# Cancer Care Review West Sussex Survey Report

April 2024

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NHS Sussex

MACMILLAN CANCER SUPPORT

healthwatch West Sussex

# Contents

**Section** **Page**

Introduction 3

Context 5

Summary 6

Next Steps 8

Cancer Care Review survey findings 9

- Cancer Care Review pre-information 10
- Cancer Care Review 13
- How cancer diagnosis affects day-to-day 18
- Making decisions what and who is important 21
- Isolation and loneliness 23
- Confidence and motivation 24
- Attending services and activities 25
- Effect of cost of living 27

Appendix One: About responders 28

Appendix Two: References 29

About Cancer United and Olive Tree Cancer Support 30

# Introduction

**Healthwatch, NHS Sussex, and [1]Macmillan are working collaboratively to gain insights from individuals with a cancer diagnosis, and those who support, carers, and family members.**

Our aim is to learn about peoples' experiences with their GP practice pre- and post-cancer diagnosis and if a Cancer Care Review took place. The survey aimed to discover the resources related to cancer diagnosis that have been found helpful and identify those that may need further consideration.

A Cancer Care Review takes a [2]holistic care lens; encompassing mental and physical health, [3]pre-habilitation (getting ready for cancer treatment), [4]rehabilitation (program that helps people with cancer maintain and restore physical and emotional well-being), work, finances, and caregiver support. Also, considers any potential barriers encountered in accessing resources and services.

**Macmillan Cancer Support survey**

**Healthwatch, NHS Sussex, and Macmillan Cancer Support wants to ensure your voice is heard.**

We're working collaboratively to gain insights from individuals who've faced a cancer diagnosis, and we're extending a warm welcome to carers, family members, and other significant individuals to share their journeys too.

And we are keen to learn about your experiences with your GP practice post-cancer diagnosis and if you have had a Cancer Care Review. Did you get the chance to express your thoughts, preferences, and discuss what truly matters to you?

**The survey closes on Wednesday 31 January 2024.**

Our survey aims to discover the resources related to cancer diagnosis that you found helpful and those that you did not.

**Please support us by answering a very short survey.**

**If you require any support please contact:**

**Lisa Gray** (Macmillan Primary Care Nurse Facilitator) **lisa.gray29@nhs.net** or if you would prefer to complete by phone, or a hard copy please call **0300 012 0122**

0300 012 0122
healthwatchwestsussex.co.uk
healthwatchwestsussex
healthwatchws

The survey opened in mid-November until the end January 2024. 26 responses were received.

The survey reopened in March for four weeks and was circulated to Cancer United and Olive Tree members only, a further 70 responses were received.

These 96 responses form the basis of this report.

## Thank you

We would like to 'thank' all who completed the survey, and shared their stories, to support this work. Special thanks to **Cancer United** and **The Olive Tree** for all of their support during this work.

## Facebook


**Healthwatch West Sussex**
Published by Hootsuite · 9 January ·

We want to learn about your experiences with your GP practice #post-cancer diagnosis and if you have had a #CancerCareReview. Did you get the chance to express your thoughts and preferences and discuss what truly matters to you?

Please support us by completing our survey - https://ow.ly/2g3X50Qnklj

Impressions: 459

Engagements: 395

## Twitter


**Healthwatch West Sussex**
@healthwatchws

We want to learn about your experiences with your GP practice #post-cancer diagnosis and if you have had a #CancerCareReview. Did you get the chance to express your thoughts and preferences and discuss what truly matters to you?

Complete our survey - ow.ly/88n950Qnklh

Impressions: 418

Engagements: 26

## Instagram

**healthwatchws**

**healthwatchws** 23 w
We want to learn about your experiences with your GP practice #post-cancer diagnosis and if you have had a #CancerCareReview. Did you get the chance to express your thoughts and preferences and discuss what truly matters to you?

Please support us by completing our survey.

2 likes
9 January

Reach: 65

Engagements: 6

# Context

**A Primary Cancer Care Review[5] is a conversation between a person living with cancer and their GP Practice. This could be a GP, practice nurse or other members of the primary care team about their cancer journey.**

The patient can invite a carer, family member or friend to be part of this conversation. The conversation could be by telephone, video, or face-to-face.

This personalised care approach helps a person living with cancer to talk about their cancer experience and concerns, understand what support is available in their local community and receive appropriate information to begin supported self-management.

Personalised care means people have choice and control over the way their care is planned and delivered. It is based on what matters to them and their individual strengths and needs.

[6]Critically, personalised care takes a whole-system approach, integrating services for the person, including health, social care, public health, and wider community services. Cancer Care Reviews are essential in supporting personalised care.

Macmillan has produced a guide which provides the knowledge, and tools to set up meaningful GP practice Cancer Care Reviews, regardless of profession or role.

MACMILLAN CANCER SUPPORT

Personalised Care: Practical Implementation Guide for Cancer Care Reviews

Macmillan have developed 10 top tips to help primary care professionals carry out effective Cancer Care Reviews: **10 top tips for primary care: Effective Cancer Care Review**

# Summary

**Supporting patients in the decisions they make about their healthcare is essential for achieving best health outcomes and effective use of limited NHS resources.**

Person centered care, shared-decision making, resilience, supportive self-management, and asset-based approaches, require healthcare professionals to work collaboratively across organisational boundaries to aid flexibility and effective care for individuals. A key area that underpins personalisation is the right communication and information, at the right time to help people navigate what is a complex system.

This report shares the experiences of people with a cancer diagnosis, and those who support them, to learn if they have received a Cancer Care Review with their GP practice. It is recognised this is a small sample size to be regarded as statistically significant. However, it does provide an indication that the Cancer Care Review is not being fully supported by primary care as it could be.

> I assume this is what I had with my GP although it was not given that title. I was invited to see GP within a few weeks of my diagnosis.

From separate conversations with healthcare professionals, we have also learned that training about how to conduct the Cancer Care Review is needed and knowledge of who to refer people to within the Voluntary, Community and Social Enterprise Sector.

In summary, the Cancer Care Review survey has highlighted that 82% (n74) people who completed our survey with a cancer diagnosis are not aware of the Cancer Care Review and the benefits this review could have to support their journey through the NHS complex system.

A Cancer Care Review is an opportunity to build positive relationships with healthcare professionals and the local community cancer charities. To provide a rounded approach for individuals, their families, and carers. The main aim being to support people and their supporters whilst on the cancer pathway to ensure that what is important to them, their needs and views are part of this.

> I was not invited but my GP phoned me out of the blue 3 months after diagnosis, was not even aware it was a Cancer Care Review.

This report has highlighted a number of areas that could improve a person's journey; the main two being communication and information.

There seems to be unclear communication with regards to:

- Awareness of the Cancer Care Review
- Benefits of pre-habilitation
- Benefits of rehabilitation
- Where to go to have questions answered
- What is important to the person and who is important?
- Who can support from the Voluntary and Community Sector.

> My surgery never reached out to me in the two years of cancer. All assistance has been through East Surrey Hospital, the Olive Tree, my own and my family's research.

It appears that services are not consistent, connected or working in a pro-active collaborative way to give people the support they need and deserve.

People were disappointed that they were still experiencing poor communication from healthcare professionals, with many citing feeling not listened to, or unheard, not being aware of their experience, feelings, perceptions, culture, and social circumstances.

This is despite a drive for healthcare professionals to attend specific communication training over the past few years, such as Having Meaningful Conversations. This is also one of the core values underpinning integrated care.

> Got more information about chances of cancer coming back - but felt it wasn't really given in a way that made me feel better or quite what I would do with information - delivered without thought of how it affects the person.

In conclusion, the report indicates that the values of the Integrated Care System and Primary Care need to be aligned and joined up, to better support people with a diagnoses of cancer and their supporters.

> I had a phone call from GP practice - 10 months after diagnosis and a telephone call from cancer nurse 16 months after diagnosis.

# Next Steps

**This report will be shared widely through our webpages and with NHS Primary Care, and Surrey and Sussex Cancer Alliance.**

The Macmillan Cancer Care poster has been designed to raise awareness of the review in Primary Care.

YOUR GP SURGERY IS HERE TO SUPPORT YOU ON YOUR CANCER JOURNEY.

NHS Sussex

**3 MONTHS**

Within 3 months of your cancer diagnosis, your GP practice will offer you an appointment to discuss what support is available to you and how they can help.

**12 MONTHS**

Within 12 months of your diagnosis (during or after treatment) you are able to have a more structured conversation with a member of the practice team.

THIS IS CALLED A CANCER CARE REVIEW.

These appointments are an opportunity to discuss any issues relating to your cancer and the effects of your cancer treatment on your quality of life, health and wellbeing.

**Your GP practice will contact you to offer these appointments, but if not, you can always ask for them.**

GP surgery name and location
Street name 123
Post code, Area

0123456789

Surgerywebsite.com

**To find out more about your Cancer Care Review:**
https://youtu.be/Lig7_Ut96t8

**For additional support:**
www.macmillan.org.uk

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GP surgery name and location
Street name 123
Post code, Area

0123456789

**To find out more about your Cancer Care Review:**
https://youtu.be/Lig7_Ut96t8

**For additional support:**

Communication and information were areas of concern for many people and there was a need for a proactive approach for the Cancer Care Review. Therefore, in order to better understand the key issues for surgery staff who complete the Cancer Care Reviews, a Focus Group will be set up.

Focus Group attendees will be invited to join a working group to scope out a specific Professional event. This working group will include lived experience, members from Cancer United and Olive Tree Horsham.

A specific Professional Event in the New Year 2025 to discuss the findings from this piece of work and report.

Our aim in these actions is to ensure that the Cancer Care Review has a consistent and connected approach for people diagnosed with cancer to be able to live well with cancer.

# Cancer Care Review survey findings

This report is based on the **96 responders** who completed or partly completed the survey.

**96** responses

86 responses from people diagnosed with cancer

3 responses on behalf of someone diagnosed with cancer

2 from someone close to someone diagnosed with cancer

**Age** of Respondents

31 responses from working age 31 to 60 years.

28 responses from 61 to 70 years.

28 responses from 71 to 80 years.

4 responses from those over 81 years.

Where Respondents **live**

Crawley (n7)
Chichester (n5)
Horsham (n18)
Mid Sussex (n20)
Arun (n11)

**Employment** Status

Retired (n52)
Working full-time (n13)
Working part-time (n13)
Long-term sickness (n6)
Volunteer (n5)
Other employment (n5)
Worthing and Adur (n27)

**Respondents use 34 different GP practices across West Sussex**

# Cancer Care Review pre-information

## Responders' cancer diagnosis was confirmed between 2013 and 2024. Some responders had two dates: original diagnosis and secondary diagnosis.

**82%** (n74) of responders stated they **were not aware of** the Cancer Care Review.

**63** people (70%) were unsure of the benefits of pre-habilitation (getting ready for cancer treatment), following a cancer diagnosis.

| Yes | % | No | % | Unsure | % |
|---|---|---|---|---|---|
| 27 | 30% | 54 | 60% | 9 | 10% |

Just over half of responders, **51%** (n46) were aware of the benefits of rehabilitation (program to maintain and restore physical and emotional well-being), following a cancer diagnosis. With **48%** (n44) not aware or unsure.

| Yes | % | No | % | Unsure | % |
|---|---|---|---|---|---|
| 46 | 51% | 40 | 44% | 4 | 4% |

**4** people were invited to a Cancer Care Review by letter with
**3** invited by telephone and **1** person by text.

> This hasn't happened yet, too soon. I had a call from my GP to offer assistance. I asked for my pre chemo bloods to be taken at the surgery. This was agreed. I then received a message to tell me that the practice doesn't get paid for the taking of blood from a chemo patient. I thought this was unnecessary and affected my well-being.

> I had a phone call from my surgery, but this didn't feel like a Cancer Care Review.

> I found out about The Olive Tree cancer support group.

> Have never had any communication from my Surgery. (n23)

> Saw breast care nurses going through treatment and given some sheets on walking groups and cancer groups. (n2)

**9** people accepted a Cancer Care Review invitation, **13** people have not accepted and **4** people were unsure. But **62%** (n43) have not yet received an invitation.

I would say that 75% plus (estimated as 225 people) had never heard of a Cancer Care Review.

This was confirmed by Cancer United members.

What prevented people from accepting the invitation:

Not been invited. (n43)

We were supported in other ways by The Marsden in Sutton e.g. bereaved parents' group.

How long after diagnosis was a Cancer Care Review offered, this ranged from: that day, 3 months, about 1 year, more than a 2 years and never offered. (n36)

I have never been offered this by my GP. All I got was a so-called holistic needs assessment done only at the end of my treatment, by phone, by a hospital Macmillan nurse. I have not [as yet] been offered a Cancer Care Review after my 2nd diagnosis in Jan 2024.

Think I had one about 6 weeks after the treatment finished.

**15%** (n6) stated that they understood what the Cancer Care Review was about. **61%** (n24) stated they did not feel they understood what the Cancer Care Review was and **23%** (n9) were unsure.

| Yes | % | No | % | Unsure | % |
|---|---|---|---|---|---|
| 6 | 15% | 24 | 61% | 9 | 23% |

**34%** (n12) people received information to support the review. **20%** (n7) did not and **46%** (n16) were unsure.

I would like any sort of contact regarding my cancer, after treatment and with ongoing scans.

People to be there and support us.

I was not given any information. Just received a call late one Friday evening from my GP. It was not expected, and I have received nothing since.

Need to receive (an appointment) first. (n13)

A Cancer Care Review sounds nice - if it had been offered.

I was not told about overall fitness help such as that offered by Cancer United in Angmering. I found out by chance after talking to another recovering cancer patient.

I didn't have a Cancer Care Review nor any info about a holistic needs assessment.

Whilst I was in the Eastbourne area it was excellent. However, upon moving to Angmering there was a huge deterioration.

Two people asked.

I would like to have been made aware that it was a review, and the scope of the review.

How do I get back to physical fitness again. I did contact nurses and had some counselling appointments via Macmillan.

# Cancer Care Review

**5%** (n3) people completed a pre-questionnaire before their Cancer Care Review. **85%** (n50) did not complete a questionnaire and **10%** (n6) were unsure.

| Yes | % | No | % | Unsure | % |
|---|---|---|---|---|---|
| 3 | 5% | 50 | 85% | 6 | 10% |

The Cancer Care Review took place by telephone **4** people and **8** people it was face-to-face.

| Telephone | Email | Face-to-face |
|---|---|---|
| 33% (n4) | 0 | 67% (n8) |

Comments received about the preferred method of communication for the Cancer Care Review.

Not aware the GP would call and had no time to prepare.

It was important to meet the person doing the review, as easier to ask questions. (n2)

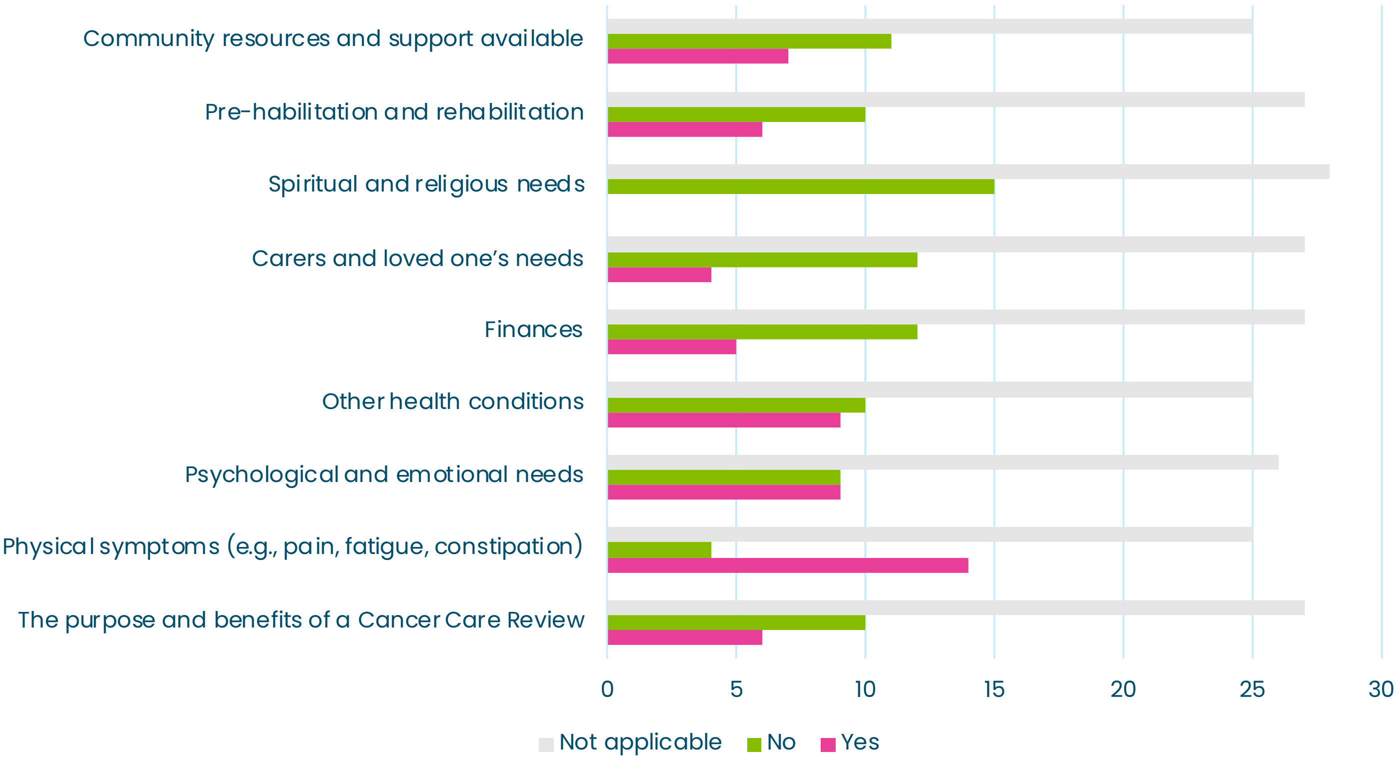
I haven't had a review. (n15)

During the Cancer Care Review respondents confirmed what was discussed during the review:

Physical symptoms in **78%** of reviews. Psychological and emotional needs in 50% of reviews. Other health conditions in **47%** of reviews. Community resources in **39%** of reviews. The main purpose and benefits and pre-habilitation and rehabilitation in **37%** of reviews.

However, finance (**29%**), the impact on carers and loved ones (**25%**), spiritual and religious needs (**0%**), were not discussed during the review.

## During your Cancer Care Review were the following discussed:



Not told GP would call. He gave no advice, said he and the other doctors had no experience of my type of cancer and suggested I make **Friends with the Haematology Secretary** at the hospital. I was astounded, and that was his advice.

A Cancer Care Review would have been very valued, but never offered one and unaware of their existence until receiving this survey.

I have not had any follow up to my cancer operation.

Some sheets given on groups when first diagnosed.

Not had a Cancer Care Review but I am very happy with my GP practice who are very efficient and supportive.

I didn't get a Care Review; so this survey is irrelevant to me. (n20)

We found out all the information on our own for my partner.

**74%** (n23) did not have an opportunity to talk about the things that are important to them, during the Cancer Care Review.

I have never been invited for a review. (n8)

I would have liked to have had this support.

During recovery felt it important to be able to ask an expert for a variety of issues -a result of recovery after cancer treatment. For example: incontinence, sexual functioning, medication etc.

## What went well during the Cancer care Review

Openness and honesty

Support and advice

## What do you feel could have made the Cancer Care Review better

Everything. We should have been told it was happening, so I had time to prepare.

An invitation

Nothing - the opportunity in itself is important.

Slightly earlier to help if I had any major issues. However, if I had needed, I did have a direct line to speak to cancer nurses at my treatment hospital.

Some local information on local accessible cancer groups.

It seems to me as a patient who was very unwell that no-one in the NHS cared one iota whether I lived or died. A Cancer Care Review is meaningless, and becomes a tick box process, unless someone is accountable for the care of the patient.

**20 responses** confirmed they did not feel they were treated as an individual during the Cancer Care Review.

| Yes | % | No | % | Unsure | % |
|---|---|---|---|---|---|
| 8 | 29% | 10 | 36% | 10 | 36% |

My GP practice seems to want to fend you off and make everything difficult all the time. My GP seems disinterested.

If this is something that was supposed to take place at my GP surgery, it never happened. There was no continuity or allocated worker and COVID made it all very scary and isolating. My GP did call me when I had a mastectomy to offer support.

The lady I saw was very caring and understanding.

I have never had support either through my GP or the hospital.

There has been no care or review offered since my diagnosis!!!

A couple - it was to support me and my husband - who had quite different questions and reactions to our loss.

**37** people stated they have been provided with leaflets and information on how to access cancer support services.

| Yes | % | No | % | Unsure | % |
|---|---|---|---|---|---|
| 37 | 59% | 22 | 35% | 4 | 6% |

Only by Social Care Services and Macmillan.

There was a very limited range of services on offer in 2020/21 due to COVID. Things seem much better now.

[information from] Worthing Hospital NOT primary care.

I have tried some online and found it difficult to access them.

Everything I have seen so far is directed at female patients.

We were given lots of bereavement support which is just as necessary as a Cancer Review.

**31** people were no referred to other services that could support them.

| Yes | % | No | % | Unsure | % |
|---|---|---|---|---|---|
| 2 | 6% | 22 | 67% | 9 | 27% |

Not in 2020/21. Although have seen the Macmillan support worker recently (2024), referred me for counselling and sent me information re local support. I would have benefitted so much from contact with her in 2020/21.

No such thing then.

We were given lots of bereavement support.

Cancer United leaflet or information would have been good

There has been no care or review offered since my diagnosis.

I found them for myself, at the hospital and via charities like Target Ovarian Cancer, Macmillan and Cancer United.

# How a cancer diagnosis affects day-to-day life

Responders informed how a cancer diagnosis effects on a day-to-day basis. The top five areas that are affected all of the time are: other activities, in the home, mood and emotions, work and relationships.

The top five areas that are sometimes affected are your mood and emotions, socially, relationships, in the home and other activities. The top five areas intermittently affected are driving, financial, relationships, home, and work.

| | All of the time | Sometimes | Intermittently |
|---|---|---|---|
| **Work** | 22 | 18 | 18 |
| **In the home** | 26 | 31 | 22 |
| **Relationships** | 20 | 33 | 23 |
| **Socially** | 15 | 38 | 21 |
| **Financially** | 18 | 24 | 25 |
| **Other activities (exercise, hobbies)** | 30 | 30 | 16 |
| **Driving** | 7 | 19 | 27 |
| **Your mood and emotions** | 24 | 38 | 13 |

Other comments fell into the categories of emotional, health, what I do now to support my health, just getting on with life and afraid that the cancer might return.

> Diagnosed at Worthing hospital in November 2023, I have not been supported by anybody. The hospital has been obstructive and supplied misinformation to my GP. This has caused undue stress and delayed any treatment plan.

> I am always anxious about the cancer returning or spreading to other organs.

> I now meditate and exercise if feeling low.

> Sometimes I get more tired and due to the major surgery, a bit uncomfortable a lot of the time.

> Very tired if doing anything very physical.

> It hasn't affected my driving, mood, or emotions.

> Cancer was treated and no lasting effects apart from emotional.

> Side effects: being very tired or not able to do as much as I used to.

The effects of a cancer diagnosis on family and those who support included emotional, day-to-day, not having anyone to support, the effect on work and financially.

## Emotional

They (family) are worried about the future, so am I. (n4)

I feel isolated, my loved ones feel the same. There's no support out there. Even the CNS nurses at my hospital know little about it.

Emotionally and physically. My husband worries and is exhausted, as not physically able to do day to day tasks anymore. Our children worry and have anxiety.

It caused a great deal of anxiety.

It's very stressful not receiving any help from anyone.

It is hard to see the stress and anxiety. Naturally, everyone is concerned about the eventual outcome.

They worry and have lost my help with childcare.

## Work

They have to do all the household jobs whilst working.

My family worry that my treatment may not prolong my life as much as they would like. When on 2 weekly chemo, my husband wanted to take me for my treatment, but it put a strain on him with the difficult parking in Guildford. The time spent waiting for me and the fact that it felt that we were always at a hospital. Life seemed very much on hold for him as well as me.

My family are of course upset by my recent diagnosis of Stage 4 cancer. My husband is upset and has lost money through accompanying me to appointments as he is self-employed. My daughters in their 20s are worried and upset.

## No family to support

I needed someone here after my operation and going through chemo. I am on my own now so just have to manage with help from friends.

No family, neighbours supporting without help from anywhere!

## General

My husband was great.

Massive repercussions on family during treatment and bereavement.

It has been hard for them, and I think more should be done on letting them know where they can get support.

Not sure we don't talk about it much.

My younger son (aged 8) said to me -We are a single parent family now. - Because my husband and I were never able to be together as one of us was at the hospital and the other at home with the other two children. We could swap, but for over 500 days of the 3 years we were split apart between home and hospital and not able to support each other's needs as a couple in the most demanding of circumstances.

**One mother shared her story.**

# Making decisions what and who is important

It is interesting that discussions with healthcare professionals (n59) people were not asked who is important to them. And (n57) people were not asked what is important.

Responders stated what they must have (n77) (or not have) (n51) in their life to make them happy and able to live well with the condition. This covered family, healthcare professionals, cancer charities, holidays, work, GP support, hobbies, and faith.

**Must have**

Family and friends' support. (n16)

A counsellor.

The Olive Tree Horsham and Crawley are amazing.

Holidays

As much normality as possible.

Home support.

Being able to get outdoors as much as possible.

Understanding from work and my doctor.

Inner strength and belief that the cancer will be overcome and cured.

Hobbies, social life, things to do.

A faith

Support from someone, could be friends too.

Things respondents did not want include assumptions, stress, feeling isolated and alone, and difficult emotions. As well as needing supportive healthcare professionals.

**Difficult emotions**

Stress lost my brother since diagnosis; it has been difficult emotionally.

Loneliness and boredom.

### Assumptions and other peoples' views

Unsolicited advice. Lack of compassion. Assumptions.

Ignorance. Because I look ok, I therefore must be ok. (n2)

People who said it was only small!

People telling me what to do, offering solutions.

People thinking its better now or its over - it's never over whether you survive or not the ripples roll on.

People thinking you are fine now treatment is finished.

People who don't help or ignore the issue.

Telling me I'm strong and ok as if it's just something to get over.

Everyone else. I look well most of the time and that's half the battle.

### Lack of support from healthcare professionals

Not having any communication with cancer specialists.

Too many questions about how my treatment is going.

Being ignored.

[Lack of] professional help.

# Isolation and loneliness

**40** people stated that they feel lonely, isolated, or socially excluded some of the time and **8** people stated often.

| | | | | | |
|---|---|---|---|---|---|
| Never | **n18** | **20%** | Some of the time | **n40** | **45%** |
| Hardly ever | **n22** | **25%** | Often | **n8** | **9%** |

**74%** (n59) people shared the things they do to make themselves feel less lonely, isolated, or socially excluded, including: social media, meeting friends, distinct groups, hobbies, support groups, work.

> There is only so much society can do - all the cancer healthcare professionals we encountered were amazing with what they offered. They never made us feel hurried, rushed or stupid.

> I found the Olive Tree Cancer Support, they have helped me so much, I can't thank them enough.

> Cancer United who has been absolutely amazing.

# Confidence and Motivation Levels

**73** people feel confident to go out, socialise or attend a group. With **16** people not feeling confident

| 1<br>No confidence | 2 | 3 | 4 | 5<br>Full confidence |
|---|---|---|---|---|
| 5 | 11 | 21 | 32 | 20 |

**67** people feel motivated to go out, socialise or attend a group and **21** people do not.

| 1<br>No confidence | 2 | 3 | 4 | 5<br>Full confidence |
|---|---|---|---|---|
| 7 | 14 | 32 | 17 | 18 |

It is interesting when comparing the responses that confidence is slightly higher than motivation.

# Attending services and activities

Community services and activities, **63** people stated they would like to be able to attend activities to support their emotional, mental, and physical health. Comments fell into the following areas: relaxation, exercise, peer and support groups, hobbies, and charities.

At diagnosis, and immediately after treatment, would have liked to have met others who have the same type of cancer, but locally. I was only made aware of a group at my treatment hospital - Brighton - too far away.

A positive cancer group within easier reach than Brighton or Chichester.

Olive Tree in Crawley are the only people that have helped us.

Olive Tree have been a fantastic support emotionally and physically.

We lived on the ward and got support from other families.

I couldn't afford regular Reiki treatment at the going rate. I am very lucky to be able to have the treatment by just making a donation to the support Charity that organises the treatment.

Work full time and have family commitments, and most evenings am too tired.

I am the only driver and have found it difficult to get to groups.

Now in remission for 2.5 years. A group to support chemo induced peripheral neuropathy would have been a lifeline.

I have moved on with my life but at the time I would have liked more support.

Chemotherapy cost me my hearing, so groups are very difficult.

## Barriers that would prevent people from attending a local community service and activities. The main areas being day and time of day of meetings, cost of activity, location, and health issues.

| | | | |
|---|---|---|---|
| Nothing | 19 | Cost | 30 |
| Location | 26 | Family commitments | 12 |
| Confidence | 10 | Transport to and from the meeting | 7 |
| Motivation | 15 | Help from transport to venue | 1 |
| Having to go alone | 9 | Work | 12 |
| Digitally excluded from online groups and activities | 4 | Health issues | 25 |
| Day and time of day of meeting | 32 | Not sure I am ready to re-join face-to-face groups | 5 |
| Frequency of the meetings (weekly, monthly) | 8 | Other please state | 11 |

> I try to help with my grandchildren at least once a week, so would not be able to attend activities if I had already committed to going to collect the children from school.

> The costs of travelling for treatment is punitive enough. Extra costs for meetings may be too much on top of everything else.

> Low immunity/ too poorly.

> The support was great when I was off work but harder to access when I went back to work.

> Unpaid carer for a disabled person. For me to have time, they would need to be supported.

> I have suffered with anxiety all my adult life and having cancer obviously doesn't help. I can manage locally but unable to travel far on my own.

> Due to chemo, I need the house to be warm and energy costs are expensive.

# Effect of cost of living

The current cost of living is affecting **35** people and their families.

| Yes | 35 | 41% | No | 51 | 59% |
|---|---|---|---|---|---|

We have had to stop heating our water since the energy crisis to reduce fuel bills and reduced the number of showers and laundry to save on water charges.

My family are worried and have issues on-going too.

Stress really, cost of living restricts what you can afford diet wise, paying bills, and added stress, as I have debts.

Getting by, that's why I had to go back to work.

I can't work full time, but not entitled to benefits.

We are managing but having to cut back on non-essentials.

Watching the pennies made it easy to ditch the junk!

Support needed is mainly financial and in the home.

| Yes | 14 | 18% | No | 66 | 83% |
|---|---|---|---|---|---|

Simply the cost-of-living increases outstrip any pension rises. Rent and council tax alone erode this. It is therefore more difficult to eat more healthily, especially in winter.

Using savings.

In the home

Our income has been fairly static for 10 years since my husband retired. We use our savings for holidays or big purchases we are managing but do think hard before making purchases.

Financial help with clearing debt advice

I have done it all for my partner

# Appendix One:

## About responders

About responders **Gender**

Male (n29)

Female (n58)

Prefer not say (n1)

**Ethnicity**

White British, Irish other (n88)

Prefer not say (n1)

**Religion** or beliefs

Christian (n46)

Buddhist (n1)

Jewish (n1)

No religion (n30)

Prefer not say (n10)

**Sexual** Orientation

Heterosexual (n86)

Prefer not say (n3)

**Disability** and long-term conditions

Disability (n7)

Long-term condition (n39)

Carer (n8)

None of the above (n34)

Prefer not say (n2)

# Appendix Two:

## References

| Number | Reference information |
|---|---|
| 1 | https://www.macmillan.org.uk/cancer-information-and-support |
| 2 | Jasemi M, Valizadeh L, Zamanzadeh V, Keogh B. A Concept Analysis of Holistic Care by Hybrid Model. Indian J Palliat Care. 2017 Jan-Mar;23(1):71-80. doi: 10.4103/0973-1075.197960. PMID: 28216867; PMCID: PMC5294442. |
| 3 | https://www.macmillan.org.uk/_images/prehabilitation-in-cancer-care_tcm9-341789.pdf |
| 4 | https://www.macmillan.org.uk/healthcare-professionals/news-and-resources/guides/cancer-rehabilitation-pathways-guidance |
| 5 | https://surreyandsussexcanceralliance.nhs.uk/our-work/personalised-care/personalised-care-interventions |
| 6 | https://www.macmillan.org.uk/healthcare-professionals/cancer-pathways/prevention-and-diagnosis/cancer-care-review/practical-implementation-guide-for-ccrs |

# Cancer United

Cancer United is a unique cancer support charity for all those whose lives have been affected by a cancer diagnosis.

They aim to improve the physical and mental wellbeing of those with cancer from diagnosis onwards, inspiring them to embrace the things they can do and to refuse to be defined by what they can't.

They are welcoming, caring, and fun to be with so please do not hesitate to get in touch with them and see how they can help and support you and your loved ones.

### For more information about Cancer United

Call 01903 779880 or visit their **website**.

# Olive Tree

Receiving a diagnosis of cancer can be difficult, stressful, and emotional for the patient and those around them. The Olive Tree aims to provide a range of services to support from the point of diagnosis, through treatment and beyond.

### For more information about the Olive Tree Cancer Support:

Crawley Centre:
01293 534465 or office@olivetreecancersupport.org.uk

Horsham Centre:
01403 672424 and horsham@olivetreecancersupport.org.uk

**www.olivetreecancersupport.org.uk**

Facebook: **OliveTreeCancerSupportCentre**

Instagram: Olive - **Tree Cancer Support Centre**

Twitter: **OliveTreeCSC**

LinkedIn: **The Olive Tree Cancer Support Group**

## Talk to us

**If you have questions about the content of this report, please either call 0300 012 0122 or email cheryl.berry@healthwatchwestsussex.co.uk**

### How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, Local Government, and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps. We see this as a continuation of discussions taking place and will continue to use this fresh insight and the solutions presented to challenge for a better future.

### For help, advice, and information or to share your experience

We also help people find the information they need about health, care and community and voluntary health and care support services in West Sussex.

Here to help you on the next step of your health and social care journey

You can review how we performed and how we report on what we have done by visiting our website **www.healthwatchwestsussex.co.uk**

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Healthwatch West Sussex works with **Help & Care** to provide its statutory activities.

w: healthwatchwestsussex.co.uk t: 0300 012 0122

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