

Living With & Beyond Cancer

Supporting people living with a cancer diagnosis





Aims & Objectives

- Understanding cancer as a long-term condition
 - Awareness of different treatment options and possible side effects
 - Understanding non-clinical concerns of those living with and beyond a cancer diagnosis
 - Awareness of support offers available to those living with and beyond a cancer diagnosis
 - Awareness of signposting offers those living with and beyond a cancer diagnosis
 - Understand how your service could support with non-clinical concerns
- 



It is estimated that 3.5 million
people in the UK living with
Cancer.



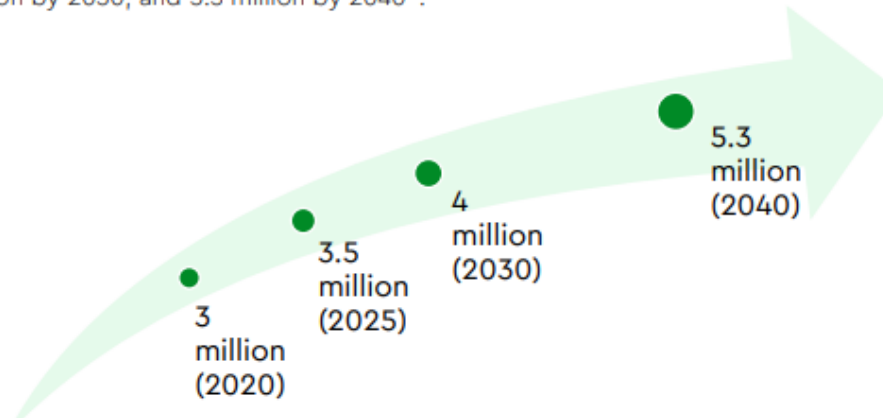
Why do I need to know about cancer?

- People are now living with cancer longer and the demand for support services closer to home is needed more than ever.
- It has been estimated that there are currently more than 3.5 million people living with cancer in the UK, rising to 5.3 million by 2040.
- Based on the latest data for median cancer survival in the UK, average survival is now estimated to be over 10 years from diagnosis

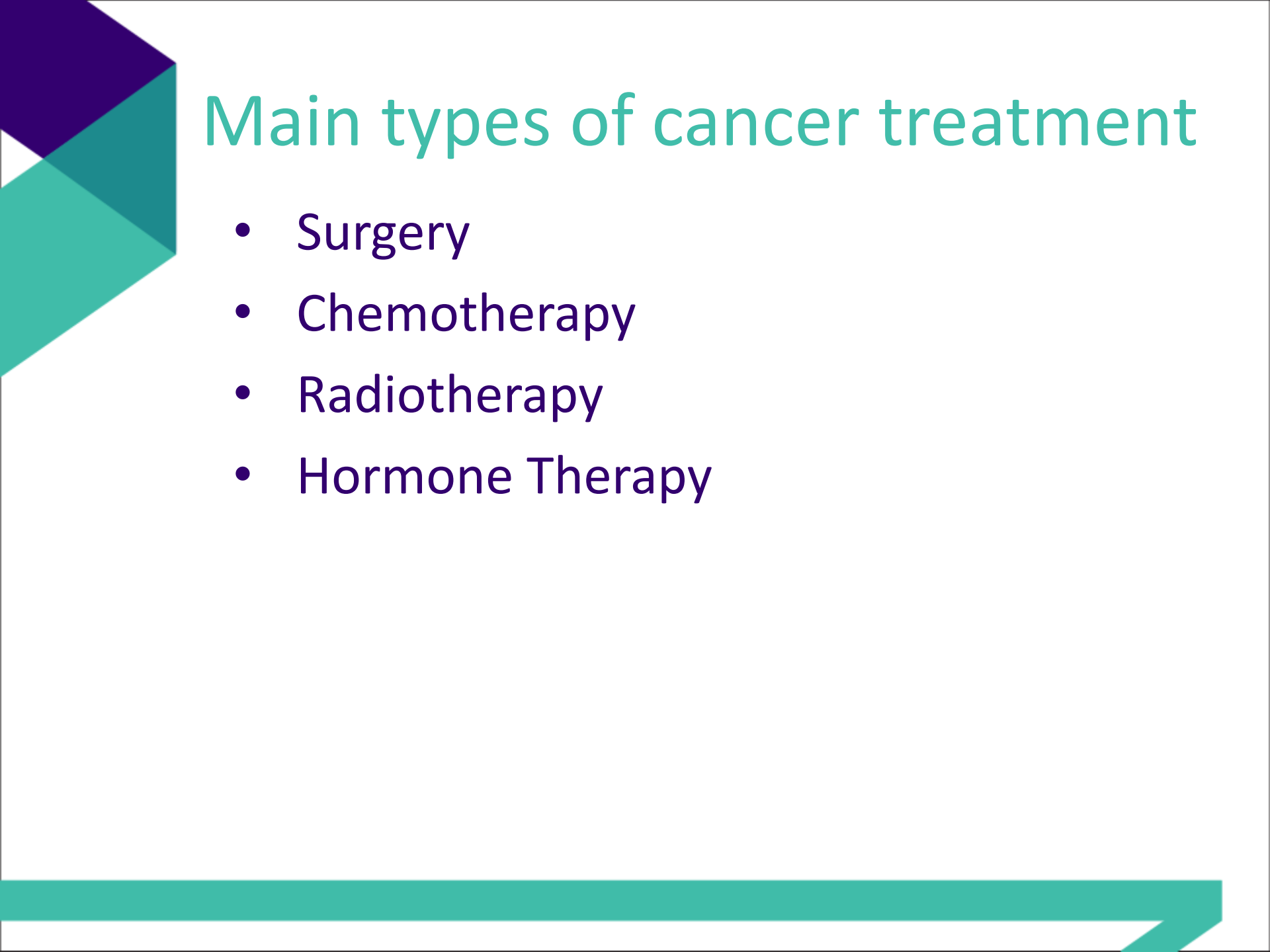
Prevalence

The number of people living with cancer.

We estimate that there are currently **more than 3 million people** living with cancer in the UK, rising to 3.5 million by 2025, 4 million by 2030, and 5.3 million by 2040 ¹.



- Both local and national feedback indicate that while care is well coordinated and personalised during treatment, the end of treatment can feel very different, leaving people feeling **"lost"** and **unsure** where to seek advice and support.



Main types of cancer treatment

- Surgery
- Chemotherapy
- Radiotherapy
- Hormone Therapy

Surgery –possible complications

- Wound infection
- Bleeding
- Constipation
- Chest infection
- Scarring



Chemotherapy

- Uses cytotoxic (toxic to cells) drugs to destroy cancer cells
- Kills cells that are dividing
- Normal cells can usually recover but cancer cells can't (hopefully)





Chemotherapy –Side effects

Areas of higher cell turnover:

- Bone marrow → Infection, fatigue, bruising
 - Hair follicles → Hair thinning/loss
 - Digestive system → Diarrhoea/constipation/nausea
 - Mouth lining → Mouth ulcers, soreness
- 

Radiotherapy

- Uses precise, targeted, high-energy radiation to destroy cancer cells
- Treatment daily for 1-7 weeks
- Damage to nearby normal cells causes side effects



Radiotherapy at St. James's Hospital Leeds

Radiotherapy side effects

- Develop during or after treatment
- Tiredness
- Appetite, eating and drinking
- Feeling sick
- Skin changes and hair loss



Radiotherapy at St. James's Hospital Leeds

Hormone Therapy

- Also known as endocrine therapy
- Most commonly used to treat breast and prostate cancers



Side effects of hormone therapy

Side effects can include:

- Tiredness
- Muscle or joint aches
- Menopause symptoms
- Hot flushes
- Memory issues
- Lowered sex drive



The Social Impact of a Cancer Diagnosis



Supportive conversations –
Holistic needs assessments

Top Reported Concerns (HNAs)

WY&H Cancer Alliance

1. Worry, fear, anxiety
2. Tired, exhausted, fatigued
3. Pain or discomfort
4. Uncertainty (about the future)
5. Eating, appetite and taste

Emotional Support

Around 1 in 4 people (100,000) living with cancer have a high level of psychological care needs. These needs are being poorly met compared to clinical needs*

West Yorkshire and Harrogate
Cancer Alliance



5 big issues for people living with cancer in the UK

Lack of support

20% of people going through cancer treatment have serious physical or emotional concerns they are not getting any support with.

Fatigue, pain and sleep

79% of people living with cancer have physical concerns like fatigue, pain or sleep problems.

Anxiety and depression

72% of people living with cancer have emotional concerns like anxiety or depression.

Loss of income, bills and insurance

66% of people with cancer have money worries. These include loss of income, increased costs and insurance.

Washing, dressing and shopping

53% of people with cancer need help with daily tasks like washing and dressing, housework and transport.

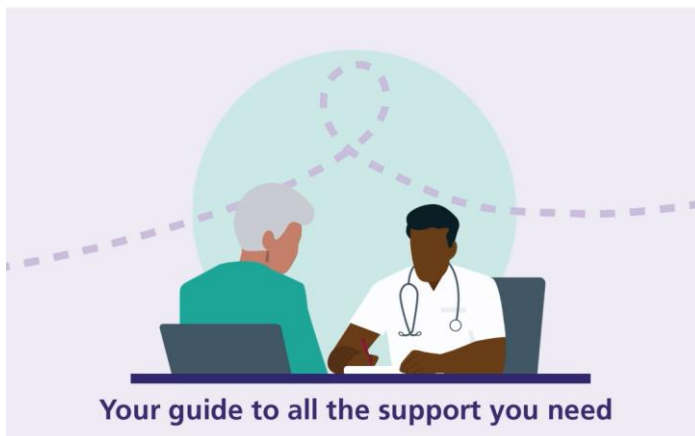
*<https://www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/psychological-care-at-macmillan>

<https://www.macmillan.org.uk/five-big-issues>



[Watch our easy-to-understand animation on how to access the support you need in your local community :: West Yorkshire and Harrogate Cancer Alliance](#)

Living with and beyond a cancer diagnosis



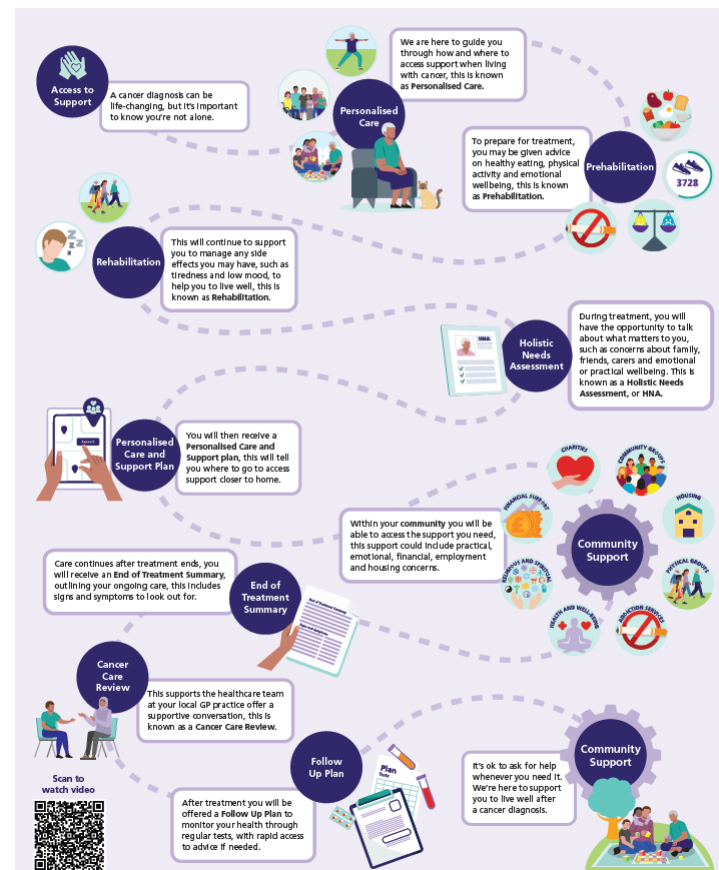
Social Media Reel

Poster



Patient Z card

Living with and beyond a cancer diagnosis





We know that talking about cancer isn't easy, but we want to help you.

To ensure you can make every conversation count, please consider these following tips.

- 1. Ask open questions**
- 2. Use simple, easy to understand language**
- 3. Encourage positive action**
- 4. Actively listen**
- 5. Normalise talking about cancer**
- 6. Signpost to reliable information**
- 7. Know how to respond if someone wants to discuss a symptom/know your boundaries**
- 8. Cancer Forums and nurse helplines**
- 9. Mental health and cancer**

Types of community support





Charities

Where can I signpost people to?

National Cancer Charities

Action Bladder Cancer UK 	https://bloodcancer.org.uk/support-for-you/ 	https://www.bobchampion.org.uk/ 	https://www.bowelcanceruk.org.uk/ 
https://breastcancer.org.uk/ 	https://www.cancercaremap.org/ 	https://www.cancerresearchuk.org/ 	https://cancersupportuk.org/ 
https://www.ella dawson foundation .uk 	Stomach Cancer - Guts UK 	HANCUK! Voice of the unheard 	Home - Kidney Cancer UK 
Support Leukaemia UK 	Liver Cancer UK - Part of the British Liver Trust 	https://www.macmillan.org.uk/ 	https://www.melanomauk.org.uk/ 
Support for you - Pancreatic Cancer UK 	https://prostatecancer.org.uk/get-support 	https://www.roycastle.org/ 	Target Ovarian Cancer The ovarian cancer charity 
https://www.teenagecancertrust.org.uk/ 	https://www.theeveappeal.org.uk/ 		



Community
Groups



Cancer Care Map

SUPPORT SERVICES ▾

WHAT IS CANCER

BLOG

ABOUT ▾

ADD A SERVICE

FIND SERVICES



Find cancer support services near you

By postcode, town or city:

Leeds

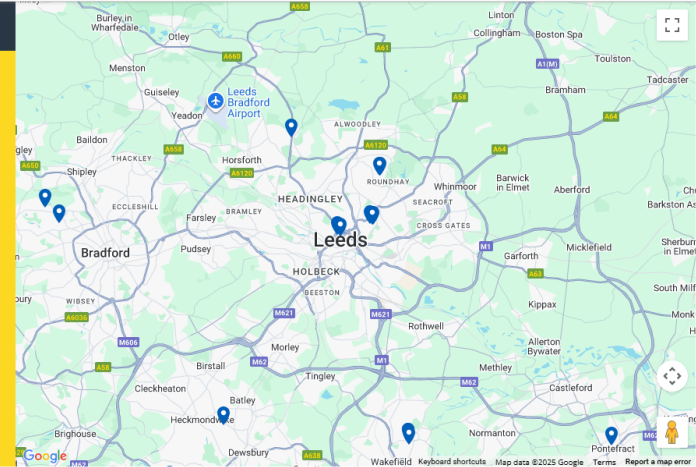
By keyword

Breast Cancer

☒ Include National Services ⓘ

FIND SERVICES

[Reset Filters](#)



What services are included?

There is a huge range of cancer-related support across the UK, run by charities, NHS organisations, community groups and some small practices or private companies. This takes many forms, including:

- information and advice
- counselling and emotional support
- coping with anxiety
- specialist massage
- transport to appointments
- hairdressers and wig fitters
- health and fitness
- nutrition and wellbeing
- financial advice...

<https://www.cancercaremap.org/>



Community
Groups

A range of support groups can offer emotional peer support to people affected by cancer.



Your location Search radius Results

Category filter Search

0.3 mi
[Directions](#)

Carers Leeds – Support After Loss
6/8 The Headrow
Leeds LS1 6PT

Carers Leeds provide support for carers who have been bereaved including running a Support After Loss group to build up confidence and offer opportunities to socialise.

[Support Groups | Yorkshire Cancer Community](#)

Local Cancer Support

Some of local hospitals have Macmillan Information and Support Centres you can refer people to:

- Leeds
- Harrogate
- Mid Yorkshire
- Calderdale & Huddersfield



There is also a regional Maggie's centre at St James Hospital, Leeds



MAGGIE'S

Contact

Team contact details and services can be found using the links below:
Everyone's home of cancer care

Airedale NHS Foundation Trust	Cancer Services - Airedale NHS Foundation Trust
Bradford Teaching Hospitals NHS Foundation Trust	Cancer Services – Bradford Teaching Hospitals NHS Foundation Trust
Calderdale and Huddersfield NHS Foundation Trust	CHFT Cancer Services - CHFT
Harrogate and District NHS Foundation Trust	Cancer Services - Harrogate District Hospital
Leeds Teaching Hospitals Trust	Leeds Cancer Centre - Leeds Teaching Hospitals NHS Trust
Mid Yorkshire Teaching NHS Trust	MY Cancer Services Mid Yorks





Physical Groups

Exercise offers numerous benefits for individuals with cancer, including improved physical health, enhanced mental well-being, better treatment outcomes, and a lower risk of cancer recurrence.

Being active is important for Cancer

What good things could being more active do for you?



Improves
cancer-related
fatigue



Helps
depression



Helps
anxiety



Improves
sleep
quality



Improves
quality
of life



Improves
cardiorespiratory
fitness



Improves
cognitive
function



Improves
muscle
strength



Helps
joint
pain



Reduces
hormone/metabolic
dysfunction



Helps
body
composition



Reduces
post-operative
complications



Helps
lymphoedema



Helps
sexual
function

Scan this code with your mobile device
to get the resource





Physical Groups

Some people affected by cancer will be offered a **Prehabilitation** programme as part of their care in the hospital. This will help them prepare for treatment, They may be given advice on healthy eating, physical activity and emotional wellbeing.



This will continue into **Rehabilitation** to support people to manage any side effects they may have, such as tiredness and low mood, to help them to live well.





Physical Groups



MOVE AGAINST CANCER- 5K YOUR WAY

A SUPPORT GROUP WITH A DIFFERENCE

Walk, jog, run, cheer, volunteer or join for a coffee at your local 5KYW group and connect with other people impacted by cancer.

Community walking and cycling hubs



What are walking and cycling hubs?

Walking and cycling hubs are “one-stop-shops” for people to access the support they need to walk and cycle, including advice on routes, equipment, training and group activities.

As places for everyone, the hubs are an inclusive, welcoming space for people who want to be more active and meet new people.

[CityConnect: Enabling more people to travel by bike and on foot](#)



MACMILLAN
CANCER SUPPORT

Who can call our money advisers?

If you are living with cancer or caring for someone with cancer, you might need extra help with money. You can contact our money advisers to find about the benefits and support you might be entitled to. Learn more about [the different ways our advisers can help you](#).

You can call our money advisers for free on [0808 808 00 00](tel:0808 808 00 00), Monday to Friday 8am to 6pm. Read on to find out what happens when you call us and what you need to have ready.

We can help you with:

- a full benefits check to see what you are entitled to apply for
- questions about different benefits such as [Universal Credit](#), [Personal Independence Payment \(PIP\)](#) and [Employment and Support Allowance \(ESA\)](#)
- completing benefit application forms
- challenging decisions on benefit claims.

What is an SR1 form?

The SR1 medical report form is a new form that can be used when people with a terminal illness are applying for specific benefits under the special rules.

Your healthcare professional fills out the SR1 medical report form to say that you have a terminal illness. This provides evidence that you are eligible to apply under the special rules.



Housing

Green Doctor

Groundwork's Green Doctors help UK residents stay warm, stay well, and save money on household bills.

We can provide different kinds of support, whether that's advice on paying off debt with energy or water companies, or spotting other concerns for a referral to other services. Some of the reasons people ask us for help are:

- they're struggling to pay energy bills or finding it hard to manage fuel debt
- they're worrying about keeping warm or choosing between eating and heating
- their home is cold, damp or draughty
- they have respiratory problems such as asthma or a persistent cough

nationalgrid

Our Priority Services Register (PSR) provides extra help and additional support during a power cut for elderly, very ill or disabled people, or those who rely on power for medical equipment. While power cuts can still happen, we will do everything we can to keep you connected.

Case Study: Personalised Cancer Support – Staying Well Project



- Silvie Jones is a Russian national who has been residing in the UK for several years.
- She is a pensioner in receipt of housing benefit and pension and has no known family support in either the UK or Russia.
- Living alone, Silvie was experiencing significant social isolation and had very limited support networks.

*name changed for anonymity

- Diagnosed July 2021 with Stage A B-cell Chronic Lymphocytic Leukaemia
- Currently on "watch and wait" treatment plan with six-monthly reviews
- Compromised immunity requiring careful infection management and avoidance of crowded places
- Recently experienced fatigue and chest infection requiring antibiotic treatment

Case Study: Personalised Cancer Support – Staying Well Project



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CANCER SUPPORT

halifax
opportunities
trust

Housing Conditions:

- Living in unsafe and unfit accommodation with shared kitchen and bathroom facilities
- Property located on third floor with no lift, creating accessibility concerns
- Rat poison present in communal areas, posing contamination risks
- Shared facilities posed high infection risk due to her compromised immune system
- Sometimes forced to use a bucket as shared toilets on ground floor were not always accessible in time

Health and Wellbeing Impact:

- Experiencing social isolation and loneliness
- Feeling unsupported and increasingly anxious about health and living situation
- Concerned about managing stairs during future chemotherapy treatment
- Housing conditions posed serious risks to her health, wellbeing, and independence

Support Issues:

- Poor responsiveness from landlord
- Limited action from environmental health services
- Referred to Staying Well service for support

Main Priority:

- Securing more appropriate and safe accommodation urgently



Case Study: Personalised Cancer Support – Staying Well Project



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Support & Outcome:

- Staying Well provided housing support letter advocating for urgent rehousing
- Liaison with Happy Days for supported housing options; encouraged bidding through Together Housing and private landlords
- Successfully secured safe, suitable property with Together Housing
- **Life-changing outcome: improved stability, safety, and independence**

Practical Moving Support:

- Home visits arranged to support move and set up utilities (gas/electricity with Octopus Energy)
- Reassured about not being liable for inherited utility debts
- Help with tenancy forms and referral to Community Support Worker for housing/welfare benefits

Financial Support:

- Discussed and applied for Attendance Allowance (previously unaware of benefits beyond pension)
- Successfully awarded Attendance Allowance, improving financial independence and ability to meet health-related needs



Case Study: Personalised Cancer Support – Staying Well Project



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opportunities
trust



Ongoing Wellbeing Support:

- Regular welfare check-ins built trusting rapport and provided reassurance
- Social prescribing introduced to reduce isolation (Arts & Crafts, Chat and Chai groups)
- Accompanied to groups; enjoyed making jewellery, meeting others, and building confidence
- Activities provided sense of belonging and significantly reduced loneliness

Overall Impact:

- Comprehensive support across housing, practical assistance, financial guidance, and social/emotional wellbeing
- Transformative outcomes: safe housing, increased independence, improved financial stability, and meaningful social connections
- Silvie now feels safer, more supported, and more confident about her future

Case Study

Client profile:



- 51-year-old male
- Company Director
- Married with Teenage Children
- Diagnosis of Prostate cancer
- Treatment required

Complex Cancer Pathway



- Lives locally to GP and **Hospital 1**
- Prostate Cancer diagnosed - **Hospital 1**
- Referred to **Hospital 2** for specialist opinion
- Referred to **Hospital 3** for treatment

What is important to the client?



- Family Relationships - Worried about his wife and teenage children
- Remaining at work



Concerns Identified



- Reports no conversation regarding what's important to him.
- Family concerned – becomes emotionally distant and angry
- Remains working - struggling with anxiety and feeling overwhelmed
- Anxious about his prognosis and financial impact on his family.
- Unsure who to contact because of complex pathway
- Contacts GP Practice
- Reluctant to take time off for support needs.

How could you / your organisation supported this individual?

What approaches or resources might have helped?





Key considerations

- Empowering people to access support
- Clinical concerns need to be referred to medical team- primary/ secondary care
- Connections across boundaries/ sectors
- Supporting the whole person, including family/ carer/ friends