Support for Supporters

The impact of Penny Brohn UK’s Living Well course for supporters of people with cancer

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Part 1

Background
Supporter Services
Background

Cancer in the UK

There are an estimated 2.5 million people living with and beyond cancer in the UK [1]. This number is continuing to rise and is predicted to reach four million by 2030 [2]. People are now twice as likely to live for at least 10 years after a cancer diagnosis than they were in the 1970s [3]. However, many of them will live with the emotional, physical and financial effects of cancer and its treatment for many years. All of this means that the number of supporters of people with cancer is also rising; and there is currently a lack of resources to systematically aid these people in the crucial role that they play [4]. Subsequently, the physical, social and psychological challenges that come with supporting a person with cancer are often faced alone, adversely impacting the supporter’s quality of life, and in turn causing greater distress for the person with cancer.

Definition of a supporter

The term ‘supporter’ or ‘informal caregiver’ has been defined as any relative, friend or partner who provides unpaid assistance to a person with a life-threatening illness [5]. They may offer practical support, such as driving to hospital appointments, as well as emotional and financial support [4].
Background

The impact of supporting someone with cancer

Research [6-15] has increasingly looked at the impact of a cancer diagnosis on the patient’s supportive network. Studies have found that levels of anxiety and depression in family caregivers are equal to and sometimes even more than those in the patients they are supporting [6-8]. This highlights the risk of supporters lacking a support network of their own. Some of the needs of supporters mirror those of the cancer patient themselves, and there is evidence that these needs are often unmet [9-14]. A recent review [15] found that on average, between 5% and 47% of supporters’ needs were unmet, with higher levels of unmet needs in supporters of people diagnosed with brain tumours or in palliative care. Unmet needs included emotional and psychological, daily activities, relationships, information and spirituality.

Macmillan Cancer Support estimate that 1.1 million people are acting as informal caregivers to someone with cancer in the UK [16], and four in five say that their caring role affects them [16]. Carers most often say that their supportive role impacts on their emotional wellbeing, social life and relationships [16]. In spite of this, half of cancer carers say that they receive no support at all [16]. Macmillan have stated that ‘early and adequate support’ for carers can improve their own health and wellbeing outcomes and those of the person they are supporting.

The NHS is currently failing to fully support people who are supporting someone with cancer [16], despite the fact that the economic value of the care they provide is around £14.5 billion per year [16]. However, in October 2014, NHS England published the NHS Five Year Forward View [17], which set out the vision and priorities of the NHS for the next five years. Supporting carers was set out as one of the priorities;

“We will find new ways to support carers, building on the new rights created by the Care Act, and especially helping the most vulnerable amongst them – the approximately 225,000 young carers and the 110,000 carers who are themselves aged over 85. This will include working with voluntary organisations and GP practices to identify them and provide better support.”

There is a strong case that the support offered by Penny Brohn UK for supporters of people with cancer is as crucial as providing support for the people with cancer themselves.
Supporter services at Penny Brohn UK

Penny Brohn UK is the leading UK charity specialising in helping people to live well with cancer. Services are developed around the Bristol Whole Life Approach, which addresses each part of a person; mind, body, spirit, emotions, relationships, community, environment and practical issues. Services include Penny Brohn UK’s flagship Living Well with the Impact of Cancer course (‘Living Well course’), launched in 2010 in response to the National Cancer Survivorship Initiative Vision Report [18]. The Living Well course is a modular 15 hour course that can be run in different formats at different locations around the UK. The course is run by fully trained AptEd accredited facilitators and provides clients with a toolkit of techniques that can help address the eight components of the Bristol Whole Life Approach (Figure 1):
Supporter Services at Penny Brohn UK

Course participants are shown simple steps they can take to address each of these components:

- **Body;** healthy eating and physical activity
- **Spirit;** connecting with joy and purpose
- **Mind;** feeling in control, managing stress
- **Emotions;** expressing emotion, acceptance
- **Relationships;** being open, giving and receiving
- **Community;** social connections, identifying sources of support
- **Practical issues;** financial stability, good work/life balance
- **Environment;** access to nature

In addition, course participants are taught simple but effective self-help techniques:

- Relaxation
- Meditation
- Mindfulness
- Imagery

Once they have attended a Living Well course, clients are invited to attend a Follow-Up Day. Follow-Up Days are an opportunity for clients to be reminded of the things they learnt on the Living Well course, including self-help techniques, nutrition and action planning. The aim is to help clients get back on track if things have slipped and provide another opportunity for them to meet with peers, including people they may have met on their original course.

All of Penny Brohn UK’s services are open to supporters of people with cancer and approximately 25% of Living Well course attendees are supporters who are attending alongside the person with cancer they are supporting. Following extensive evaluation of the Living Well course for all clients combined [19], and for people with cancer [20], the aim of this evaluation report is to outline the specific impact of the Living Well course on supporters only. Data was taken from supporters of people with cancer who attended a Living Well course between June 2014 and May 2016.
Part 2

Methods
Results
Discussion
Methods

The Living Well course was evaluated using a mixed-methods approach, combining qualitative and quantitative data collected using paper-based questionnaires. The evaluation was observational, with no control group. A pre-post data collection method was used, gathering data at the time-points specified below. Quantitative data was analysed using SPSS V21. Qualitative data was thematically analysed.

The following outcome measures were used to evaluate the Living Well course for supporters:

**MYCaW (Measure Yourself Concern and Wellbeing)**
MYCaW is a Patient Centred Outcome Measure (PCOM) designed specifically for the evaluation of cancer support services and validated against an internationally used measure of health related quality of life [21]. It was developed in the UK and is also used by integrative cancer centres and cancer support centres in the US, Canada and Israel [22-24]. The MYCaW questionnaire was designed to measure the impact of cancer support services on the severity of people's cancer related concerns and wellbeing. Severity of concerns and wellbeing are rated on a scale of 1 to 6, with 1 being the best and 6 being the worst. MYCaW was administered at two time-points; before the course and 6 weeks after the course.

**Patient Activation Measure® (PAM®) (since April 2015)**
PAM is an internationally used and validated Patient Reported Outcome Measure (PROM) measuring level of ‘activation’; the knowledge, skills and confidence to manage one’s own health [25]. Research from America has shown that higher levels of activation are associated with better long term health outcomes and reduced healthcare costs [26]. PAM scores range from 0 to 100, with higher scores indicating higher activation. Scores can also be transposed into a ‘level’ of activation ranging from 1 (overwhelmed and lacking confidence) to 4 (maintaining a healthy lifestyle). The 10-item PAM was used. PAM was administered at two time-points; before the course and 6 weeks after the course.
Methods

Health & Wellbeing Wheel (since March 2015)
A Penny Brohn UK bespoke tool which asked people to rate all aspects of their health and wellbeing; Mind, Community, Body, Practical Issues, Spirit, Environment, Emotions and Relationships. This tool was designed to reflect the Bristol Whole Life Approach. Each area is rated on a scale of 1 to 6, where 6 is the best. The Health & Wellbeing Wheel was administered at two time-points; before the course and 6 weeks after the course.

6 week Patient Reported Experience Measure (PREM)
A bespoke PREM designed to collect in-depth information on clients’ experience of the Living Well course and changes that may have happened in their life as a result. Data was collected on:

- Diet
- Exercise
- Relationships
- Use of self-help techniques
- Lifestyle changes
- Unexpected benefits of the course
- Ability to self-manage
- Progress with SMART goals made on the course
- Additional open ended questions specifically for supporters
Results

Supporter characteristics

Between June 2014 and May 2016, 480 unique supporters attended a Living Well course (97%) or Follow-Up Day (3%). Supporters were mostly female (58%), White British (83%), with a mean age of 55 years (range 18-85).

MYCaW

Full pre- and post-course MYCaW data was received from 118 supporters who attended a Living Well course. Supporters rated their concerns fairly severely, with mean ratings of 4.6/6 and 4.2/6 for Concern 1 and Concern 2 respectively (with 6 being the worst). Wellbeing ratings were less severe with a mean rating of 2.6/6. Six weeks after the Living Well course, concern ratings had improved, with mean ratings of 3.5/6 and 3.2/6 for Concern 1 and Concern 2 respectively. These improvements were statistically significant (p<.000 for both). Wellbeing remained stable at 2.6/6 (Chart 1).

Chart 1. Supporters' MYCaW scores before and after the Living Well course (a decrease denotes an improvement)


## Results

### Patient Activation Measure

Full pre- and post-course PAM data was received from 33 supporters who attended a Living Well course. There was a small improvement in PAM scores after 6 weeks (61.8 pre-course vs. 62.8 at 6 weeks), which was not significant (p>.05). However, 36% of supporters had a meaningful improvement in their PAM score (≥4 points) [26].

When change scores were stratified by baseline levels of activation, the biggest changes were in those with the lowest levels of activation (levels 1 and 2) before the course. Supporters who were at level 1 pre-course (n=5) had a mean change of 7.3 and those who were at level 2 had a mean change of 5.0 (n=6). Supporters who were already at level 3 pre-course were fairly stable with a mean change of 1.2 (n=17). Five supporters who were at level 4 pre-course actually had a deterioration in their PAM score (mean change -10.7). A similar pattern was evident when looking at the proportion of supporters who had a meaningful improvement in PAM scores relative to their baseline level; 80% at level 1 and 33% at level 2 had meaningful improvements, compared to 30% of those at level 3 and 20% at level 4 (Figure 2).

![Figure 2. The percentage of supporters at each pre-course PAM level with meaningful improvements in PAM score after 6 weeks](image)
Results

Health & Wellbeing Wheel

Full pre- and post-course data was received from 43 supporters who attended a Living Well course.

- The lowest ratings on the Health & Wellbeing Wheel before the course were in the areas of Emotions and Spirit, with mean ratings of 3.3 and 3.7 out of 6 respectively. This suggests that these were the areas where supporters needed the most support.
- Subsequently, **Emotions and Spirit were two of the three areas significantly improved** after the course (Emotions post-course mean 3.9, p=.014; Spirit post-course mean 4.3, p=.015).
- **The other area with a significant improvement was Mind** (pre-course mean 3.8, post-course mean 4.2, p=.029).
- Community, Body and Relationships ratings also improved, although the improvements were not significant.
- Practical issues did not change and environment ratings went down; see Chart 3 below.

![Health & Wellbeing Wheel ratings before and 6 weeks after the Living Well course](chart2.png)

**Chart 2.** Supporters’ Health & Wellbeing Wheel ratings before and 6 weeks after the Living Well course
Results

6 week follow-up PREM

The aim of the 6 week follow-up PREM was to explore supporters’ experiences in the 6 weeks since they attended the Living Well course and to establish whether the learning from the course had translated into lifestyle and wider life changes. Data was received from 66 supporters.

Supporter lifestyle changes

Reflecting on lifestyle changes made as a result of the course, 83% of supporters reported that their diet had improved, 63% said the course had improved their level of exercise, 73% said the course had improved their relationships and 85% said that the course had improved their use of self-help techniques.

Reflecting on lifestyle changes overall, 64% reported that they had made ‘a few’ positive lifestyle changes, 20% said they had made ‘lots’ of positive lifestyle changes. Just 6% said they had not made any positive lifestyle changes, 7% said they were not sure how many changes they had made, and the remaining 3% said they needed more support from Penny Brohn UK to make lifestyle changes.
Self-management

Six weeks after the Living Well course, 87% of supporters reported that the course had helped them to self-manage their own health more effectively. When asked how the course had helped them to self-manage, three key themes emerged:

- Improved diet

  “I now see that nutritious food, fresh air and exercise are so important. I feel encouraged about my own lifestyle, and being able to follow it, with the full support of my family.”

- Using self-help techniques/ managing stress

  “By keeping calmer, meditating and making sure to talk to friends and family or counsellor when feeling stressed.”

- Importance of looking after self

  “Made me more aware that I need to take care of myself.”
Results

6 week follow-up PREM

SMART goals
On the Living Well course, all clients are asked to write SMART goals addressing six key areas; healthy eating, physical activity, spirit, relationships and community, practical issues and environment, and mind and emotions. After 6 weeks, supporters were asked to rate how happy they were with their progress against each goal. The lowest level of satisfaction was for relationships and community (54%), suggesting that supporters found this area the most difficult to make changes in. The highest level of satisfaction was for healthy eating (77%), followed by mind and emotions (60%).

Wider benefits of the course
After 6 weeks, supporters were asked if anything else had changed in their life as a result of the course; three keys themes emerged:

• Improved relationships

“It has helped my relationship with ‘X’, plus the children. We also made new friends, and meeting these people at the group was very important.”

• Improved diet

“Diet – more fruit and veg, different herbal teas, more fish – less meat. Leave work on time more often. Less stress, more humour, light-heartedness.”

• Using self-help techniques/relaxation

“I do a simple breathing meditation I learnt from the course, which helps me to cope with feeling stressed and to sleep at night.”
Results

Supporters were also asked if they had experienced any unexpected benefits of attending the course; by far the most common themes were meeting others and making new friends.

“Meeting other supporters and other cancer sufferers was enlightening and very special.”

“Meeting the other participants and being able to share my concerns and worries about my wife having cancer. It was the first time I talked openly and freely with somebody.”

“Yes, connections made with some of the other course attendees. We have kept in touch and support each other.”

In order to fully understand the impact of the Living Well course specifically for supporters, two additional open-ended question were asked. The first of these questions was:

“Are there any particular aspects of the Living Well course that have helped you cope with supporting a person with cancer?”

The following key themes emerged from the responses received:

• Meeting other supporters

“Oh I have felt less involved in the process. The course helped me contribute, get involved and also feel I can help. It’s a great opportunity to talk with my wife and others going through the same/similar experiences.”

• Understanding how to support effectively

“Realising the better I can support myself, the better I can support him. Also, that I need to find other supporters to share with.”

• Having a better understanding of what the person with cancer is going through

“The whole course and meeting other supporters helped me a lot in understanding how to help and what the cancer sufferer is going through.”
The second open-ended question specifically for supporters was: ‘

Is there anything you would say to a supporter who is thinking of coming on the Living Well course but isn’t sure that it is right for them?’

Two people (out of 77) responded negatively; one who felt that it could be upsetting listening to peoples’ stories and one who felt that there should be a separate course for supporters as the focus is mostly on the person with cancer. The vast majority (97%) of the responses received were around encouraging other supporters to go.

“Supporters’ issues are mostly ignored and unacknowledged in my experience. Absolutely do this course, you have nothing to lose and so much to gain.”

“I would definitely recommend it as a lot of the recommendations go beyond the individual and need to be provided for in the home/family environment. Also a lot of the advice is relevant to other health issues and preventing cancer and general wellbeing.”

“I think that this course would help greatly. The more knowledge you have, the more confidence you have, the more help you can give and the more you understand.”

“Do please come on the course. It will give you a better understanding of what it is like to have cancer, and how it doesn’t have to be a passive experience, there are techniques that can help you both.”
Discussion

This evaluation of Penny Brohn’s Living Well course shows that, for supporters, the Living Well course:

- Led to reported improvements in lifestyle (diet, exercise and using self-help techniques)
- Led to reported better self-management of health
- Significantly reduced concerns
- Was an opportunity to meet with other supporters
- Enabled a better understanding of the needs of the person with cancer
- Taught supporters new ways of supporting effectively
- Would be recommended to other supporters of people with cancer

Almost no negative feedback was received from the supporters who responded to the 6 week follow-up questionnaires. There were only two criticisms; one supporter said they would warn other supporters that they might find the course upsetting due to hearing people’s cancer stories, and another supporter thought that there should be a separate course for supporters so that the focus is solely on them.

Overall, the findings suggest that the Living Well course can improve the health and wellbeing of supporters themselves and give them the knowledge and skills to support more effectively. This may have a knock-on effect, improving the health and wellbeing of the person with cancer as 1) they are receiving more effective support and 2) they may be less worried about the impact of cancer on their loved ones, if they know that they have also received support.

The Living Well course is also unique in that it is as much for the supporter as the person with cancer. This shared experience means that the person with cancer and supporter can leave the course with the same knowledge and skills, and a mutual understanding of how to move forwards as a dyad in their experience of cancer. Clients who attend the course alone may struggle when explaining what they have learnt to their friends and family, and previous evaluation has found that friends and family not understanding why the person with cancer wants to make changes, is one of the challenges they face [27]. The data collected in this evaluation, particularly the qualitative data, suggests that the impact of the Living Well course may be greatest when the person with cancer and their closest supporter attend as a dyad.

Improved lifestyle behaviours and better self-management of health in supporters may also have a knock-on effect of preventing disease in this group. Research is increasingly demonstrating the protective effect of a healthy lifestyle (diet and physical activity), on a range of chronic diseases including cancer [28], diabetes [29], heart disease [30], and stroke [31]. It is possible that diseases such as these could be prevented through the provision of lifestyle advice to people who are currently in a supporting role and not ill themselves. The fact that 83% and 63% of supporters respectively said that the Living Well course had helped improve their diet and exercise, suggests that a preventative aspect to the course is possible.
Discussion

Limitations

This evaluation has some limitations. Only 25% of Penny Brohn UK’s clients are supporters (although all clients are invited to bring a supporter with them to courses), and the response rate to the 6 week follow-up evaluation forms at Penny Brohn UK is typically around 30-40%. This means that for some outcomes, the amount of data available to analyse was relatively small. In addition, lifestyle changes are self-reported; it is not known to what extent these respondents actually changed their behaviour. It is possible that people are overly positive when responding to the questionnaires. Finally, it is not possible to know the outcomes for those supporters who chose not to respond to the follow-up questionnaires; perhaps those supporters did not have a good experience on the course or did not feel that it had an impact on them. However, ‘non-responders’ data collected as part of a previous evaluation [20] found that the main reasons for not responding were not to do with the course; they were mostly forgetting to fill in the questionnaires, losing the questionnaires or being too busy.
Discussion

Future development of supporter services at Penny Brohn UK

At the time of writing this report, Penny Brohn UK is involved in a partnership with the Teenage Cancer Trust and the TYA Cancer Service at University Hospitals Bristol to deliver Living Well courses for the supporters of teenagers and young adults (TYAs) with cancer in the South West. “On Target”, a service evaluation programme funded by Macmillan Cancer Support [32], explored the needs of patients, networkers (those around the TYA patient) and the professionals caring for them. The study found that while 61% of patients said that support for their supporters would have been helpful, over half reported that their family members hadn’t received any. Patient networkers felt ‘constrained’ in accessing support for themselves. Almost 50% of the networkers reported a ‘high/very high impact of a TYA’s diagnosis on their daily life’, and almost 80% ‘recorded adverse effects on their physical wellbeing’. The study also found that professionals working with the TYA patients recognised the need for networkers to receive psychosocial support.

A successful pilot Living Well course for TYA cancer supporters ran in June 2016 with 10 attendees and further courses are planned for 2017. The course was well received, with supporters rating it as 4.3/5 for meetings their needs and 4.4/5 for meeting their expectations. Supporters reported that the main message they got from the course was to look after themselves, including staying active, eating well, managing stress and acceptance. At the 6 week follow-up, there was good evidence that some supporters had implemented healthy lifestyle behaviours as a result of the course. Feedback from the TYA patients themselves suggested they also found it beneficial.

The evidence presented in this report responds to the priority set out in the NHS Five Year Forward View [17], that the NHS should work with voluntary sector organisations to ensure that carers/supporters receive the right support themselves. Penny Brohn UK’s Living Well course is unique, as robust evaluation evidence has shown it can lead to positive health and wellbeing outcomes in both people with cancer and their close supporters [20,27]. It is hoped that this evaluation will alert commissioners to the potential of self-management interventions such as the Living Well course for people with cancer and their supporters.

Penny Brohn UK is committed to reaching as many people as possible who have been affected by a cancer diagnosis, enabling both people with cancer and their supporters to live as well as possible with the impact of the disease.
References

References


