



**BREAST
CANCER
NOW** The research &
support charity

INSIGHT

Barriers to physical activity
after breast cancer



There is growing evidence of the benefits physical activity has on health and wellbeing. It's widely accepted that being physically active can reduce the chances of developing breast cancer and there is now growing evidence to support the role of physical activity during and after breast cancer treatment.

Regular physical activity can help maintain or improve health and wellbeing following a breast cancer diagnosis and positively impacts recovery. It can alleviate some side effects of cancer treatment, prevent the decline of physical function, improve long-term health, and may reduce the risk of cancer recurrence.

However, many adults do not meet the current physical activity guidelines of at least 150 minutes of moderate intensity activity each week. Women are less likely to be active than men and we know that a breast cancer diagnosis can reduce physical activity levels for many women.

As part of our bold four year 'Turning the Tide' strategy, we want to improve support for the physical and mental health and the emotional wellbeing of people affected by breast cancer.

Carrying out this insight has allowed us to better understand why women are inactive and what barriers exist in preventing women with breast cancer from being physically active. In turn and importantly therefore, it has also given us an opportunity to find out what motivations and opportunities we can build on to enable women, who are living with a breast cancer diagnosis, to increase their physical activity and ensure they are supported to sustain these changes.

This insight will be a powerful tool to ensure that we are able to better support people affected by breast cancer, empowering us and them to help improve their mental and physical wellbeing through a breast cancer diagnosis, and beyond.



Baroness Delyth Morgan
Chief Executive,
Breast Cancer Now

A handwritten signature in black ink, which appears to read 'D Morgan'. The signature is fluid and cursive, written on a white background.

ACKNOWLEDGEMENTS

Breast Cancer Now is part of the Richmond Group of Charities, a collaboration of 16 leading health and social care organisations in the voluntary sector. We are working with Sport England to combine our knowledge and share good practice to better understand how we can support people with breast cancer to become and stay active.

Thank you to the women, families and healthcare professionals who took part in this work and shared their thoughts and experiences with us. It's given us a valuable insight into the barriers a diagnosis of breast cancer created for physical activity, meaning we'll be able to better understand the gaps and ways in which we can better support similar people affected by the disease in the future.

We would like to express our huge thanks to the project team at Women in Sport for their involvement, contribution and collaboration on this insight.

EXECUTIVE SUMMARY

- Physical activity provides clear benefits to physical and mental health and wellbeing, however, many people are not meeting the recommended guidelines; breast cancer diagnosis and treatment reduces physical activity levels for many women.
- What women do to stay physically active before diagnosis is key. Although some women were active before diagnosis, many women's levels of activity had already started to decline due to ingrained habits, finances and (especially important) the perceived 'selfishness' of taking me-time, plus the skewed work/life balance whilst raising a family.
- During treatment, physical activity totally changes its meaning. It goes from being one of 'exercise' to simply getting to the shop or continuing to work, even for women who had previously been active. Women experience a loss of control; their lives are dominated by medical appointments and, in the short term, making it through to the other side. At this point, physical activity is not the priority.
- After treatment, women are relieved but are left with both psychological and physical scars. Women are unprepared for the sudden end and return to their 'normal' lives, which now feel different and can be filled with anxiety. If women were inactive before, they now have even more psychological and physical barriers, further impairing their ability to participate in mainstream activities. They are also at a low point in their fitness levels.
- Healthcare professionals and doctors are busy and overstretched. They sometimes lack the knowledge needed to answer specific questions and concerns about safety, side effects and how to match the right activities to someone's unique symptoms, attitudes and experiences. Healthcare professionals can emphasise the benefits and encourage women to stay active but more tailored support is needed to help them engage. Unfortunately, healthcare professionals are not physical activity experts.
- Breast cancer patients are individuals yet, often, there are no tailored approaches available to guide them into the right activities. As a starting point, there needs to be recognition of individual circumstances, personality types and what they enjoy, as well as treatment backgrounds and health profiles.
- Interventions need to be more effectively considering the who, what, when and where to reach patients at intervals in which they are both psychologically and physically able to engage.
- Care with language and 'positioning' of activities is crucial. It's less about an extended 'treatment', and more about being in control and doing something for you.
- Good practice is evident. However, although current physical activity initiatives have benefitted many patients, services are geographically patchy and not always available. Cost is a big issue, especially in cases where there has been a loss of income due to breast cancer, so free access and low cost options need to be available.
- A structured framework needs to be developed involving a national network of professionals from sporting and health sectors, using on and offline resources to create plans which can be more tailored to individual motivations and capabilities. Include step-by-step progression and celebration of achievements along the way.

OVERVIEW OF PHYSICAL ACTIVITY

Physical activity guidelines

Physical activity is an important component of a healthy lifestyle, with many benefits to health including improved sleep, maintenance of a healthy weight and a reduction in risk of conditions such as diabetes, cardiovascular disease and some cancers.¹

The UK Chief Medical Officers' Physical Activity Guidelines recommend adults are active daily, and do at least 150 minutes of moderate intensity activity per week (defined as increased breathing, you are still able to talk but not sing, your heart rate is raised, and you feel warmer)² or at least 75 minutes of vigorous intensity activity per week (breathing is faster and talking is difficult, you can't say a few words without pausing for breath)² or a combination of the two. To keep muscles, bones and joints strong, it is recommended that on two days, strength activities are undertaken.¹

The guidelines also apply to adults over the age of 65 years and otherwise healthy cancer survivors, with the added consideration of activities to improve balance. The advice is to build up gradually,¹ depending upon their current activity levels. With this in mind, the guidance is clear that any activity is better than nothing. It is important to break up periods of sedentary activity throughout the day and to think about simple things that can bring more activity into the day. This could be as simple as carrying heavy shopping bags to the car, standing or marching during advert breaks on the tv or taking up yoga or chair aerobics.

Adults should do some type of physical activity every day. Any type of activity is good for you. The more you do the better.²

Examples of activity

Moderate aerobic activities	Vigorous activities	Very vigorous activities	Strengthening activities
Brisk walking	Jogging or running	Lifting heavy weights	Carrying heavy shopping bags
Water aerobics	Swimming fast	Circuit training	Yoga and Pilates
Riding a bike	Riding a bike fast or on hills	Sprinting up hills	Tai chi
Dancing	Walking up the stairs	Interval running	Lifting weights
Gardening	Sports – e.g., football, rugby, netball and hockey	Running upstairs	Working with resistance bands
Hiking	Skipping rope	Spinning classes	Body weight exercises such as pushups and sit ups
Rollerblading	Aerobics		Heavy gardening
	Gymnastics		Wheeling a wheelchair
	Martial arts		Lifting and carrying children

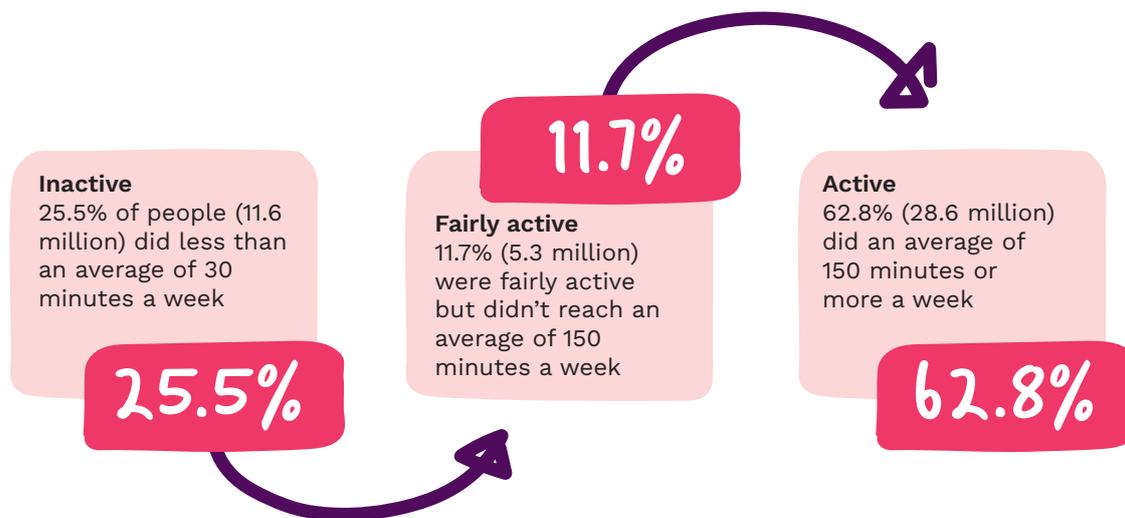
Status of activity

Definitions of activity levels:

Inactive	Fairly active	Active
less than 30 minutes a week	30 – 149 minutes per week	at least 150 minutes per week

Sport England survey data from 2019 – 2020 showed that just over 6 in 10 adults achieved at least 150 minutes of activity a week:³

Categorisation of adults' physical activity levels according to their weekly active minutes



The findings varied by various demographic features, for example men were more likely to be active compared to women (65% vs 61% respectively) and activity levels decreased with age with a sharp decline over the age of 75 (69% active for 16–34 year-olds, 66% for 35–54 year-olds, 60% for 55–74 year-olds and just 40% for over 75 year-olds). Activity levels were lower in those with disabilities and long-term health conditions compared to no disability (47% vs 67% respectively).³

Importance of physical activity

We know from existing evidence that the risk of developing breast cancer increases with age, with the majority of breast cancers occurring in women aged over 50, and we also know that this risk can be lowered by being more physically active. It is estimated that in the UK around 1% (3,400 cases per year) may be linked to individuals doing less than the Chief Medical Officer's recommendation of 150 minutes of physical activity per week.

However, figures indicate that 36% of women aged 45–54 do not meet the recommended levels of physical activity and 22% are considered inactive, with this figure increasing the older women get. Following a cancer diagnosis, being physically active has a positive impact on recovery and can be beneficial in reducing re-occurrence.⁴

RESEARCH APPROACH

Physical activity is an important component for health, yet we can see that current physical guidelines are not being met. Therefore, supporting an increase in physical activity levels for women over the age of 45 is important in terms of the prevention and recovery from breast cancer; so we wanted to understand how to give women the best support at different stages following a breast cancer diagnosis.

Stage 1: Literature review

Our initial research phase was to review information published online which included specific terms including: breast cancer, prevalence, diagnosis, treatment, survivorship, physical activity. Key reports and projects from 2009 were included from UK cancer charities (for example Cancer Research UK, Breast Cancer Now and Macmillan) and Health/sport organisations (the NHS, Department for Health and Sport England) in addition to academic research from the past five to ten years.

Stage 2: Qualitative and quantitative research

Following the literature review our research aimed to:

- Understand the relative importance of breast cancer on activity levels compared to other variables (such as age, hormones, menopause, weight, lifestyle, and caring for others) when it comes to engaging in physical activity for post-menopausal women
- Determine the best ways to engage (or re-engage) older women in mainstream physical activity following their breast cancer diagnosis
- Identify the role that positive influencers, such as friends and family and healthcare professionals can and should play in supporting and motivating women to be physically active

To do this, we spoke to women with a breast cancer diagnosis within the past five years who had completed the intensive phase of their treatment. The majority of the women were post-menopausal and aged 45-65. To get a full picture of their health, we also spoke to the friends and family of women with a breast cancer diagnosis, in addition to speaking with breast cancer nurses. This gave us a better insight into the barriers to physical activity and what we could do to support this issue.

The gathering of insight was obtained through a variety of approaches:

- Online survey of 112 women to explore attitudes and experiences towards physical activity using Breast Cancer Now's Insight and Experience Panel
- Four interviews with women who were physically active to understand their attitude towards activity
- Four interviews with breast care nurses to understand the healthcare professionals' attitude towards physical activity and the advice they currently give to breast cancer patients
- Three focus groups with women with a breast cancer diagnosis focusing on particular physical activity themes which are highlighted through surveys and in-depth interviews
- Focus groups and interviews with friends and family (key influencers) of women with a breast cancer diagnosis

Following all of these activities, there was a workshop to review the findings and outcomes which included women who had experienced breast cancer, physical activity providers, Sport England, staff from Breast Cancer Now and Women in Sport.

The rest of this report describes the research.

OVERVIEW OF FINDINGS FROM LITERATURE SEARCH

Physical activity and breast cancer

Although physical activity participation data for cancer survivors in the UK is somewhat limited, Macmillan Cancer Support estimates that there are 2 million cancer survivors in the UK and around 1.6 million do not meet the Chief Medical Officer's recommended levels of physical activity. However, it is unclear how many of these individuals are female breast cancer survivors.⁵ We did see consensus within the literature review that physical activity levels are low after breast cancer treatment and there is a significant decline in physical activity following breast cancer diagnosis and treatment.⁶⁻⁸

Macmillan Cancer Support suggests that there are four key stages within the cancer care pathway where physical activity may be beneficial to cancer patients: pre-treatment (prehabilitation), treatment (symptom control) and post-treatment (rehabilitation), which are broken into two further strands: survivorship (health promotion) and palliative care (quality of life).⁹

Prevention and recurrence

The Department of Health state there is 'strong evidence' to support an inverse association between physical activity and risk of breast cancer specifically¹⁰, with a 20% lower risk for adults who participate in daily physical activity. Breast Cancer UK¹¹ report that the effect exercise has on reducing the risk of breast cancer is 'considerable', especially for postmenopausal women, and cites research that moderate exercise of 150 minutes per week is estimated to reduce the risk of breast cancer in postmenopausal women by 20–30%. The specific percentages for risk reduction vary in the literature that was reviewed, however, all discussed a link between being physically active and a lower risk of breast cancer.

We also saw growing evidence that physical activity may also reduce cancer patients' risk of a breast cancer recurrence and of dying from the disease.⁹

Treatment side effects and recovery

Macmillan's Move More report refers to physical activity as the 'underrated wonder drug' that can help cancer survivors cope with both the short and long-term side effects of cancer.⁵ Living with primary and/or secondary breast cancer can be an overwhelming and life changing experience. Receiving a diagnosis can be very distressing and it is common for women to experience feelings of shock, anger, anxiety and uncertainty about the future, which can lead to depressive symptoms. After treatment, some women also experience lower body-image perceptions (due to weight gain, hair loss, skin/breast changes) and reduced confidence.

Breast cancer treatment can be physically and emotionally taxing for women and Macmillan state that during treatment, cancer patients often become 'physically deconditioned', losing cardiovascular and muscular fitness, and experience fatigue. This leads to the traditional view that 'rest' is required; however, this only adds to the decline in physical fitness. A number of studies have investigated the positive impact that regular physical activity can have on both physical and psychological health during treatment for breast cancer.

Physical activity interventions

There were a number of studies which supported being physically active post breast cancer diagnosis and, in particular, the positive outcome in quality of life. Despite this, however, Macmillan's Move More¹² report revealed some troubling



findings with regards to the education and promotion of physical activity within general cancer care. While this is not specific to breast cancer, it still remains relevant. One in 10 doctors and nurses believe it's more important to encourage cancer patients to 'rest up' than to be active and only 6% of those surveyed talk to all their patients with cancer about physical activity. The Move More report presented four key findings, two of which are important to this review and breast cancer survivors:

- 'Breast cancer patients' risk of recurrence and of dying from the disease can be reduced by up to 40% by achieving the recommended levels of physical activity'
- After treatment, all cancer patients can reduce their risk of experiencing side effects of cancer and its treatment by achieving the recommended levels of physical activity. These include fatigue, depression, osteoporosis and heart disease.'

Therefore, Macmillan recommended that physical activity should form part of standard NHS care for all cancer patients, and that every person with a cancer diagnosis should be offered support and guidance to encourage them to gradually build up to 150 minutes of physical activity per week.

OVERVIEW OF FINDINGS FROM RESEARCH INTERVIEWS

Overview of activity rates pre- and post-breast cancer diagnosis

Within the survey results, most respondents were aged 55-64 years old, they had received their cancer diagnosis within the past five years, just over half had received their diagnosis within the previous two years and had received a variety of treatment types for their breast cancer, with 64% still receiving hormone treatment. Only 10% of respondents were no longer experiencing regular side effects.

Prior to their breast cancer diagnosis, around 49% were doing physical activity most days (still well below the national average); 28% were active at least once a week and the remaining 23% were active twice a month or less (or not at all).

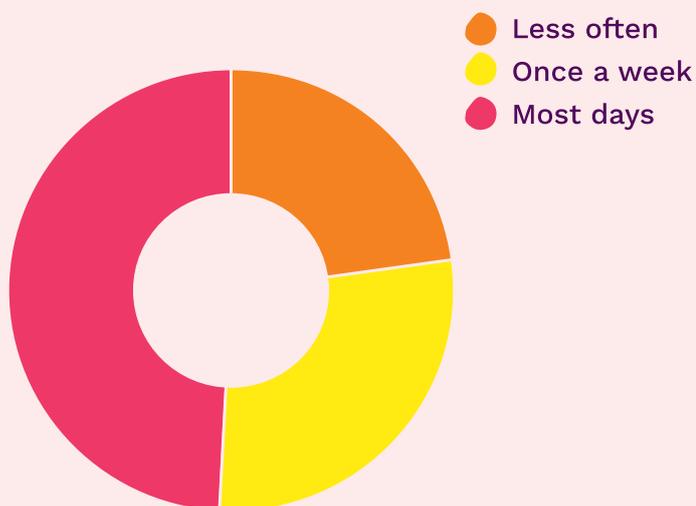
When asked the same question regarding their activity levels now, 43% were doing physical activity most days and 30% were active at least once a week, with 27% being less active.

When asked to compare how active they felt they were pre- versus post-breast cancer diagnosis, women reported:

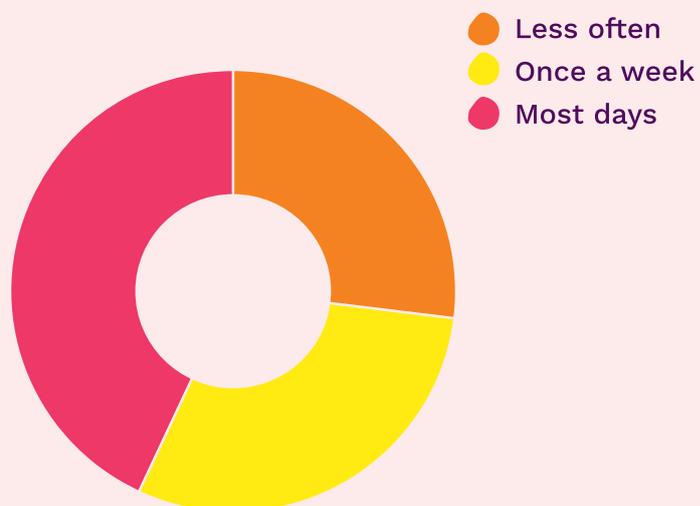
- More physically active – 29%
- No change – 13%
- Less physically active – 58%

This suggests that the diagnosis and treatment of breast cancer has negatively impacted activity levels for the majority. When asked if they would like to be more active, a resounding 84% replied 'yes'. So there is a wish to make a change, yet 61% report that they avoided exercise altogether.

There were barriers to physical activity for women prior to their breast cancer diagnosis. These included weight and confidence considerations, health problems, menopause and other life factors such as work and family taking priority, so activity levels had already begun to decrease. Side effects following treatments for breast cancer was reported as the main reason for avoiding physical activity (66%), followed by feeling too unfit (41%), being concerned about injury following surgery (22%), or not knowing which activities are appropriate (19%).

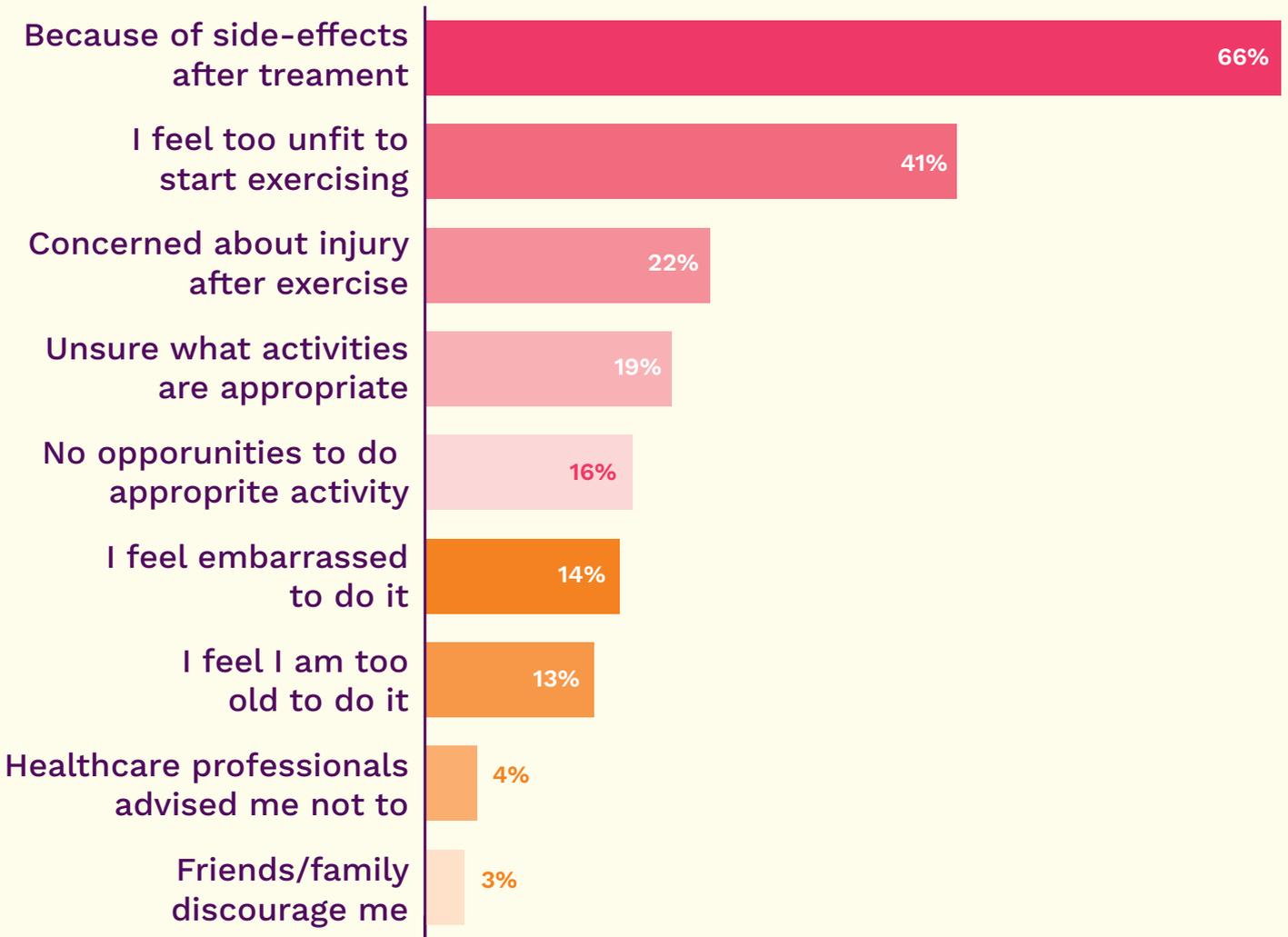


Frequency of physical activity – pre-diagnosis



Frequency of physical activity – post-diagnosis

Why avoid exercise? (amongst those who avoid exercise)



At diagnosis

Diagnosis can come as a major shock to patients and their families, turning their lives upside down. Once treatment begins, women are at a low point physically and vulnerable to exhaustion, infection and in pain, with their lives scheduled around appointments, treatments and surgery.

Day-to-day life is put on hold. This is a time where the short-term focus is on 'getting better' and 'getting through it' and while some women try and keep active, it can be hard as even daily activities become difficult to manage.

As mentioned above, one of the barriers to physical activity for women was being concerned about injury or not knowing what is appropriate for them to do, with messages mixed and loved ones not knowing how they can support.

"If someone had said exercise to me, I probably would have felt quite upset."

Inactive woman, Hunts

"You can't swim cos you'll get an infection so you can't go to the local baths or anything like that."

Inactive woman, Manchester

" I was so poorly at one point my husband had to carry me to the bath and wash me, he was fantastic... I didn't realise that happened to people unless they were like in a nursing home. "

Inactive woman, Manchester

" I said I was really tired and a bit depressed and they would say, 'Oh well, just rest and take it easy', there was no suggestion that if I did something I enjoyed it might make me feel better. "

Bright Spot, London C

Few patients reported receiving clear advice on maintaining physical activity, and many were confused by conflicting advice such as 'stay away from infections', but not the detail of what that actually meant.

When asked if, since diagnosis, a healthcare professional had provided guidance on exercise or physical activity, 42% said they had been encouraged to do physical activity, 2% were discouraged and 56% said no.

There are many missed opportunities to reach women with information to support physical activity, such as during their routine follow-up appointments, especially when they were in the hospital for significant periods of time (bloods/ chemotherapy) and so could have been given advice by healthcare professionals, booklets, apps or websites, LCD screens and so on.

Post-treatment

When the phase of intensive treatment has passed, the number of appointments and impact of the treatment regimen decreases significantly, and life for some will return to a welcome 'normal'. For some women however, this can cause new difficulties and anxieties which are confusing and overwhelming, especially with reduced contact time and less opportunity to ask about everyday things such as physical activity. For many, treatment doesn't stop altogether (64% of the women we spoke to were still on hormone therapy) and they bring their own side effects in addition to the continual worry that the cancer may return.

" I just walked the dogs as much as I could. But I wasn't really told anything about exercising or not exercising... Nothing from chemo nurses or breast care nurses, there just didn't seem to be much information. The Move More (Macmillan) was the only thing I found... But it wasn't close enough to make it workable. "

Active woman, London

" I can't remember talking about exercise but the problem was we didn't know what exercise or how much. Should she be doing any exercise or should she not be doing any, and should she be resting? "

Friends and Family, Mother

" There's an awful lot of advice to take it easy, so you don't really know how much to push yourself. I didn't come from a family that would push themselves but I was very conscious of wishing I could do more because I was worried about weight. "

Active woman, London

There are both physical and emotional impacts on how women feel after treatment:

Physical impacts	Emotional impacts
Fitness levels are at an all-time low. They may feel fatigue for a long time after treatment ends and have lost muscle tone. Surgery may also mean an extended recovery period.	The desire to take back control of their lives and what they choose to do.
Women's appearance has changed, particularly when surgery formed part of treatment.	Women's confidence is low, regardless of where they were before their diagnosis. They lack self-confidence and feel more self-conscious.
Women experience a range of side effects, which for some can be extremely debilitating.	Women want to get back to 'normal' but are worried about the cancer coming back, wanting to give themselves the best chances and not do things wrong.
Women who completed our survey had been through a range of treatments and often surgery.	Anxiety about what's best, uncertainty about what they can and can't do.
Women are unclear how quickly they should expect to feel fully 'recovered'.	

The ending is not the new beginning most breast cancer patients were hoping for.

How women feel both physically and emotionally will vary in the same way that their approach to support groups, physical activity and life in general does. That's why thinking about each person as an individual and tailoring any plans to them is critical to a successful intervention.

Beliefs and barriers to physical activity

The barriers to behaviour change can be considered in terms of capability, opportunity and motivation. We put together a series of questions utilising University College London's Capability Opportunity Motivation-Behaviour (COM-B) model¹² in order to help us understand

activity behaviour among women with a breast cancer diagnosis. We wanted to explore:

- Physical capability – do they have the skills, ability, strength and fitness to take part in a sport or physical activity?
- Psychological capability – do they have the capacity to engage in the necessary thought processes such as comprehension and reasoning?
- Physical opportunity – are there opportunities to do physical activity such as access to leisure centres, do they own the right clothing or footwear?
- Social opportunity – are there cultural and social norms to be active, are their friends and family active, is there an assumption that women with breast cancer should not be active?
- Reflective motivation – do the women wish to do physical activity? Do they believe activity is good for them?
- Automatic motivation – do the women anticipate enjoyment when taking part in sport or physical activity?

In terms of the barriers to physical activity, capability is typically the strongest. Women are experiencing unexpected trauma physically and emotionally which are tough barriers to overcome, especially with limited or no support and guidance. We have listed some of the different barriers women told us about below.

Capability barriers:

PHYSICAL	PSYCHOLOGICAL
Weight gain leads to women feeling insecure with other women and not wanting to wear skimpy Lycra	Lack of knowledge about what to do to prevent recurrence, fear that 'it'll just come back'
Women's fitness levels are at a low; a combination of treatment, extra rest and putting on weight	'What is the cancer?' and 'What is me getting old?'
Pain, soreness, nerve damage and other side effects	Lack of knowledge about own limitations or safety
Fatigue, muscle weakness, aching bones, heavy body	Too many other things to think about
Worrying about being knocked and pain increasing	Fear of judgement, fear of failure, feeling unfeminine
Body adjusting to new medications takes time	Frustration with skill or fitness level and having to go bit by bit
Increased heart rate, sweating, early menopause	Guilt at not being there for family like before
No feeling on one side – leads to dangerous falls	Nobody to talk to about apprehensions, impossible role models
Feeling of inflation or water retention in one side	Issues with relationships that may have changed
	Unprepared for side effects that continue

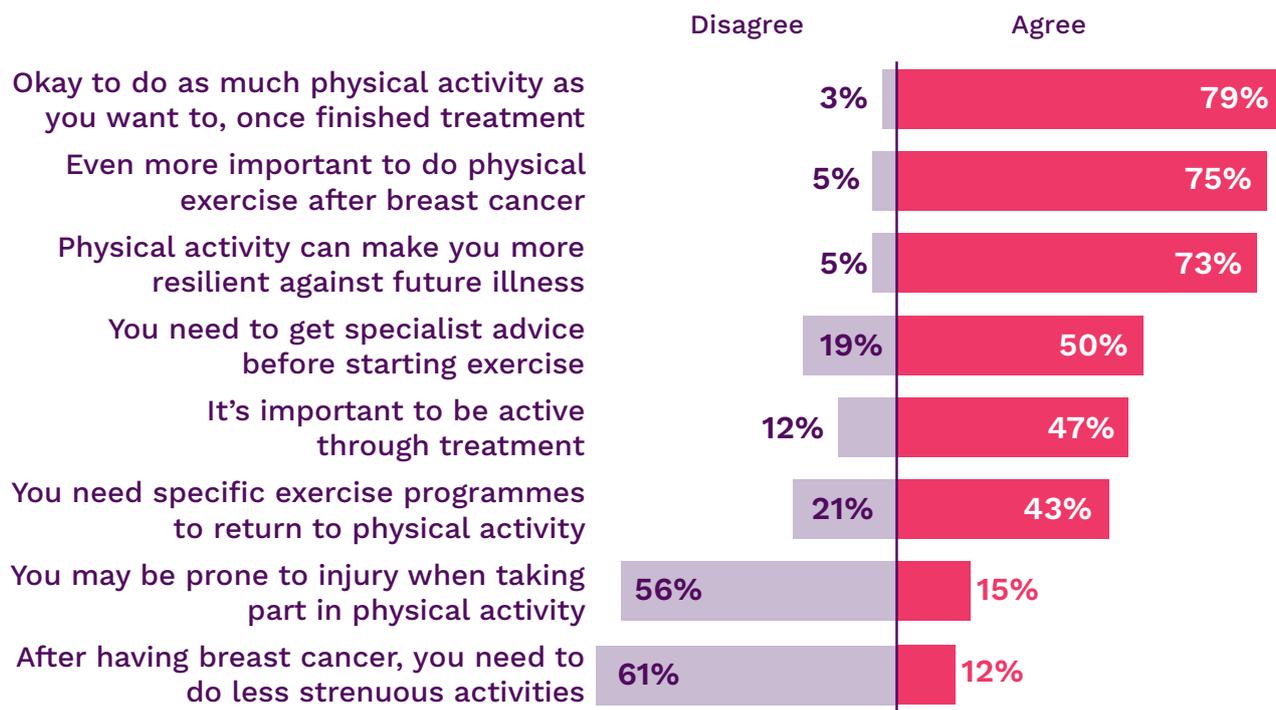
Opportunity barriers:

PHYSICAL	SOCIAL
No evening classes available for working women or sporting activities at the right time	Feel the need to be at a certain level to 'fit in'
Limited funds for exercise; having reduced earnings because of cancer	Groups create an expectation that all should keep up
Difficulty in finding information	Lack of specialists – you can't just walk up to an instructor and say 'Hey, I've had cancer' as they're likely to say take it easy
No help and advice on individual situations	Advice is around what to avoid rather than how to push further – nothing tailored
Have to plan ahead for classes, but lost spontaneity for individual activities	Feeling guilty for time off work to exercise after having had time off sick already
Don't always want to hang around with other patients	Good teachers exist but once they leave, their classes fall apart, such a dance group at the Haven where 10 ladies were left without a teacher
Loss of old relationships with teammates, classmates, or national groups and networks	
Effective sportswear is expensive, so prohibitive for some	
Unsupportive friends and family	

Motivation barriers:

REFLECTIVE – CONSCIOUS REASONING	AUTOMATIC – UNCONSCIOUS HABITS
Unsure of right things to do. What is best for me given my symptoms? What will I enjoy it? Who will go with me? Will I make myself worse?	Habit of exercise is gone – unconsciously feel should be resting, putting family first, taking it easy (self-care = relaxation)
I can't compete any more	Anxiety about survival such as work, earning money, being a mother. Exercise seems indulgent (not an integrated part of recovery)
Exercise has lost its excitement	Don't like 'battle' talk – turns many off
I've no control over my body	Only one (limited) energy source – if I spend it on exercise, there's a fear I won't get up again
I'll make a fool of myself or hold people up	Physical activity interpreted as 'exercise'
My mind is willing, my body is not	
Unsure it is possible to ever feel fit again	
Nobody to celebrate with me when I do well	

Perceptions of taking part in physical activity following a diagnosis of breast cancer



We asked the women in our survey whether they agreed or disagreed with a series of statements as above. The outcomes indicate that it is less about education regarding the benefits of physical activity, and more about the provision of support and advice on which activities are suitable for their level of physical ability. There is also evidence of anxiety and uncertainty faced by the women for which support and reassurance are required.

When comparing cancer-related barriers with other variables, it is clear that those highlighted pre-diagnosis are further exacerbated post-diagnosis, in addition to more barriers being created. A key point here is that women do not have time to prepare for a breast cancer diagnosis. It happens fast and control is quickly lost, resulting in a high level of anxiety, which adds to the physical and psychological barriers they have post-treatment.

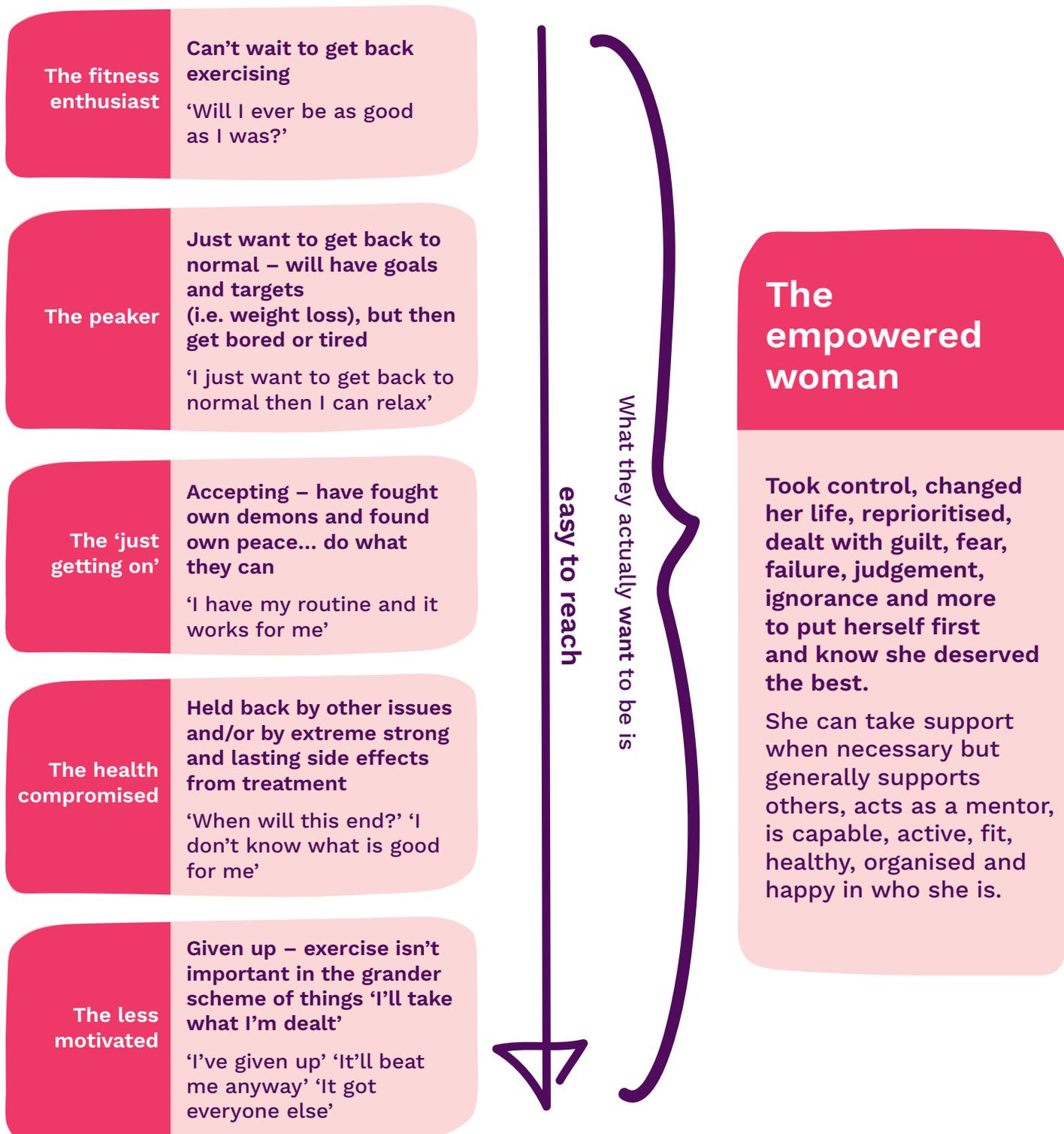
Considerations to support physical activity, therefore, needs to be specific to those who have direct experience of cancer, rather than the general female population within this age bracket. That said, physical activity should not be seen as a continuation of breast cancer treatment, but instead as something they are doing for themselves and with a variety of activity options, tailored to their individual needs.

“ You don't want to make yourself worse and you know that could happen if you go to a mainstream gym because they don't understand. ”

Inactive woman, Manchester

Segmentation of women into attitudinal types

Through our research with women, we began to see patterns in their perceptions and beliefs and how they may impact their approach to physical activity. These are detailed below but could be utilised to support the creation of tailored programmes which speak to the needs of individual motivators.



Some examples from our research of women who fit each of the segments:

THE FITNESS ENTHUSIAST

" I agree there's a turning point – recovery then prevention. When she had done the triathlon she was so high she just loved it. She had success and made friends on the team and she saw it's not just her going through it, that was her turning point. She kept in touch with them and now she wants to stay healthy because of it. "

Friend, London

" She's doing stuff now, learning stuff she didn't know before, like a course on crawl. She did cancer fundraising swim last year which was fantastic as well. "

Husband

THE 'JUST GETTING ON'

" If I want to go swimming, my husband will say I'll come with you, or if I want to go for a bike ride, he'll get his bike out. "

Inactive woman, Hunts

" She works from home, it's brilliant she can just go across to the gym in the daytime, that's her routine and she loves it. I think she goes three times a week and sometimes takes her boy. She acknowledges it helps her, yes. "

Friend

THE HEALTH COMPROMISED

" She really couldn't do any exercise, she could walk but if she came to swimming or anything she couldn't because she ended up with cellulitis and she'd get it in her legs, so she has always been restricted really even before the cancer. She tried to get about make sure it didn't travel even further up her leg. She did the sitting Zumba before she had the cancer, because another problem was the weight. "

Mother of inactive woman

THE PEAKER

" Recently I've spent far too much time sitting on my bum, despite the light evenings and the gadded. It's just boring, I could make more productive use of my time, like going to the David Lloyd as I know people there. "

Inactive woman, London

THE LESS MOTIVATED

" I've asked her to come and she has promised but she never has. We are all rooting for her but it's like she doesn't want it... She said to me I don't see the point of any of it because it's just going to come back, the cancer. She wants to lose weight and live her life but what's the point if it just comes back? "

Active woman, London

OTHER PERSPECTIVES

Healthcare professionals

Within our survey, we found that 56% of women hadn't discussed physical activity with their healthcare professional. Clinics are often overstretched which is a key barrier for healthcare professionals to providing more in-depth consultations and support. Simply put, there are too many patients and not enough staff to provide the service patients need and healthcare professionals want to deliver. Some breast cancer nurses do provide support around physical activity, but this is highly variable across services. In addition, whereas previously patients would stay within the hospital service for five years, this is no longer happening.

The majority of low-risk patients are discharged after one year and managed through a self-directed care package with limited contact.

It's support women need rather than more treatment. The focus needs to be on enjoyment and what they will get from it.

Although oncologists are extremely influential, it is the breast cancer nurse who is more likely to discuss physical activity with women, particularly with the emphasis on health as opposed to weight. Oncologists typically talk about physical activity in relation to keeping weight down which can turn off many

women. Referrals to programmes have their own issues if not clearly outlined or with follow up, and GPs don't seem to be well versed in supporting women in physical activity. Currently, there isn't anyone who is tasked with talking about physical activity, meaning women do not know who they should address their questions with.

While a breast cancer nurse isn't a fitness expert, they may be well placed in supporting someone to get active in their own way. They should be reinforcing the benefits of being active, but they need somewhere to refer these women to. This aspect should be distinct from treatment interventions and tailored to each woman, but there is a clear need for more support for healthcare professionals so they can help women in this area.

Family and friends

Friends and family can provide great support and are generally untapped and under-utilised, despite many being desperate to help. Most are supportive of being active and can be a buddy or motivator. 45% of women in our survey said their friends and family had encouraged them to be more active. Friends and family still need the support and information in terms of what level of activity is suitable, and how to motivate their loved one while ensuring that they are not compromising recovery. There is a huge opportunity to use them in future initiatives, communications and support.

FUTURE CONSIDERATIONS

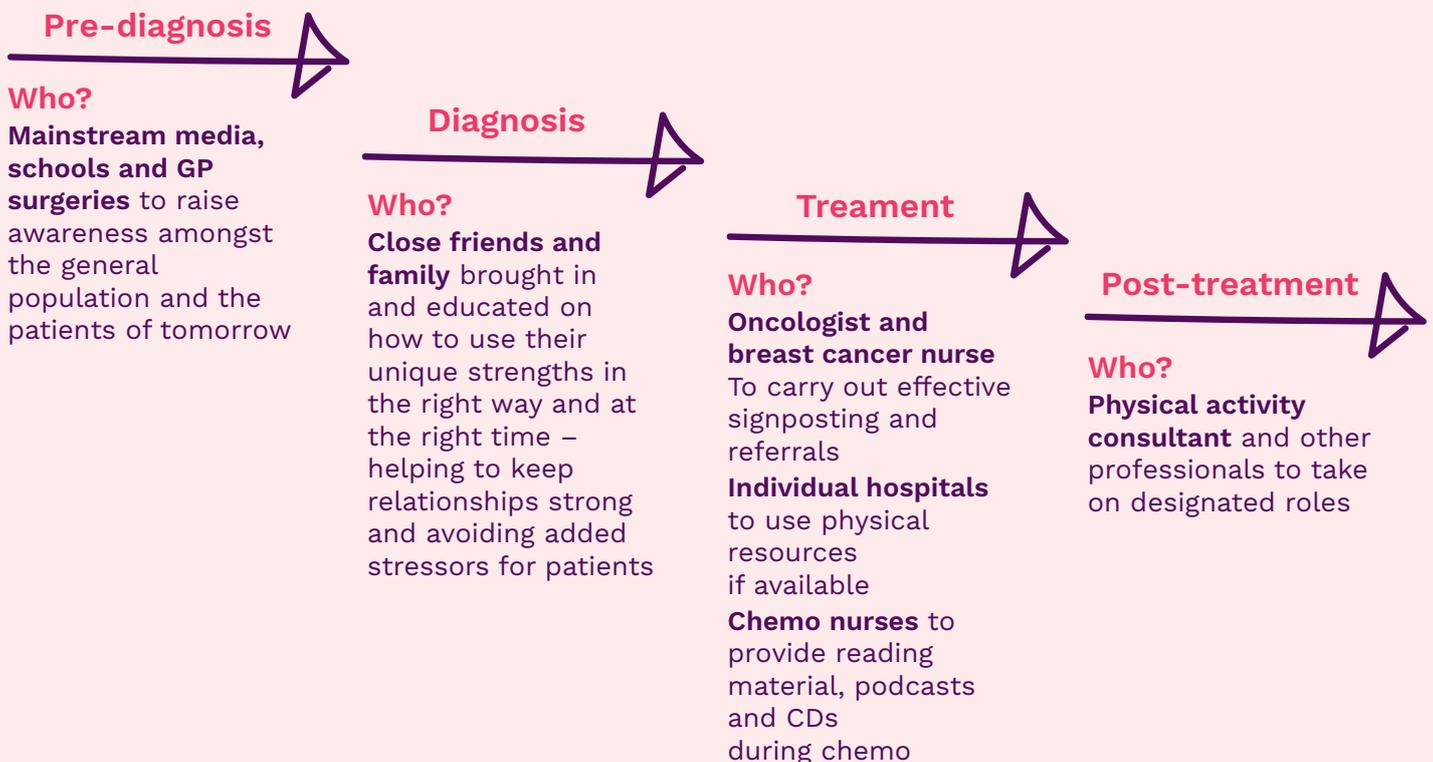
An intervention development workshop took place in Birmingham to share these insights and bring together a number of stakeholders from both the sport and leisure sector, including women with a lived experience of breast cancer. Below are some of the considerations and ambitions that need to be built into physical activity programmes.

Programmes need to be realistic in their expectations of women while being flexible enough to fit with different motivators, capabilities and preferences. For those who feel unwell and have side effects, it may take a lot of effort to feel motivated and get going again. There will be good and bad days, so we need to be mindful that programmes should be reflective of this. Above all there needs to be support, reassurance and encouragement along the way.

Creating a post-treatment plan

It is important to consider the patient journey when planning any intervention relating to physical activity. In the early stages post-diagnosis, there is the grief and shock for a woman to deal with, then treatment. Once those stages pass, it's time to encourage physical activity. That said, the psychological preparation and the introduction of thoughts around physical activity should come earlier, to ensure it feels like a natural progression and a continuation of their holistic healing. As shown above, a designated professional would instigate this, but the ideal scenario would be to bring in the engagement and support of friends and family to implement the plan.

Who could be involved and when?



Key objectives for a post-treatment plan are:

Clearing confusion and managing expectations: Create a clear and concise approach to conveying ‘what’s harmful’ and ‘what’s good for me’ after treatment, led by healthcare professionals and accredited trainers, including education on potential side effects and finding ways to navigate around them

Mind and body integration: Although much is made of the physical journey women have in re-engaging in mainstream activity, the mind is just as important a barrier. Aim to deliver techniques that engage both mind and body in order to focus, empower and put women back in control.

New habits: Often, the types of physical activity that are both possible and beneficial following breast cancer are different to those activities carried out prior. We must be aware of how alien and disconcerting it is to some women to seek out new activities, new friendship groups, new classes, new timetables and new networks – and make it both exciting and easier.

Building trust: It is far too hard to find activities where women feel they can show up, as they are, without being judged. Create an accreditation scheme for licensed and experienced personal trainers, as well as a solid referral process for healthcare professionals to use nationwide and membership platforms where patients can share experiences locally.

Using friends and family: Following treatment, patients try to focus energy on repaying the support they received during treatment, at the expense of self-care. We need to engage friends and family to become more conscious and engaged enablers throughout the whole process.

Celebrating small wins: Ensure patients can celebrate progress, no matter how seemingly small the achievement. Provide a platform to encourage that, bring through realistic people and achievable goals.

Creating realistic and reflective programmes

The messaging and language used for programmes need to be positive and talk about ‘moving forwards’, being ‘healthy’, making ‘progress’ and undertaking ‘movement’. It’s about women taking back control, putting their health first and feeling empowered to be a ‘new, more confident version of themselves’. In addition, imagery used is reflective of the majority. There will always be amazing stories of women able to run marathons not long after surgery, but this won’t appeal to the masses and may switch many women off completely. Any programmes need to be positive, realistic and feel personal to each individual, and be fun and achievable.

Above all, women need active support, encouragement about their capability, easily accessible opportunities. The language used and positioning of physical activity is critical. It needs to resonate and nurture their wellbeing and not just be seen as another treatment.

“ A friend sent me a booklet that a friend of hers had written where she’s managed to exercise at high performance all through her chemo, and that felt like a slightly impossible standard. ...there were lots of online support groups I was a member of, and again, there would be high achievers, the sporty people, there’s no sort of middle ground. ”

Active woman, London

TRACKING PROGRESS

NATIONWIDE CAMPAIGN

PSYCHOLOGICAL PREPARATION

BUDDY SYSTEM

PODCASTS

SELF-CARE

TRAINING FOR
HEALTHCARE
PROFESSIONALS

REGULAR CHECK-INS

TAILORED APPROACH

POSITIVE FEEDBACK LOOPS

MINDFULNESS

PHYSICAL ACTIVITY WEBSITE AND APP

TRANSITION THERAPIST

ONLINE CHAT AND SUPPORT

CATALOGUE OF ACTIVITIES

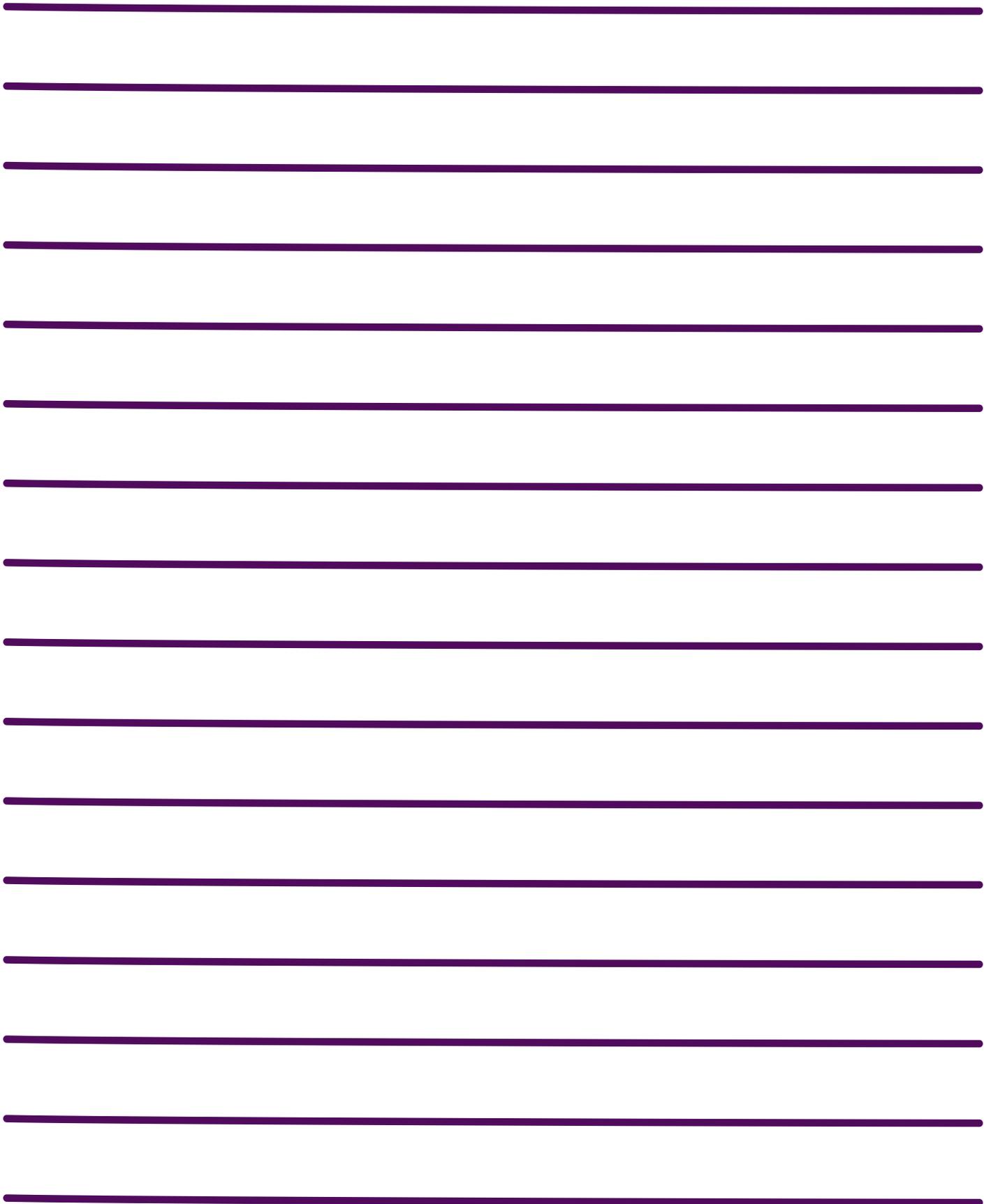
EXERCISE REFERRAL

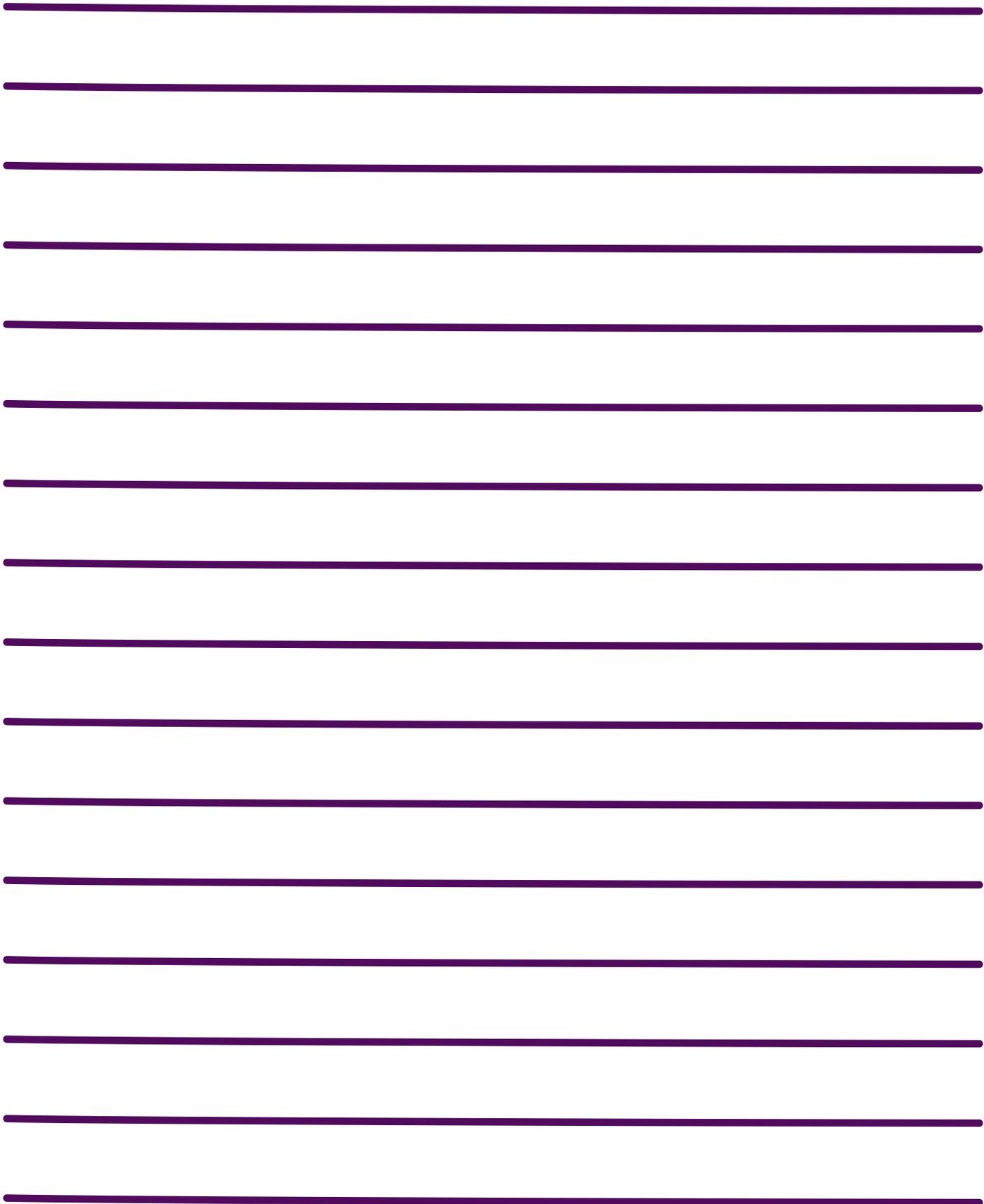
FAMILY AND FRIENDS

PHYSICAL ACTIVITY
IDEAS FROM WOMEN
WITH BREAST CANCER

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