



# Living well with cancer

## Barriers and facilitators to physical activity following a cancer diagnosis

### Why we did this

Research evidence suggests that physical activity and exercise is beneficial for people following a diagnosis of cancer. However many people report a reduction in physical activities following diagnosis and treatment as well as a difficulty taking up activities again.

We aimed to:

- Find out from people in New Zealand with a diagnosis of cancer what helps or hinders their involvement in physical activity.
- Suggest ways to support people's involvement in physical activity and exercise following a cancer diagnosis.

### Who we are:



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### What we did

We interviewed 25 people - 10 men and 15 women, with various types of cancer who were aged between 33 and 84 years. We asked them about the types of physical activities they currently took part in and explored their experiences of taking part in physical activity following their diagnosis. We also asked them to describe key features of their ideal exercise-based rehabilitation programme.

### What we found

While everyone's experience was unique, there were common threads running through the interviews. We grouped our findings under five interrelated themes which represent the views and perspectives of our participants regarding physical activity following their cancer diagnosis. A description of each of these themes is included in the pages that follow. Participant names have been changed to maintain privacy.

## What we learnt about people's experience of physical activity after a diagnosis of cancer

### **A sense of isolation - You're on your own**

Following the intense period of medical care they had received, many people talked about feeling isolated, abandoned and on their own after they had been discharged from care. This feeling was exacerbated by the limited information they received. Many people felt the information they did receive was too generic and not relevant to their situation or focused on the medical aspects of their care, rather than being about getting back to activities that were important to them.

*Cancer's a funny thing because while you're having the treatment and things you get a lot of attention – cancer society's great – they have counselling and that sort of thing. But ...once you're put out back into the world, you're left hung out to dry a wee bit – its quite a difficult time. (Glenda 55)*



### **A sense of dis-ease**

People described the way the cancer diagnosis and treatment had disrupted their sense of self. Many people we talked to described having a heightened sense of their body, of feeling fragile, self-conscious, lacking confidence and experiencing loss of identity. This included feelings of embarrassment and uncertainty about their physical abilities, and a fear that activity would cause them further harm. Some people felt depleted of physical and emotional resources. These feelings affected their ability to seek out information or to engage in opportunities for being active.

*I feel completely overwhelmed, deflated, jaded, dejected. I think you just feel fragile after the operation – you don't have the confidence in your body. I'm less robust than I used to be. (Heather 63)*

### **Becoming acclimatised**

Many of the people experienced residual difficulties following their treatment that required them to make adjustments to their everyday activities. People were often left searching for ways to adjust and manage situations such as dealing with stoma bags, fatigue, loss of sensation, loss of strength and weight gain. The practical advice and help people received at this stage was often a crucial factor affecting their return to physical activity.



*I've got to adjust to be able to walk properly with my feet as they are. It's like becoming acclimatised to the situation. (Lloyd 69)*

*I'd mentioned it to my specialist – 'what should I be doing?' I'm having trouble with my walking because my muscles didn't work and not a lot of information was forthcoming on that—'oh you'll get better – you'll be fine'. (Melanie 37)*

### **The importance of others**

Other people were important, especially family and friends who were valued for the encouragement and support they offered which helped them to take part in physical activities. For family members, this was one area they felt they could actively contribute to the recovery of their loved one. Some of the people we talked with had attended exercise programmes that were specifically designed for people with a cancer diagnosis. These provided a safe place to restore their physical abilities and gave them access to expert advice and support from others. For these people, a crucial part of attending these groups was the shared experience. When it was available, advice from a health professional about taking part in physical activity was highly valued and was often the prompt to return to physical activity.



*I've hit a bit of a brick wall and I really need help and I'm really in this maze. And I don't know quite how to get out of the maze - I really want help directing me and coming up with a plan that is realistic and workable. (Olivia 55)*

### **The meanings people ascribe to physical activity**

What physical activity meant to people affected how they approached activity after their cancer diagnosis. For some of the people we spoke to, physical activity was an important part of their life pre-diagnosis. They described pushing hard to regain their levels of activity through trial and error. Some succeeded in returning to their important activities and others adjusted the type or level of activity to their current ability. However others found this difficult and stopped being physically active because they couldn't exercise the way they used to.



*I'm trying to exercise more every day, because I'm really aware that to keep cancer away I need to keep my blood oxygenated, you know... And I don't want it coming back. (Wendy 60)*

For many people physical activity was seen as a tool for recovery or as necessary to maintain physical and psychological well-being and prevent reoccurrence.

For others, the cancer diagnosis precipitated a change in attitude which prompted a renewed focus on health and well-being which prompted them to actively seek out support and information about ways to exercise.

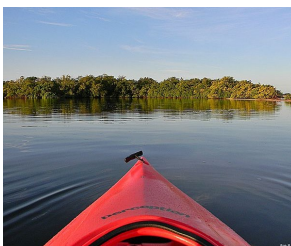
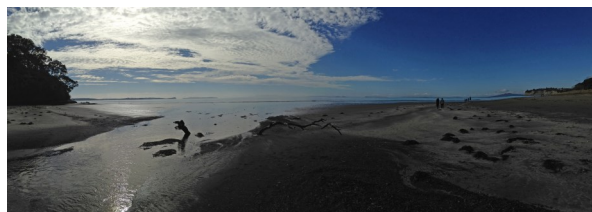


image from: dc.ecowomen.org/Arrival\_at\_Munyon\_Island

*But now I want to be well and I want to do everything I can to be as healthy as possible and I don't know where to go to find out because the oncologist, my doctor ... they're - 'just keep taking the tablets'. (Wendy 60)*

## Our conclusion



Re-engaging with physical activity following a diagnosis of cancer appeared important to many of the people we spoke to. It often represented a return to meaningful activities. Physical activity was also considered important in the management of the residual effects of treatment and for maintaining broader health and well-being. However, people also described a number of challenges that appeared to impact upon their participation in physical activity, including a perceived lack of support and guidance from health professionals.

**Support and practical tailored advice regarding how to safely integrate physical activity into their lives following a diagnosis of cancer would aid people take up or return to physical activities that are important to them.**

*People keep going on about exercise but they don't tell you what exactly—or how ... Because you're going through so much....my brain is actually in overdrive thinking of the other things I'm dealing with and, actually if you can just spoon feed me that kind of information... (Melanie 37)*

*[I'd love the chance]...to get fit under the guidance of someone hopefully who would understand what I'd been through and tailor exercises for me (Glenda 55)*

## Where to from here?

This summary of findings is being distributed to all those who took part in this research, cancer-related support services and existing cancer-specific exercise-based programmes. We will also publish our findings in an international academic journal targeting health professionals working in cancer services. Finally, we would like to use these findings to develop a resource for health professionals and support staff working in cancer-related services which we hope can inform service development in this area.

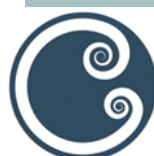
## Thank you

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**If you have any comments or questions about these findings please contact the researchers:**

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