I can help other people I will do something about it even if it means I have to keep thinking about it when I'd rather not.

INT: Does helping other people legitimise being able to think about cancer? I mean, erm does that make sense?

*I think it makes it worthwhile. Erm, it kind of *sighs* it makes up for the fact that I do still have it in my head it gives it a value and a purpose. – EMILY*

Theme 4:

Theme Four: My relationships

Subthemes: Mothers; daughters; husbands; friends

Mothers

Mothers were referred to as fragile and emotional about their daughter's cancer.

I can't talk to her because she gets upset. I completely understand that because especially of her age...she says to me "I wish it was me." But I go "yeah mum but I'm glad it was me and not my children" – BETH

She still can't talk about me having cancer without crying. She's still really emotional that it will come back – EMILY

The cancer was probably the straw that broke the camel's back for my mum. So...I mean she is happy in her own self but I look at her and I think "I'm not doing that I'm not going to sit there" – JOSIE



Daughters

The daughters' behaviour or actions were a reminder of having had cancer, such as the daughter receiving HPV vaccines. Similar to the mother's reaction to the participant's cancer, the daughter was seen as anxious and reacted through emotional means – either through personal accusations or controlling the environment around her.

Actually last night she said to me "I don't want you to die, mum." – JOSIE

my daughter has very recently had her HPV vaccine, and again that is a reminder of it you know at least it might not happen to them. – EMILY



Our daughter-in-law...I think it's quite affected her that her mum had breast cancer a couple of years ago and my husband has slow-growing prostate cancer so she has become vegetarian herself and they got our grandson, who is two, but ever since he was born she's fed him in particular very differently make sure he's got no chemicals on him – BETH

Husbands

In the case of Lola, her husband's caring expectations took a step back as his working responsibilities returned immediately as soon as her cancer treatment ended.

My husband used to be away a lot and then when I was ill his job were very flexible and said you don't need to travel but literally the date of my last treatment they were like "right you're off" which was great, you know being left on my own with a small toddler
– LOLA

This is a contrast to Lucy's experience:

I don't think getting married made the relationship stronger. I think the cancer made the relationship stronger. He was very, very supportive. "We will do this together." – LUCY.

Beth and Emily's husbands both became ill after their experiences with cancer. This is experienced differently, Beth felt she could not talk about having had cancer since his cancer was present. Conversely, Emily's husband was able to talk to her about his worries and anxieties, increasing her ability to share her cancer experiences.

My husband and me we don't talk about it a lot but we're both more fragile now...He can have this cancer for the rest of his life whereas mine is all gone. If I'm having an anxious time I don't feel like I can always say to him "I am worried about this" because actually he is going through a worse time than me. – BETH

Early this year my husband developed epilepsy suddenly out of the blue and often we will draw comparisons about it because it is life changing and if I have an abdominal twinge I will always think "is it cancer"...every time he has a twinge in his right leg he thinks "oh is it a seizure?" – EMILY

It is interesting to note that neither sons nor fathers were mentioned except in passing in the interviews.



Friends

There was a filtering of friends throughout participants cancer treatment, meaning that the overall quantity afterwards was fewer. But the quality of remaining friendships improved. It appeared to be a process of surprise, where close friends were not as supportive as expected, and previous acquaintances were a positive source of support. This was viewed as a positive, however the process of filtering seemed complicated, where

There was a definite – this sounds harsh- but a filtering of friends but there was a definite some people who I thought would be amazing were awful and some people that I hardly knew were really amazing – LOLA

one participant mentioned she 'ghosted' people – where she told them she would meet them and then never reply – to avoid the awkward honesty that she did not want to continue friendship. Beyond cancer there is a smaller but more manageable circle of friends as these friends were a more positive influence on the participants.

Some people never even mentioned anything and would just talk to me at the playground or the school gates like it was any another day and sometimes I found that quite refreshing and sometimes I found that quite annoying. I mean it was obvious. Different people handle serious situations differently don't they? – SUE

Why previous friends and acquaintances reacted negatively to participant's cancer in the past was presently questioned. There was some reflection to why that was, but the question was still unanswered.

I've cut out a few friends because they are very negative and that's really draining I don't want that around me anymore – JOSIE

If anything, I think people are almost nicer. I think people who you realise were not your friends or as close of a friend, have been concerned. – BETH



It was really surprising how they reacted. I think some of it was fear of "that could be me. I don't want to see it." It was interesting in how people dealt with it – LOLA

The need for counselling.

Subthemes: Treatment ceases, what now?;
Circumstances outside of cancer; I don't
know what I would have done.

Treatment ceases, what now?

There was a definite end chapter felt by participants during the final stages of major treatment. This end chapter was written by others who defined it as the clearing of physical cancer and was seen as a celebratory event. However, for some participants this ending was isolating: there was a conflict to present as grateful for the medical help received and to recover, against the uncertainty and reality on how to function after this chapter had finished.

My friends wanted to celebrate the end of treatment, but I was like "d'ya know what? I don't feel like it." I just dragged myself through... all of this fresh start bollocks...you come out and you're basically on your own, you feel like you're on your own and you should be grateful because you're alive... it's a very odd feeling – LOLA

In contrast, Sue has been given the all clear however still needs treatment every six months for the next year. She is aware of the feeling of isolation that may come with the 'end' of cancer, but balances it with a distancing she has with her cancer.

The further away I move from being diagnosed, I kind of feel more optimistic. It's not as close to me as it was. There's a bit of distance between me and "it." But I may feel differently after this other treatment I'm on has finished and then there is that sense of you're off on your own. Hopefully everything will be alright – SUE



The worst day the day you're finishing your treatment they say "that's it you're fine off you go, go and live your life" and you feel you know, how do I do that now? – JOSIE

Lucy had positive experiences of her last days of treatment, seeing it as symbolic of cancer finishing.

[on the last day of treatment] We came out of the hospital, and you know that bit from Morecombe and Wise where they would go off stage singing that erm, oh what was it, "bring me sunshine" I felt like that! I felt whoopee, great! This little black cloud I had over by the side of my vision for the last five years, that was gone. – LUCY

Circumstances outside of cancer

The emotional side effects of cancer manifested differently in participants and were unpredictable in nature.

In some cases, it was not down to the singularity of cancer, but an accumulation of negative experiences that included cancer. Participants explained their circumstances outside of cancer that happened around the same times and demonstrated how this impacted on them psychologically.



We had had a really stressful year, just one thing after another, like a car catching fire in the drive for no reason, then our first grandchild was born and she had erm, she had a difficult birth so her head and that was quite misshapen and...then my dog died and then we were having some building work done and then I got a lump in my neck. – BETH

Your dad died you had a baby and then your husband left and you couldn't deal with it "cause you got a baby to bring up then your mum got ill didn't deal with that because you got ill and you had a small child...I've never felt suicidal or anything like that...I just...got angry. – JOSIE

I don't know what I would have done

Participants who spoke of counselling mentioned that they would not know how they would have coped if they did not receive counselling. Group and individual counselling was found to be useful.



When I felt like I wasn't able to talk much about it in depth online I had WHY as a place where I could go and talk to... professionals there, talk to other people who were at other points of their cancer journey...I don't know how I would have coped without having that talk and to get information. – EMILY

Sue was training to become a counsellor whilst she was diagnosed. It allowed her to talk through her journey right from diagnosis and she continues to receive supervision. She reflects that if cancer were to happen to her, it happened at the 'right time' when there was an availability of counselling to her.

I'm unsure how it would have impacted me had this come along if I wasn't doing the counselling...it meant I was able to deal with it in the best possible way. If it was going to happen, it happened in the best time. I'm not sure how that would have been in different circumstances – SUE

Providing free counselling is of importance to Lola. Without that availability, her opportunity to talk through her experiences would have been limited.

Finances are rubbish erm but it was great having WHY because it was free. I could have never paid for counselling. – LOLA

Recommendations

Good quality, exploratory research to build the evidence base looking into the effectiveness of counselling in cancer.

This study demonstrated new themes that have not been represented in previous research. It also provided more evidence that the cancer survivorship narrative could potentially damage the wellbeing of those living beyond cancer. The exploratory nature of the research allows experiences outside of normal parameters to be explored. Due to the humanistic nature of WHY, this type of research is a good fit for the charity.

In order for successful referral pathways from primary care to be developed and maintained, primary care often need assurance that the ongoing care is of good quality, which is usually shown through the backing of good quality research evidence. Working alongside other cancer counselling charities who are developing this evidence base to demonstrate their effectiveness may be of benefit to WHY.

An effective referral route between primary health care and WHY during the end of cancer treatment.

WHY are in a good position at being able to provide further care that is not restricted in the same way as NHS therapy. Once an effective research base is established, then effective pathways from ending primary

care onto ongoing care such as WHY can be further developed and maintained. By referral pathway, I mean primary care and community care such as WHY to present as a joint team at final appointments if the need is picked up by primary care, or for primary care to accurately present WHY as an ongoing service before treatment is completed to ensure a seamless transition of care. This is a joint responsibility and demonstrates a continuation of care that government targets are attempting to reach.

Client advocacy to help form future services or promote current ones, research or strategy.

There was a strong desire from the participants to continue to help in other ways for WHY. Enabling this resource has the potential for WHY to be a pioneer in utilising experts by experience. Client advocacy could help promote WHY's current range of services. This advocacy could also form a learning network that looks to share information with other resources, lessening the strain of resources it takes for a small charity to network. Of course, current capacity and resources needs to be first established before taking on new advocacy strategy. A preliminary focus group to assess the desire for client advocacy in both WHY staff and the client and ex-client populations may be beneficial, and this work should feed into the continuing growth and development of the charity.

Further insight and awareness campaigns, in particular:

- 'Normality' after cancer, and
- Recognising that the cancer diagnosis is not an isolated event in an individual's life.

Increasing awareness can be a successful way to promote services as well as solidify an organisation's stance on key issues that affect its clients. This study highlights how current language discourse can contribute to a sense of inadequacy in feeling fatigued or maintaining a mundane routine once cancer treatment has ended, and could contribute to significant distress. It also demonstrated that distress came from not only the cancer diagnosis, but from other experiences that were occurring during the diagnosis, which were not dealt with until the cancer treatment was finishing or had finished. Current literature often deals with the cancer diagnosis as an isolated event, ignoring familial, societal or cultural structures that may be negatively impacting on an individual during diagnosis. Further research into this may be helpful.

An awareness campaign highlighting this could be facilitated through a client-based advocacy group and communicated through the communications team. A volunteer advocacy manager could be established to maintain the advocacy network, with that manager supervised by the team.

Summary and Conclusions

The findings in this report demonstrate the unique needs of those living with and beyond cancer and how the psychological impacts of the disease can last for many years. The five themes emerging around the survivor narrative, body disassociation, constructs of altruism, personal relationships and the need for counselling are all areas of work that WHY would like to study further to build on the current literature.

Similar to previous research, leaving cancer treatment was seen as a daunting prospect²⁵. However, the cancer counselling was beneficial to participants, and knowing that the service was free gave participants some of that feeling of safety they received whilst under hospital care. There were felt to be minimal links between cancer treatment and the next steps of living with and beyond cancer and this was when cancer counselling may have been the most beneficial. There was a coping process used by some participants of body disassociation, this helped participants to get through treatment with minimal emotional disruption, however this process could continue well past remission, and in some cases becoming a form of self-harm to a body that 'betrayed' the health of the participant. This betrayal and feeling of being let down by a body that is meant to be in good health has

been mentioned previously¹⁷. It represents a relationship between the body and the perception of health and illness that warrants further investigation.

The questionnaire upon which the interview schedule was based²² saw altruism and empathy as part of the beyond cancer experience, as a subscale to post-traumatic growth²⁶. Whilst there was a self-reported increase in both empathetic and altruistic incidences, the altruistic acts were generally constructed by others increasing their outreach for assistance. Altruism may not completely stem from inward reflection creating the posttraumatic growth said to produce such behaviour.

The type of altruistic act others constructed focused almost entirely on cancer. Others outside of family would bring up the topic of cancer if its purpose was to gain further information or support for someone they knew. It was seen either as tiring, or as a positive opportunity to educate other people.

The act of advocacy was not wholly for the benefit of others. Whilst this definitely was a large factor, it was also used as an opportunity to keep talking about cancer experiences as it became more difficult to discuss this since remission.



A cancer diagnosis does not happen in isolation but can often be the catalyst for a change in wellbeing, with other certainties changing people can often feel overwhelmed and with nowhere to go, this is why the service that WHY provides is so vital to ensure that people do not reach a crisis point before they seek help.

WHY is unique in its provision of a free service to anyone who has been touched by cancer at any point, and as such supports many people

who are living beyond cancer as well as their families, as this group of individuals increases it will become ever more important to realise their needs and to ensure that they can be supported to live a good quality, as well as quantity of life.

There is an acknowledgement that those living beyond cancer need ongoing support, however there is little responsibility for this²⁷. This gap could potentially be filled through counselling.

Overall, WHY has an in-depth knowledge of the population they cater to, clients and ex clients have enthused about the good it has done them. With further research to back up the knowledge within the staff team, furthering the slim evidence of the benefit of counselling in cancer in general, and with a stronger presence of clients taking opportunities to raise awareness of current services, WHY should continue to thrive as a dedicated counselling charity within the local community.



References

1. Department of Health, Macmillan Cancer Support and NHS Improvement (2010) The National Cancer Survivorship Initiative Vision.
2. Jefford, M., Rowland, J., Grunfeld, E., Richards, M., Maher, J., & Glaser, A., (2012). Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA.
3. Maddams, J., Utley, M., & Møller, H. (2012). Projections of cancer prevalence in the United Kingdom, 2010–2040. *British journal of cancer*, 107, 1195–1202. doi: 10.1038/bjc.2012.366.
4. Macmillan Cancer Support (2015). Statistics fact sheet. from www.macmillan.org.uk/documents/aboutus/research/keystats/statisticsfactsheet.pdf.
5. Clarke, J. N., & James, S. (2003). The radicalized self: The impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science & Medicine*, 57, pp. 1387–1395. doi:[http://dx.doi.org/10.1016/S0277-9536\(02\)00515-4](http://dx.doi.org/10.1016/S0277-9536(02)00515-4)
6. Maguire, R., Hanly, P., Drummond, F., Gavin, A., & Sharp, L. (2017). Regret and fear in prostate cancer: The relationship between treatment appraisals and fear of recurrence in prostate cancer survivors. *Psycho-Oncology*, 26(11), 1825–1831..
7. Spiegel, D. (2014). Minding the body: Psychotherapy and cancer survival. *British Journal of Health Psychology*, 19(3), 465–485.
8. Keesing, S., Rosenwax, L., & Mcnamara, B. (2016). A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship. *Bmc Womens Health*, 16(1), 57.
9. Perl, M., Quigley, J., & Hevey, D. (2013). 'I'm not complaining because I'm alive': Barriers to the emergence of a discourse of cancer-related fatigue. *Psychology & Health*, 29(2), 141–161.
10. Llewellyn, C.D., Weinman, J., McGurk, M & Humphris, G (2008). Can we predict which head and neck cancer survivors develop fears of recurrence? *J Psychosom Res*;65:525–532.
11. Hodges, L. J., Humphris, G. M. (2009). Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psycho-Oncology*; 18:841–848.
12. Kennedy, F., Haslam, C., Munir, F., & Pryce, J. (2007). Returning to work following cancer: a qualitative exploratory study into the experience of returning to work following cancer. *European Journal of Cancer Care*, 16(1), 17–25. doi: 10.1111/j.1365-2354.2007.00729.x.
13. Wells, M., Williams, B., Firnigl, D., Lang, H., Coyle, J., Kroll, T., & MacGillivray, S. (2013). Supporting 'work-related goals' rather than 'return to work' after cancer? A systematic review and meta-synthesis of 25 qualitative studies. *Psycho-Oncology*, 22(6), 1208–1219.
14. Yagil, D., Eshed-Lavi, N., Carel, R., & Cohen, M. (2018). Health care professionals' perspective on return to work in cancer survivors. *Psycho-Oncology*, 27(4), 1206–1212.
15. Amir, Z., Moran, T., Walsh, L. et al. *J Cancer Surviv* (2007) 1: 129. <https://doi-org.ezproxy1.bath.ac.uk/10.1007/s11764-007-0021-2>
16. Calhoun, L.G., & Tedeschi, R.G. (2006). The foundations of posttraumatic growth: An expanded framework. In L.G. Calhoun & R.G. Tedeschi (Eds.), *Handbook of posttraumatic growth: Research and practice* (pp. 3–23) Mahwah, NJ: Lawrence Erlbaum.
17. Sadler-Gerhardt (2010), *Women Breast Cancer Survivors: Stories of Change and Meaning*.
18. Hodgkinson, K., Butow, P., Hunt, G. E., Pendlebury, S., Hobbs, K. M. and Wain, G. 2007. Breast cancer survivors' supportive care needs 2–10 years after diagnosis. *Supportive Care in Cancer*, 15: 515–523. doi:10.1007/s00520-006-0170-2
19. Zollman, C., Walther, A., Seers, H., Jolliffe, R., & Polley, M. (2017). Integrative Whole-Person Oncology Care in the UK. *Journal of the National Cancer Institute Monographs*, 2017(52), 26–28.
20. Collie, K., & Long, B.C. (2005). Considering 'meaning' in the context of breast cancer. *Journal of Health Psychology*, 10, 843–853.
21. Richards, M., Corner, J., & Maher, J. (2011). The National Cancer Survivorship Initiative: New and emerging evidence on the ongoing needs of cancer survivors. *British Journal of Cancer*, 105(1), S1–4.
22. Crespi, C. M, Ganz, P. A., Petersen, L., Castillo, A., & Caan B. (2008). Refinement and psychometric evaluation of the Impact of Cancer scale. 15301541.
23. Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage
24. Yardley, L., & Bishop, F. (2015). Using mixed methods in health research: Benefits and challenges. *British Journal of Health Psychology*, 20(1), 1–4.
25. Zebrack, B. J., Ganz, P. A., Bernards, C. A., Petersen, L., & Abraham, L. (2006). Assessing the impact of cancer: development of a new instrument for long-term survivors. *Psycho-oncology*, 15(5), 407–21.
26. Kantsiper, M., McDonald, E. L., Geller, G., Schockney, L., Snyder, C., & Wolff, A.C. (2009). Transitioning to breast cancer survivorship: perspectives of patients, cancer specialists, and primary care providers. *J Gen Intern Med*. 24 (2):459–66.
27. Borofka, K., Boren, J., & Ellingson, L. (2015). 'Kind, Sensitive, and Above All, Honest': Long-Term Cancer Survivors' Quality of Life and Self-Advocacy. *Communication Research Reports*, 32(4), 373–378.
28. Sprung, B., Janotha, B., & Steckel, A. (2011). The lived experience of breast cancer patients and couple distress. *Journal of the American Academy of Nurse Practitioners*, 23(11), 619–627.
29. Kim, M., Yi, J., Sang, J., & Molloy, J. (2018). The Impact of a Child's Cancer on the Father's Relationship with His Spouse in Korea. *Journal of Child and Family Studies*, 27(1), 166–175.
30. Hudson, S. V., Miller, S. M., Hemler, J., Ferrante, J. M., Lyle, J., Oeffinger, K. C., & Dipaola, R. S. (2012). Adult cancer survivors discuss follow-up in primary care: 'not what I want, but maybe what I need'. *Annals of family medicine*, 10(5), 418–27.
31. <https://www.nice.org.uk/guidance/cg90/chapter/1-guidance#step-2-recognised-depression-persistent-subthreshold-depressive-symptoms-or-mild-to-moderate> (accessed Jan 2019)
32. Worried sick the emotional impact of cancer, research for Macmillan Cancer Support conducted by Opinion Leader Research, April 2006.

“I will forever be grateful to WHY for the support I received. I don't think I would mentally be in the place I am now without it. I was provided with a lifeboat when I felt like I was swimming”



why...

we hear you

We Hear You supports children, young people and adults offering up to 16 counselling sessions free of charge. Counselling takes place each week, at the same time and place with the same counsellor. This approach helps to ensure regular contact and consistent support is provided to people who use the service.

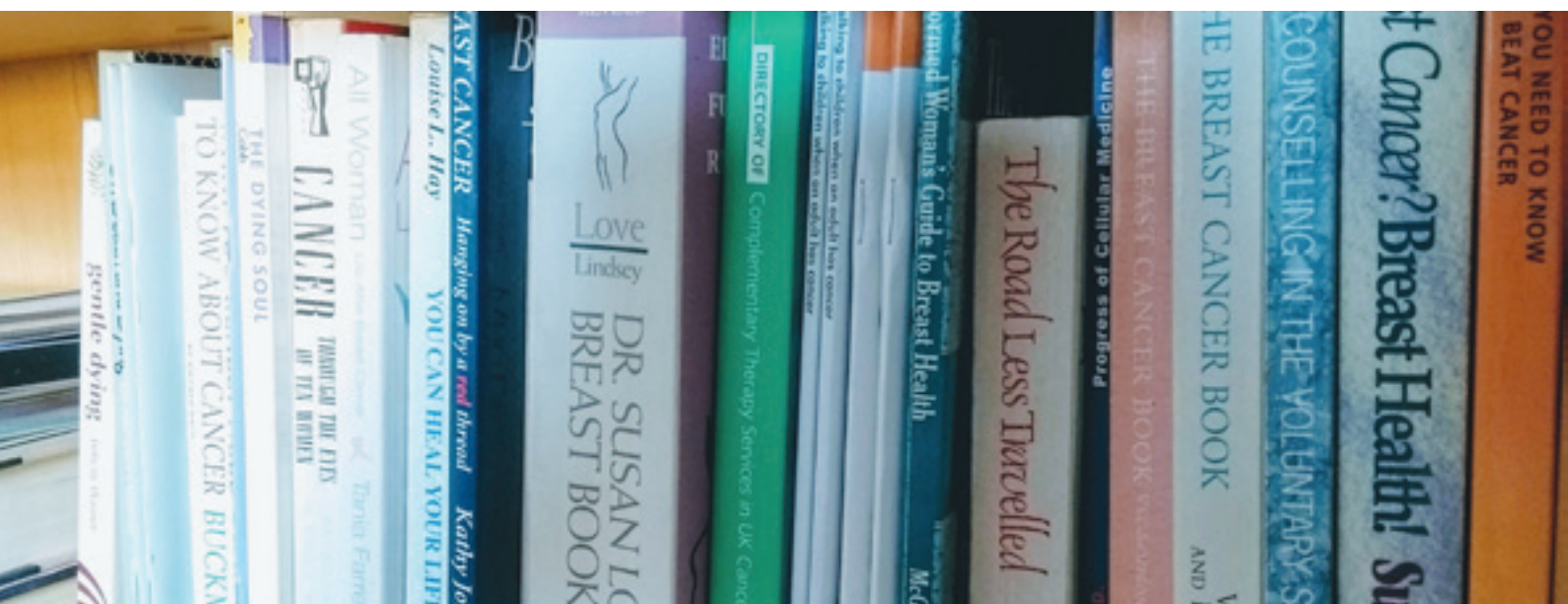
All counsellors at WHY... are highly skilled and experienced in supporting people affected by life threatening conditions.

- * **WHY... supports those affected by cancer at all stages of their experience**
- * **Counselling takes place each week, at the same time and place with the same counsellor**

Our counsellors use an integrative approach. All counsellors are required to be registered with an accreditation body such as the British Association for Counselling and Psychotherapy (BACP) and

We Hear You as an organisation is an associated member of the BACP and adheres to its guidelines for best practice.

This evaluation was carried out by a researcher from the University of Bath as part of her MSc in Health Psychology with the full support from We Hear You. It received Bath University ethics approval in April 2018.







Who we support

- Carers
- Children
- Friends and loved ones
- Patients
- Relatives
- Young people
- Anyone bereaved by cancer or other life threatening conditions

Where we offer counselling

- Bath
- Bradford on Avon
- Frome
- In various schools
- Midsomer Norton
- Online
- Group therapy
- Street
- Trowbridge
- Warminster
- Yeovil

We rely entirely on voluntary donations from our clients, local businesses, individuals, community groups and grant making trusts.

If you would like to support our work or find out more about the emotional support we provide please do get in touch.



**Cancer
Counselling**

We Hear You,

Frome Town Hall,
Christchurch Street West,
Frome, Somerset, BA11 1EB



t 01373 455255

e info@wehearyou.org.uk

w www.wehearyou.org.uk

Follow us on



Registered charity number 1156001