



# WHAT MOTIVATES PEOPLE WITH CANCER TO GET ACTIVE?

Understanding the motivations and barriers to physical activity in people living with cancer.

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CANCER SUPPORT

# Foreword

The story of cancer is changing. Macmillan's own research reveals that the number of people living with a cancer diagnosis in 2010 was two million. We know that this number reached 2.5 million in 2015, and is set to rise to four million by 2030.

Cancer patients are living longer following diagnosis than they did 40 years ago. Today a cancer diagnosis increasingly means living with the disease. Many people are experiencing consequences of cancer which require support for many years after diagnosis and treatment.

We need to recognise cancer's long term impact on people's lives. Unfortunately many will suffer from long-term physical and psychological adverse effects. These are not only uncomfortable, but affect individual and family quality of life, can be financially damaging, and often require more frequent and costly medical interventions.

As many as 70% of people living with cancer will have at least one other long-term condition and 29% will suffer from three or more. Many treated for a primary cancer will also develop a secondary or metastatic cancer which can often be incurable. Nevertheless,

these patients may live for many years with cancer and they should be supported to live as long, and as well, as possible.

Leading a physically active lifestyle both during and after cancer is linked to an improvement in many of its adverse effects and its treatments. Physical activity helps to overcome fatigue, anxiety and depression, whilst protecting the heart, lungs and bones. Being active can support the maintenance of a healthy weight as well as helping to tackle over 20 other long-term conditions. Moving more can help maintain and improve physical function, and enable people to return to work.

In some cases, being physically active has been shown to slow disease progression and improve survival. What's more, the benefits of physical activity span across several common cancer types involving a range of treatments, including surgery, radiotherapy, chemotherapy, and hormonal and biological therapies.

To enable people affected by cancer to feel the benefits of physical activity it is important to fully understand the barriers they face, and what might motivate them to become more active. This research aims to answer these questions.

At Macmillan Cancer Support, we want to ensure that everyone living with and beyond cancer is aware of the benefits of physical activity. We want people to choose to become active, at a level which is right for them, in an activity that they enjoy. Hopefully this will encourage them to stay active.

From diagnosis, through treatment and beyond, Macmillan is a constant source of support, giving people affected by cancer the energy and inspiration to help them take back control of their lives.



Rosie Loftus



Jane Maher

Joint Chief Medical Officers

# Objectives

This research aims to:

1. Understand the barriers and motivators to physical activity experienced by people living with and beyond cancer.
2. Situate findings in the wider behaviour-change literature, taking learning's from the general population and exploring what this means for the cancer population.
3. Explore whether, and how, drivers of physical activity behaviour differ for particular sub-groups.
4. Identify opportunities for change.



Walking group, Reading

# Our approach

This research involves three phases:

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## Phase one

Assessment of the existing evidence.



**Review of 55 articles**

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## Phase two

Qualitative research involving 20 in-depth interviews with people living with cancer (60 to 90 mins), plus ten with family members to understand their role in supporting or undermining physical activity (30 mins). An additional 26 people used a smartphone app to complete a mobile diary to record in-the-moment thoughts and identify real-time motivations and barriers to activity. This recorded reflective activities when people wanted to do something but were unable. Most participants also took part in an online discussion forum to reflect on their week, and discuss the kinds of support and information they would need to become more active.



**20 in-depth interviews,  
10 including family and friends**



**26 mobile ethnographies:  
in-the-moment motivations**



**21 online discussions:  
self-reflection and discussion**

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## Phase three

We surveyed 1,011 people from across the UK for their views on physical activity, based upon the findings of the qualitative research in phase two.



**Survey to 1,011 people  
living with cancer**

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# Our findings

## Phase one

### Assessment of the existing evidence

A review of the existing literature was completed to understand the barriers and motivations to physical activity in people living with and beyond

cancer with 55 articles identified. A full reference list of these articles is included within the bibliography.

Whilst several key barriers and motivations are identified as unique to people living with cancer, others are shared with the general population. These are presented in Table 1.

Table 1: The barriers and motivations to physical activity in people living with and beyond cancer as identified within the existing literature.

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	Shared with general population:	Cancer-specific:
<b>Motivations</b>	<ul style="list-style-type: none"><li>• Spending time with family and friends.</li><li>• Increasing quality of life.</li><li>• Proving they still can.</li><li>• Staying fit and healthy.</li><li>• Personal time.</li><li>• To feel good.</li><li>• Expanding social circle.</li></ul>	<ul style="list-style-type: none"><li>• Confidence in ability to become active (self-efficacy).</li><li>• Returning to normal.</li><li>• Gaining control.</li><li>• Social support.</li><li>• Spending time with people like them.</li><li>• Improving strength and fitness after treatment.</li></ul>
<b>Barriers</b>	<ul style="list-style-type: none"><li>• Lack of confidence.</li><li>• Lack of motivation.</li><li>• Embarrassment.</li><li>• Fear.</li><li>• Looking after family.</li><li>• Bad weather.</li><li>• Dislike of the gym; not the sporty type.</li><li>• Suffering from another health condition (not cancer).</li><li>• Lack of time.</li><li>• Lack of local opportunities to become active.</li></ul>	<ul style="list-style-type: none"><li>• Fatigue.</li><li>• Anxiety around safety.</li><li>• Perception that it is too hard.</li><li>• Weight gain during treatment.</li><li>• Family or health professionals discourage it.</li><li>• Uncomfortable in classes.</li><li>• Uncomfortable using communal changing rooms.</li></ul>

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These barriers and motivations to becoming active are reported across a number of tumour sites. However, there is evidence to suggest that certain barriers and motivators uniquely affect upon particular types of cancer:

- **Breast cancer:** A desire to improve body image is a motivator but embarrassment of body image can also be a barrier. Caring for a family can be a barrier to being more active however, being active as part of this role could also be a motivator. Finally, fear of developing lymphoedema is identified as a barrier.
- **Prostate cancer:** Depression, fear of incontinence, and embarrassment in public places, are all identified as barriers to activity.
- **Colorectal cancer:** Issues with a stoma or diarrhoea, are identified as barriers, making people less willing to participate in a public or group setting.

The evidence on the barriers to physical activity specific to other cancers is sparse, and mainly mention fatigue in relation to cancers with very aggressive chemotherapy treatment.

The difference between the barriers and motivators to physical activity for people at different stages of their cancer journey receives very little coverage or discussion in the literature.

While the literature provides considerable evidence of the

primary barriers and motivations for physical activity in people with and beyond cancer, the focus of the literature is:

- Rarely explicitly related to behaviour change, i.e. evidence on what is more or less effective at overcoming barriers or increasing motivations to improve levels of physical activity.
- Mainly focused on rational, reflective drivers of behaviour. There is very little evidence about the more automatic drivers of behaviour, such as habit or social norms.
- Mainly focused on breast cancer survivors, with some studies with colorectal and prostate cancer survivors.

This presents an opportunity to fill gaps in the existing literature, in terms of:

- Providing a more robust sample size than is typical of the current qualitative literature.
- Understanding what people consider to be 'physical activity'.
- Understanding the behavioural drivers for, and experience of, physical activity amongst a more varied group of people living with and beyond cancer, in particular, addressing the current over representation of breast cancer survivors in the literature.
- Understanding more about the role of family and carers in supporting or undermining interest in physical activity.

## Phases two and three

### Qualitative sample

The findings from the evidence assessment directly informed the sampling criteria for the qualitative research. The following groups were identified as being underrepresented in the existing literature.

- Young people aged 14 to 20.
- Those aged over 75.
- Those with less common tumour sites.
- People at different treatment

- stages, including those with an incurable cancer or in palliative care.
- Family members and carers.

A total of 46 people living with and beyond cancer took part. The primary quotas for recruitment were age (with over-sampling for people aged under 20, and 75 and older – highlighted in dark green in Figure 1), and treatment stage, with ten in treatment, ten living with an incurable cancer, seven with an incurable cancer and in palliative care, with remaining participants living beyond cancer.

Figure 1: Sample (n=46) by age bracket.

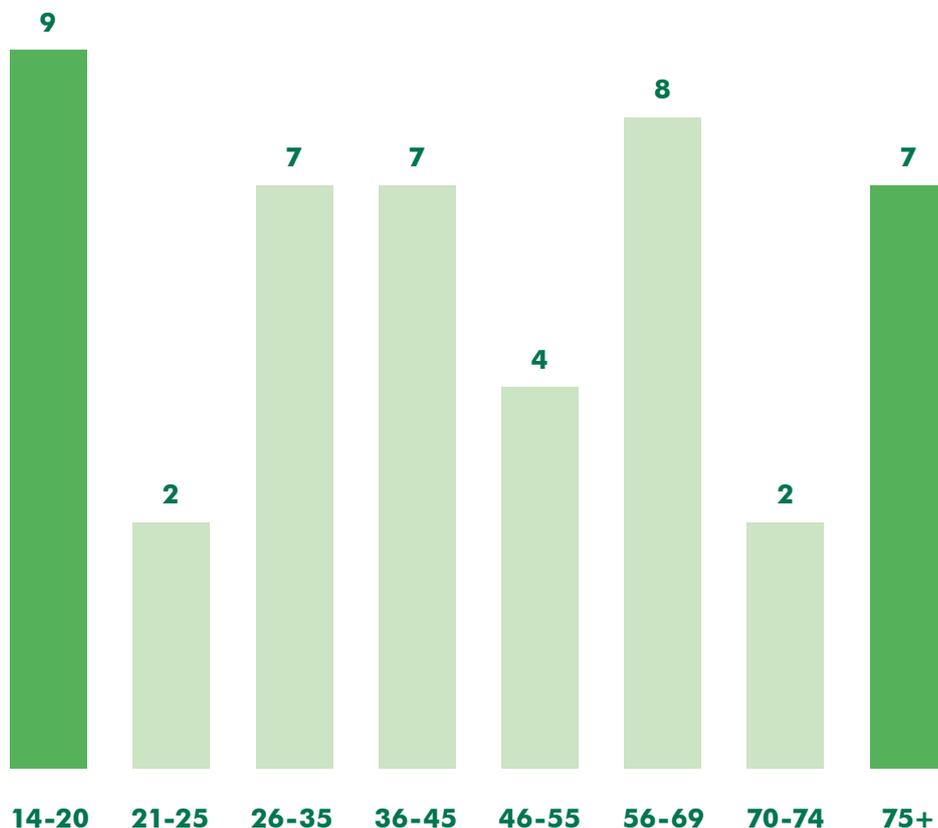
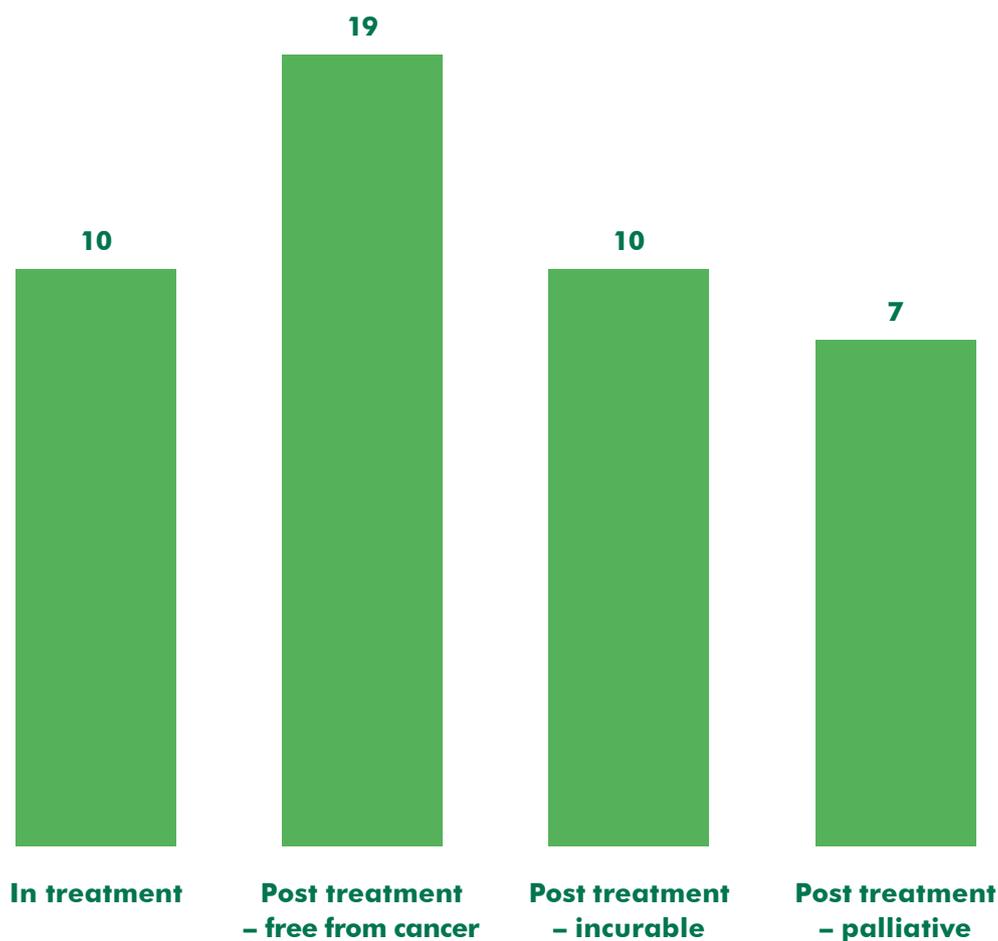


Figure 2: Sample (n=46) by treatment stage.



Participants came from across the UK with a mixture of people living in a rural or urban setting.

- 18% were living with at least one additional long-term condition.
- 10% were from a minority ethnic group.
- 76% were from a lower socio-economic group.
- 63% were female.
- Only 4% were living with and beyond breast cancer.

### Quantitative sample

Our survey (n=1,011) aimed to achieve a broad representation of those living with or beyond cancer, to confirm the drivers of physical activity identified within the evidence assessment and the qualitative research.



## What is physical activity?

It was an important first step to investigate peoples understanding of the term 'physical activity'. 'Physical activity' was associated with more formal exercise and sport. It was seen as medium to high-level intensity activities, such as running, dancing, exercise classes and going to the gym. Young people particularly interpreted physical activity as higher intensity activities.

Once prompted to think about physical activity in the context of cancer, respondents' definition shifted to include non-formalised and lower intensity activities that are part of their everyday lives. This included climbing stairs, household chores, gardening, walking pets and playing with their children/grandchildren. Often these activities were not thought of as 'physical activity' despite the medium to high levels of exertion involved.

**'These days for me physical activity is anything that means moving, such as chores, walking, getting dressed. Basically anything that's not resting.'** Female, 40-49, ovarian cancer, incurable.

Respondents often revert to understanding physical activity as formal exercise when prompted to think about increasing their physical activity level. They sometimes became

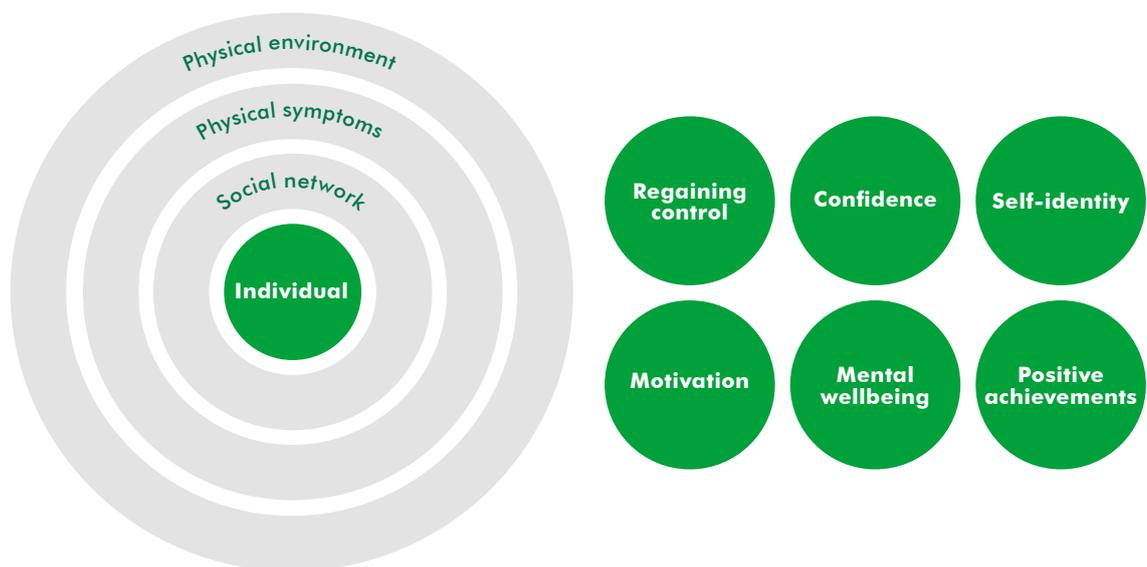
defensive about doing more when they did not feel it was achievable or appropriate for them. Respondents automatically correlated an increase in activity with strenuous exercise done for its own sake, such as going to the gym.

## What drives physical activity behaviours?

There are many complex influences on behaviour however, it was clear across all respondents, regardless of age, treatment stage, or cancer type, that despite some small differences, the most important drivers related to four areas: (1) individual drivers, (2) social network, (3) physical symptoms and the (4) physical environment.

## Individual drivers

Figure 3: The individual drivers of physical activity in people living with and beyond cancer.



Individual level drivers were highly influential on behaviour and a predictor of whether or not a person was physically active during and after their cancer diagnosis and treatment.

Individual drivers relate to a person's emotional state including their level of confidence, response to cancer, mental wellbeing, and their **self-identity**. Many respondents reported **low confidence** in their ability to engage in physical activity, their physical safety and being in public. A positive response to their cancer can mean people

are determined to fight the disease and make changes, which may include adopting a healthier lifestyle including becoming more active.

**'Clearly I wanted to fight my illness and I thought fitness would play a part. The turning point was most likely a combination of two things: concern about health in the longer term and work related stress, perhaps feeding each other. I wanted to halt that slide.'**

Male, 50-59, neuroendocrine cancer, incurable.

Respondents who rarely engaged in physical activity before cancer were unlikely to take on new activities after their diagnosis. This was particularly noticeable in older people who felt it was too late to create new habits or try new activities. Those who were previously active and experienced difficult side effects of treatments found the inability to return to previous levels of activity psychologically challenging and demotivating.

**‘All my friends go jogging. They all go to the gym. They all go to, like, high intensity cardio classes. But even swimming, I can’t do. I tried every type of exercise, and I can’t do anything. Everything causes me pain ...’** Female, 20-29, leukaemia, remission.

Wanting to **regain control** of their lives, with a focus on **positive achievements**, were strong drivers of physical activity. The act of keeping a diary, through the smartphone app, was motivating in itself. It provided recognition of their current levels of activity and helped realise the emotional benefits of moving more.

**‘I was also determined I would return to work, I did not want cancer to have the power and stop me from returning to my school. I wanted to decide myself when the time was right to retire.** Female, 60-69, pancreatic cancer, remission.

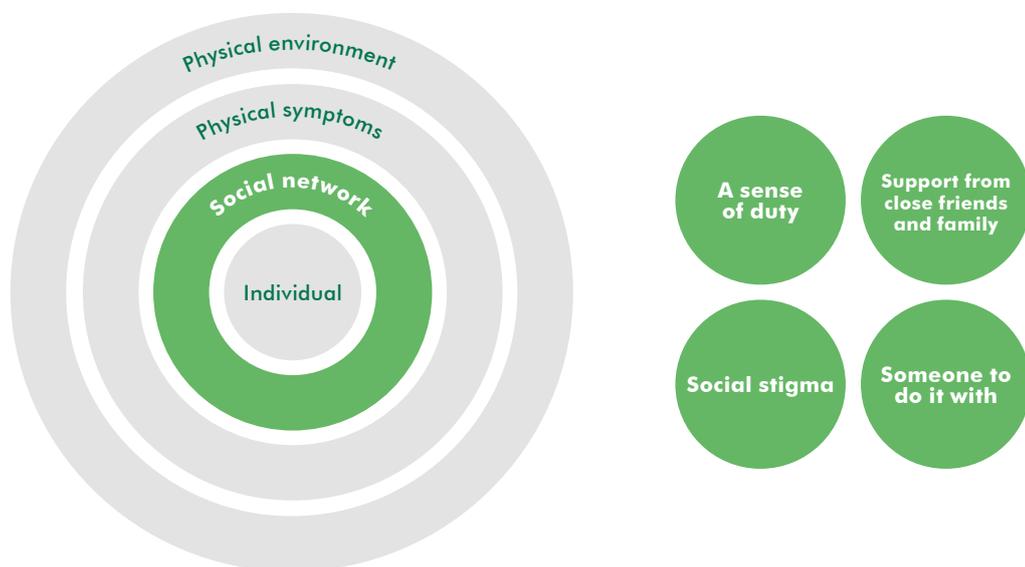
An individual’s **mental wellbeing** also had a strong influence on their attitude towards activity. Feelings of powerlessness, depression, anxiety and a lack of interest in all activities were common barriers that could be experienced at any point in the cancer journey. Our survey suggests that 38% experienced anxiety or depression as a result of cancer and its treatments.

**Motivation** towards physical activity was lowest amongst older people, those with incurable cancer and people in palliative care.

Spending quality time with family most motivated those with an incurable cancer or in palliative care.

## Social network

Figure 4: The social network of a person living with and beyond cancer can influence their physical activity behaviour.



Having a strong social network and the **support of family and friends** were strong drivers of physical activity.

Closer family and friends tended to be encouraging of activity, as they saw it as beneficial and part of their loved one 'getting back to normal'. However, our survey suggests that only 20% encourage their loved one to be more physically active. Our participants told us that more distant relatives, friends and colleagues, those who were less familiar with their capabilities, were more uneasy about physical activity and encouraged them

to rest up. Our survey showed that 29% of people living with and beyond cancer are encouraged to take it easy by their friends and family.

Family members were concerned about the physical safety and psychological wellbeing of their loved one. This was built from the perception that energy is required to fight the cancer and that energy expended being active was at the expense of this. Some feared their loved-one physically injuring themselves or psychologically damaging their recovery if they could not achieve their goals. Our survey found that

14% of people living with and beyond cancer state that family members and/or friends often worry that they are physically pushing themselves too hard. Many relatives had not discussed this with their loved ones considering it to be potentially upsetting if their views differ.

**'He'll want to polish the car, it makes me cross because he's on chemo, and it's tiring! Then if he fails it will be damaging psychologically. It reminds him he can't do what he did before.'** Wife of male, 40-49, bowel cancer, advanced.

Having **someone to do activity with** was a strong driver. Our survey showed that 61% of people living with and beyond cancer said that having a friend or a family member to be active with would be beneficial. The mobile diary revealed moments where respondents did not start or complete physical activities because there was no one to do activities with or for, or conversely they only took part in activity because someone else prompted them to do so. Older people, in particular, described that losing a partner, friend, or pet, broke routines of activity, which were very difficult to replace.

**'My grandsons also motivate me with a quick kickabout plus I recently discovered table tennis after a 40 year gap – but only because it was there and the family wanted to play.'** Male, 50-59, neuroendocrine cancer, incurable.

Social barriers derived from **social stigma** made it difficult for some to be in public spaces. This was exacerbated for those who were socially isolated with no one to accompany them out. Social barriers, fearing social stigma from peers, and fear of being left behind more acutely affected younger people.

**'Work colleagues are very aware and anxious about how I look. If I look unwell they make me sit down and rest.'** Female, 30-39, colon cancer, incurable.

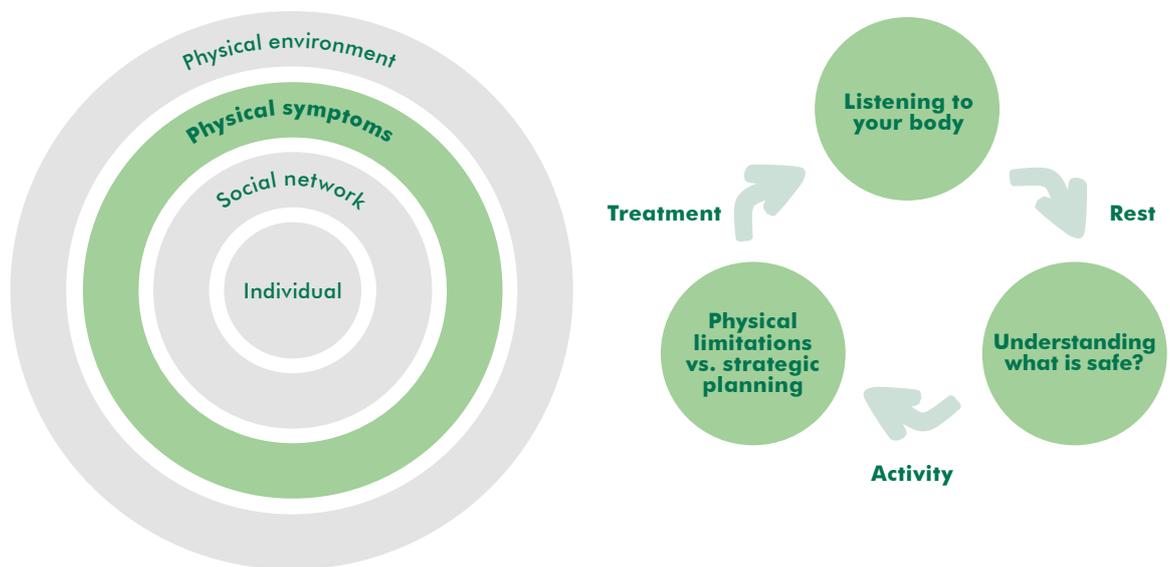
Having an external motivation such as a **sense of duty** to children, partners and pets, coupled with continuing daily life, helped create a routine to becoming active and was a strong driver especially for women.

Some respondents expressed concern about not letting other people down which could facilitate greater activity levels. However, this also acted as a barrier, with some reluctant to make plans.

**'My spaniel sat and barked at me while I tried to eat my lunch, telling me that it was time to burn off some of his energy!'** Male, 30-39, testicular cancer, remission.

## Physical symptoms of cancer and its treatments

Figure 5: The impact of physical symptoms of cancer and its treatments on physical activity in people living with and beyond cancer.



The physical symptoms and side effects of cancer and its treatments were identified as barriers to physical activity, notably fatigue and pain, incontinence (for bowel and prostate cancers), scars from surgery affecting certain muscle groups and breathlessness in those suffering from lung cancer. Our survey found 16% of people said that the emotional and physical effects of cancer made them feel unable to wear gym kit or a swimming costume.

Barriers were strongest when respondents were concerned

that activity might harm their body or slow recovery. Not knowing what kinds of physical activity to do and what level was appropriate for their particular cancer type or treatment stage was a strong barrier for some, particularly those returning from surgery that wanted specific exercises.

People wanted to know **what is safe** and appropriate for their situation, cancer type and treatment stage. They wanted information specific to them and their individual symptoms.



Scottish cancer patients participating in gentle movement class

Some respondents were able to **strategically plan** around their **physical limitations**. Others spoke about “not being disheartened” by fatigue, **“listening to your body”** and “doing whatever you can, no matter how small.”

**‘Due to lung operations and varied and multiple treatments my lung capacity is poor and I have lost weight and suffer from fatigue. I have to plan very carefully what I can and can't do during the course of the day.’**

Female, 60-29, sarcoma, remission.

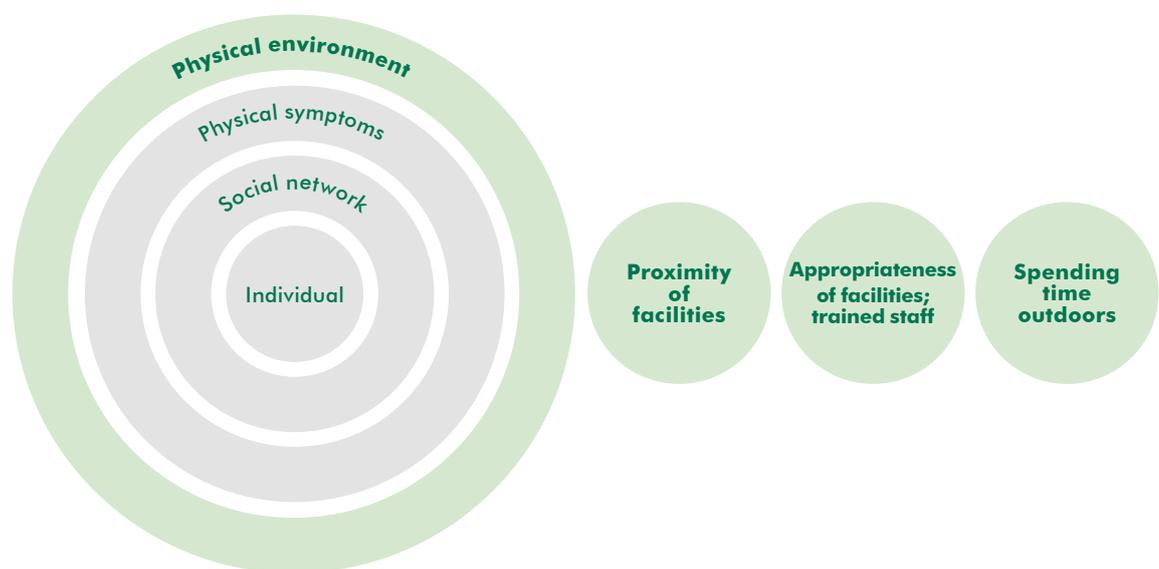
Those who were previously more active before diagnosis spoke of capitalising on good days and resting when needed. These people mentioned their struggle with not

being able to get back to previous levels as quickly as they would like.

Physical symptoms of cancer and side effects of treatment were a barrier to activity, but where the individual drivers were present, supported by a social network, people were able to plan around these.

## The physical environment

Figure 6: The influence of the physical environment on physical activity in people living with and beyond cancer.



The physical environment and the **proximity of facilities** can both widen (if they are available) or narrow possibilities (if they are lacking).

Having access to **appropriate facilities** was also a driver of physical activity. Social stigma again plays a role, with people feeling uncomfortable in public places. Often people felt uncomfortable sharing swimming pools and communal changing rooms due to discomfort showing their physical symptoms, scars, or side effects. They also had a fear of infection. People felt embarrassed to

be exhausted by a small amount of activity, as they did not look unwell.

**'The trouble I find is, because I look so healthy people forget you aren't the same inside, health wise.'**

Female, 50-59, non Hodgkin's lymphoma, remission.

**'I've got my hair now, no one sees me and thinks I was ill ... I'm not a huge person, they just don't understand why I'm walking to the corner and I'm out of breath; I don't fit the picture.'** Female, 14-19, Hodgkin's lymphoma, survivorship.

Those with pelvic cancers discussed problems with incontinence and the need for nearby toilet facilities. Our survey supported this and showed that 45% of people living with cancer were at least sometimes worried about having access to a toilet when away from the home.

Of those surveyed 39% percent said that having easier access to group activities would be useful, however, during the qualitative research, some were put off by attending formal exercise classes with the general public. The following groups tended to prefer classes specific to their needs and abilities:

- Those suffering from incontinence problems, for practical reasons as well as embarrassment and social stigma.
- Those weaker or with shortness of breath wanted a slower-paced class.
- Those who felt isolated wanted to the opportunity to meet people with similar experiences.
- Older adults preferred social and family activities.

Some did not want to attend a cancer-specific class as they did not want to feel defined by their cancer and wanted to get 'back to normal'; particularly those living with the disease for a long time who had lost friends met through cancer-specific groups.

Some wanted an option to take part in low-intensity classes, on a drop in basis,

with **appropriately trained staff** who knew what was safe for them. They also wanted the option to bring along a friend or family member.

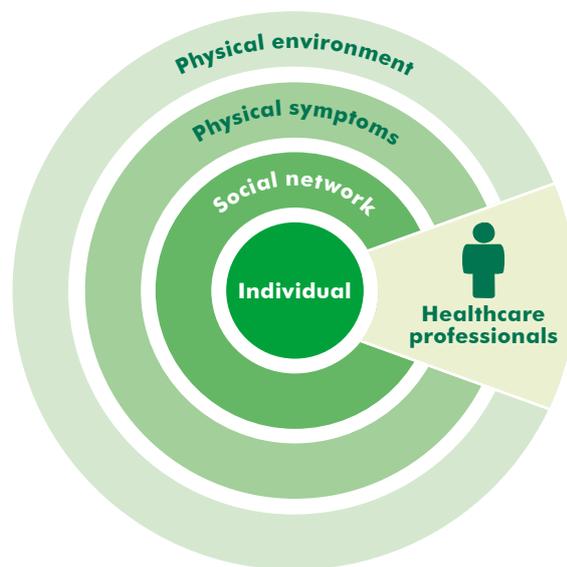
Some respondents wanted access to small pieces of equipment at home to build strength and confidence, and another respondent suggested equipment and classes to be installed at treatment centres to reduce travel.

### **Spending time outdoors**

was desirable as it was seen as 'rejuvenating' and good for mental and physical health, although bad weather was universally mentioned as a strong in-the-moment driver.

## Healthcare professionals

Figure 7 : Healthcare professionals can have a strong impact on the drivers of physical activity in people living with cancer.



Healthcare professionals can have a strong influence on physical activity behaviour. Our survey asked people living with cancer who they considered to be experts in physical activity for their condition with hospital consultants (76%) and physiotherapists (75%) coming out highest, followed by nurses (64%) and GPs (63%).

Some of those interviewed had heard messages about resting after treatment but had not received advice about what to do after this. Those who stated that they had received advice were likely to act

on it however many told us that they had not had such advice. Our survey suggests that 43% of people living with cancer do not receive any support or advice on physical activity from a healthcare professional.

**'If someone said to me "Do this much exercise, but don't do too much." Or just showed me some exercises to do ... just "build yourself up" or "do a few stretches" or whatever. I think that would have been really helpful.'** Female, 14-20, melanoma, survivorship.

Many of our participants and their family members were sceptical about the evidence of the benefits of physical activity for people living with and beyond cancer. They wanted to hear these messages from trusted healthcare professionals, gaining permission to be active, to know that it is safe and right for them and their condition.

**‘Just because you exercise, does that help the process? That has never been explained to us.**

**Is the advice available and is it supported by medical science?’**

Partner of respondent, female, 70-79, breast and liver cancer, incurable.



Macmillan professional at Luton Information Centre

## In summary

People living with and beyond cancer have their own unique barriers and motivators to physical activity however many are also shared with the general population. Some of these shared motivators take on a greater meaning following a cancer diagnosis such as spending time with family and friends, increasing their quality of life, proving they still can and staying fit and healthy. Likewise, some of the barriers shared with the general population take on a greater meaning such as a lack of confidence and motivation, embarrassment and fear, and the need to look after a family.

There are various drivers of physical activity behaviour in people living with and beyond cancer. If an individual is motivated, confident, focusing on positive achievements and regaining control, with a social network in place, then they are likely to find ways to become active and overcome any physical symptoms and limitations in their physical environment. Conversely, if they are not motivated, confident and suffering from anxiety or depression with no social network, even with few physical symptoms, with plenty of opportunities within their physical environment, they are unlikely to become active.

People living with and beyond cancer need to know that it is

safe to become and stay active, at a level that is right for them, listening to their body, starting slowly, building gradually, and planning around treatment cycles and physical limitations. These messages need to come from trusted healthcare professionals. Messages should be delivered sensitively, with useful examples and information.

People are motivated to do physical activity with family, friends, and pets, wanting it to be part of family time rather than competing with it. Family members and friends would benefit from receiving advice along with their loved one on physical activity, encouraging their involvement in discussions, planning and taking part.

The terminology used when communicating with people living with and beyond cancer about physical activity is likely to be important and could affect whether people are engaged or put off. Language could focus on 'moving more', 'increasing everyday activities', and 'reducing sedentary time'. Use of the phrase 'increase physical activity' could be off-putting for some people who were not engaged in formal exercise or sports before their diagnosis.

People may categorise themselves as inactive, even if they are seldom sedentary and take part in some, or many, activities that they do not classify as ‘physical activity’. Examples of lower-intensity activities, and ways to reduce sedentary behaviour, should be given when talking about increasing physical activity levels in the context of cancer. The expectations of those that were active before diagnosis and struggling to get back to the

levels that they once achieved should be managed.

Physical activity post-diagnosis tends to reflect pre-diagnosis levels and this should be taken into account. However, some do change their physical activity behaviours from pre-diagnosis. These are presented in Table 2.

Table 2: Physical activity – pre-diagnosis to post-diagnosis.

Active to active  → 	Inactive to active  → 
<ul style="list-style-type: none"> <li>• Initial decline during treatment, before attempts to work back up to pre-diagnosis levels.</li> <li>• Motivations to be active are similar to pre-diagnosis.</li> <li>• They have direct experience of the benefits of physical activity.</li> <li>• The habit of being active is already formed.</li> <li>• They already have the ‘skills’ and confidence to be active.</li> </ul>	<ul style="list-style-type: none"> <li>• Cancer is a turning point, especially for survivorship.</li> <li>• Supported by friends and family.</li> <li>• A way to spend time with friends and family.</li> <li>• An enjoyable ‘event.’</li> </ul>
Active to inactive  → 	Inactive to inactive  → 
<ul style="list-style-type: none"> <li>• A loss of interest in all activities.</li> <li>• Linked to depression, loss of confidence, feeling weaker and less independent.</li> <li>• Pronounced in those with incurable cancer, or of older age.</li> </ul>	<ul style="list-style-type: none"> <li>• They have never been interested in formal physical activity.</li> <li>• Sedentary habits are already formed.</li> <li>• May be older people.</li> <li>• There are multiple barriers interacting, many of which were already in place before diagnosis.</li> <li>• A lack confidence.</li> <li>• A lack of support.</li> </ul>

Some do not want to be defined by their cancer and as such would not want to attend a cancer specific class. They would welcome activities that they can attend with family or friends; led by people who understand their needs, that are appropriate for their condition and where they are not concerned of social stigma.

Establishing a routine around running the household can also help people become more active. This could incorporate activities such as playing with children or grandchildren, walking pets, and essential tasks such as shopping and cleaning.

It is the individual drivers and social network that are the key determinants of physical activity behaviour across all the sub groups involved in this research with a high degree of similarity. However, some specific barriers and motivators are identified for different age groups, cancer types and treatment stages:

Age:

- Young people tend to be more acutely affected by social barriers, fearing social stigma from their peers and being 'left behind'.
- Older people are more likely to have suffered a loss of a partner or friend, making it less likely to have someone to take part in activity with.

Cancer type:

- People with lung cancer report problems with breathlessness and lung capacity.
- Those with pelvic cancers discuss problems with incontinence and the need for nearby toilet facilities.

Treatment stage:

- People with incurable cancer may suffer from lower motivation and depression.
- Those with advanced cancer and those in palliative care tend to be most motivated by spending quality time with their family.
- Those in survivorship/remission tend to be more motivated by wanting to 'get back to normal'.

# Thanks

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