



Penny Brohn UK
Living Well with Cancer



The long-term impact of the Living Well course

Results from a 5 year follow-up

Background

In 2013, Penny Brohn UK published the results of a longitudinal service evaluation of the Living Well course, with a final follow-up time point of 12 months [1,2]. The evaluation found that the Living Well course led to improvements in Health Related Quality of Life (HRQoL) and wellbeing, reduced the severity of cancer-related concerns and led to the implementation of positive lifestyle changes. The data also showed that many people started struggling with lifestyle changes such as improved diet and exercise, around 3-6 months after the course. This led to the implementation of additional follow-up support (e.g. emails, Follow-Up Days).

In August 2016, the Research & Evaluation Team at Penny Brohn UK administered a five year follow-up, to evaluate the long-term impact of the Living Well course. A five year follow-up Patient Reported Experience Measure (PREM) was sent to 81 Living Well clients who participated in the original service evaluation (original number of participants=171). This was after taking out those who were deceased, had moved away, had contact restrictions, or had withdrawn from the original study. A follow-up measure of HRQoL (FACIT-SpEx) was also administered.

Thirty three responses were received (41% response rate); 82% people who have/had cancer, 18% supporters; 76% female; mean age 57 years. Crucially, 85% no longer had active cancer and the majority (75%) had finished their treatment over a year ago.

Key outcomes

Key outcomes from the 5 year follow-up PREM were:

- 97% reported making positive lifestyle changes after the Living Well course
- 75% said they had maintained the positive changes they made for 4-5 years or were still maintaining them.
- 85% said the Living Well course had enabled them to self-manage their health more effectively.

“It helped me to think carefully about the food I eat and how it can affect my health. It helped me to look at nature and the beauty of nature which gave me a sense of wellbeing.”

“I meditated for the first time in my life at the course. I’m now having to go through some problems (health) and meditation is helping.”

- The most common techniques/advice that clients were still using were diet and exercise (both 85%) and the relaxation techniques (73%).
- 100% said the Living Well course was important in their overall experience of cancer

“It made me fear cancer less. I am able to be my own best friend as a result of the course and manage my stage iv well – I believe.”

“I felt so alone following my diagnosis. The course and the people I met helped me to realise cancer affects everybody but there is still so much to live for by altering your way of thinking and gaining strength from others.”

- 37% said the Living Well course had helped them manage other long-term conditions, including mental health issues, diabetes and hypertension.

“Depression – I use mindfulness a lot to try to appreciate the present moment.”

“Diabetes – in changing my diet for cancer it means those changes have also been good for my diabetes and I am still able to control it with diet rather than taking medication.”

“High cholesterol/hypertension”

- FACIT-SpEx total scores were maintained relative to the 12 month follow-up.

Limitations

One hundred percent of the 33 clients who responded to the questionnaires said that the Living Well course was either quite important or very important in their overall experience of cancer. This means that no one who felt the course was not important to their overall experience replied to the questionnaires.

In addition, 85% of respondents no longer had active cancer, so it is possible that those whose health had not improved over the past five years also did not respond to the questionnaires. So the results only give us a picture of what the long-term impact of the Living Well course may be for those who 1) are in at least fairly good health five years later, 2) engaged fully with the course and 3) replied to the questionnaires.

Conclusion

The results clearly show that for some clients, the Living Well course can lead to long-term positive benefits in terms of lifestyle behaviours and self-management of health and wellbeing. For some Living Well clients, the course appears to lead to wider positive benefits, including helping them in the management of other long-term health conditions. Although there is no data to suggest there are long-term benefits for all people who attend the Living Well course, for a number of people, the course appears to have been key to their ability to live well with cancer.

References

1. Polley M, Jolliffe R, Jackson S, Boxell E, Seers H. Penny Brohn Cancer Care: Service Evaluation of 'Living Well with the Impact of Cancer' Courses, Penny Brohn Cancer Care, University of Westminster, 2013.
2. Polley M, Jolliffe R, Boxell E, Zollman C, Jackson S, Seers H. Using a whole person approach to support people with cancer: a longitudinal, mixed-methods service evaluation. *Integrative Cancer Therapies*, 2016: 1-11. DOI: 10.1177/1534735416632060



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