



Evidence for a whole life approach to cancer care



Penny Brohn UK
Living Well with Cancer

GenesisCare

“The holistic caring approach by Penny Brohn staff as part of an integrated cancer treatment package within the GenesisCare centre was extremely beneficial, supportive and helpful”

Patient,
GenesisCare Oxford



Penny Brohn UK

GenesisCare is the only private provider in the UK to embed a specialist wellbeing service within our clinical care pathway — and to fully fund it for all patients. We deliver this through a unique partnership with Penny Brohn UK — an evidence-based charity that uses a proven integrated care plan called the Bristol Whole Life Approach. This approach helps patients pay attention to their mind, body, spirit and emotions as an important component of their cancer experience.

Introduction

At GenesisCare, we fully support and recognise the vital role of a whole life approach and more than 95% of our patients now access wellbeing services as part of their care pathway.

This brochure summarises the research evidence for the Penny Brohn UK Living Well with the Impact of Cancer Course (LWC) and Bristol Whole Life Approach.

Contents

Meeting the clinical needs of cancer patients	4
The Penny Brohn UK Living Well with the Impact of Cancer Course	5
Using a Whole Person Approach to support people with cancer: a longitudinal, mixed-methods service evaluation	6
The Penny Brohn UK Bristol Whole Life Approach at GenesisCare	9
Evaluation of the Penny Brohn UK wellbeing service at GenesisCare	10

Meeting the clinical needs of cancer patients

It has long been recognised that people with cancer have needs that extend far beyond the medical and physical. It is estimated that up to 93% of cancer patients have unmet holistic needs¹. They have poorer wellbeing and health than the general population and often need further support at the end of medical treatment^{2,3}.

These needs are recognised as psychological, emotional, physical, sexual, occupational, social and existential^{4,5,6,7,8}.

The Living Well with the Impact of Cancer Course (LWC) was introduced by Penny Brohn UK in 2010 in response to the National Cancer Survivorship Initiative (NCSI) Vision Report⁷. The NCSI Vision was that by 2012 people living with and beyond cancer would be supported to live as healthy and active a life as possible for as long as possible. This would involve a shift towards supported self-management where patients are more informed and involved in their treatment.

In parallel with this individual focus, there is an increased emphasis on measuring experiences and outcomes through the use of Patient Reported Outcome Measures (PROMs) to evaluate treatment and care protocols.

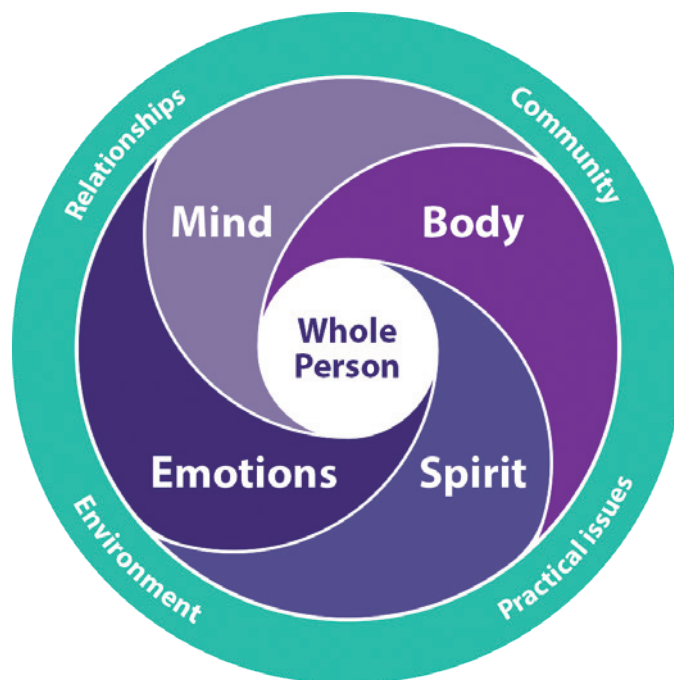


References:

- ¹ Puts MT, Papoutsis A, Springall E, Tourangeau AE. A systematic review of unmet needs of newly diagnosed older cancer patients undergoing active cancer treatment. *Support Care Cancer*. 2012;20(7):1377-94
- ² Maddams J, Utley M, Moller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer*. 2012;107:1195-1202
- ³ Macmillan Cancer Support. *Cancer in the UK 2014: State of the Nation Report*. 2014
- ⁴ Armes J, Crowe M, Colbourne L, et al. Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *J Clin Oncol*. 2009;27:6172-6179
- ⁵ Cancer52 and National Cancer Survivorship Initiative Research Workstream Consultation. *Less common cancers consultation 9 June 2009 report*
- ⁶ Rowland J. What are cancer survivors telling us? *Cancer J*. 2008;14:361-368
- ⁷ Department of Health, Macmillan Cancer Support, NHS Improvement. *National Cancer Survivorship Initiative (NCSI) vision*. 2010
- ⁸ Edman JS, Roberts RS, Dusek JA, Dolor R, Wolever RQ, Abrams DI. Characteristics of cancer patients presenting to an integrative medicine practice-based research network. *Integr Cancer Ther*. 2014;13:405-410

The Penny Brohn UK Living Well with the Impact of Cancer Course

Fig. 1
The Bristol Whole Life Approach



Penny Brohn UK is the leading national charity specialising in an integrated and whole person approach to cancer support. The charity has developed The Bristol Whole Life Approach (fig. 1) which addresses each part of a person — mind, body, spirit and emotions — recognising that these parts are interconnected and work together to support the immune system.

The Living Well with the Impact of Cancer Course (LWC) is based on the principles of the Bristol Whole Life Approach to supporting a person with cancer.

It comprises a motivational facilitated 15-hour group intervention, to promote long-term health and wellbeing and support self-management of health. It involves physical, psychological, emotional and support interventions as well as financial and relationship support. After the course, clients are offered therapies and follow-up support to encourage self-care and living well beyond the course. These include acupuncture, counselling, reflexology, relaxation and mindfulness, shared experiences, self-help techniques and goal-setting.

Clinically meaningful patient outcome data to reflect the whole person approach

The LWC was designed by healthcare professionals, including medical doctors, nutritional therapists and psychotherapists, to run alongside conventional cancer treatment.

Evaluation is an essential component and utilises a mixed-method assessment to capture clinically meaningful patient outcome data that represents

the whole person approach used. At the beginning of the course, patients are asked to identify their main cancer concerns using a standardised tool, Measure Yourself Concerns and Wellbeing (MYCaW). This assessment is repeated six weeks after the course to measure clinical improvements and also identify any further needs that can be addressed using the Bristol Whole Life Approach.

The clinical evidence:

Using a whole person approach to support people with cancer: a longitudinal mixed-service evaluation

In 2011 Penny Brohn UK initiated a longitudinal study with the University of Westminster, to evaluate how patients were responding to the Penny Brohn UK Bristol Whole Life Approach as delivered through the Living Well with the Impact of Cancer Course (LWC). This would enable the charity to extend models of cancer support and survivorship by understanding how patients respond to them¹.



Study design

All patients with a cancer diagnosis who attended the LWC at the Penny Brohn UK national centre in Bristol between August 2011 and January 2012 were invited to take part, with 171 recruited. The patient profile (fig. 2) was largely female and represented 21 cancer types. Data were collected immediately post course and then 6 weeks and 3, 6 and 12 months after using a mixed-method approach and these tools:

- Measure Yourself Concerns and Wellbeing (MYCaW) — a validated PROM that measures an individual's two most pressing concerns as well as their overall wellbeing²
- Functional Assessment of Chronic Illness Therapy Extended Spiritual questionnaire (FACIT-SpEx) — a validated psychological PROM that assesses management of chronic illness. A total health-related quality of life (HRQoL) score can be calculated, as well as discrete aspects such as emotional, spiritual and functional wellbeing
- Questionnaire about satisfaction with LWC
- Questionnaires about diet, exercise and stress management
- Participant experience questionnaires about LWC (6 weeks post course)
- Exploration of enablers and barriers to maintaining a healthy lifestyle (12 months post course)

Analysis of clinically relevant changes

Patient responses were analysed to account for variables and characteristics such as primary versus metastatic disease and baseline differences such as age, cancer type, treatment stage and additional life events that may affect health.

Score changes relative to baseline were calculated at each follow-up point time for MYCaW and FACIT-SpEx data. The percentage of patients with clinically relevant changes at 12 months follow-up were calculated — classed as at least a 1 point change for MYCaW as shown in (fig. 3).

Fig. 2
Participant characteristics at baseline and 12 months post course

	Baseline (n = 135)	12 months (n = 70)
Male, %	17.7	15.7
Female, %	82.3	84.3
Residential Weekly, %	92.9	Not applicable
Age (years)	7.1	-
Minimum	27	27
Maximum	84	84
Mean	53	52
Cancer type, %		
Breast	57.5	57.7
Lung	3.1	1.4
Bowel	10.2	5.6
Prostate	6.3	8.5
Gynaecological	7.9	11.3
Other	15.0	14.1
Disease stage, %		
Primary treatment	57.9	9.1
Finished treatment	22.3	62.3 ^a
Secondary	19.8	16.9
Deceased	Not applicable	9.6

^aIn all, 5% still had cancer present, 17% were still experiencing side effects, despite having completed treatment

Fig. 3

Changes in MYCaW and FACIT-SpEx scores over 12 months post course^a

	Baseline scores	Mean change (±SD)					Significant change over time?	Clinical relevance at 12 months (%)
		Baseline-post LWC	Baseline-6 weeks	Baseline-3 months	Baseline-6 months	Baseline-12 months		
MYCaW								
Concern 1	4.71 (±1.2)	1.40 (±1.43)***	1.49 (±1.41)***	1.67 (±1.86)***	1.80 (±1.81)***	2.23 (±1.86)***	Yes***	82.8
Concern 2	4.42 (±1.2)	1.31 (±1.42)***	1.35 (±1.44)***	1.48 (±1.83)***	1.61 (±1.75)***	1.89 (±1.78)***	Yes***	80.6
Wellbeing	2.78 (±1.3)	0.86 (±1.15)***	0.55 (±1.25)***	0.43 (±1.53)*	0.51 (±1.48)***	0.63 (±1.75)**	Yes***	56.9
Profile	3.96 (±1.0)	1.16 (±1.07)***	1.14 (±1.04)***	1.22 (±1.39)***	1.3 (±1.3)***	1.57 (±1.43)***	Yes***	63.0
FACIT-SpEx total score	132.06	—	7.77	4.51	9.0	15.78	Yes***	61.5

Abbreviations: MYCaW, Measure Yourself Concerns and Wellbeing; FACIT-SpEx, Functional Assessment of Chronic Illness Therapy Extended Spiritual questionnaire; LWC, Living Well with the Impact of Cancer Course. ^aFor MYCaW scores, 0 is the best and 6 is the worst, clinically relevant change was a mean change of 1 point or more. Profile score is concern and wellbeing scores combined. For FACIT-SpEx, an increase in score denotes improvement. Clinical significance was calculated according to Yost and Eton.³ Statistical significance was set at P = .05. *P ≤ .05. **P ≤ .01. ***P ≤ .001.

There was a significant reduction in patients in primary treatment at 12 months compared with baseline and responses dropped over time to n=70 (52%) by 12 months.

MYCaW Concerns

At baseline MYCaW Concern 1 (n=128) and Concern 2 (n=123) were classified as follows:

- 45% concerns were in the psychological and emotional category, including family problems and relationships, psychological and emotional problems, adapting and coping
- 20% concerns about wellbeing including general wellbeing, nutrition and exercise
- 16% physical concerns such as recurrence and spread, poor energy levels, pain
- 12% concerns about practical issues such as work and finance
- 7% treatment concerns

Results

For both MYCaW Concerns 1 and 2, statistically significant mean improvements were reported directly after the LWC. These improvements continued throughout the next 12 months.

There were statistically significant improvements in mean total health-related quality of life scores at all time points:

82.8% of participants had a **clinically relevant** improvement in **MYCaW Concern 1** at 12 months post-course. **80.6%** for Concern 2.

61.5% of participants had maintained a **clinically relevant** improvement in their **health-related quality of life** score at 12 months post course.

The clinical evidence (cont.)

Conclusion

Using a whole person approach such as the LWC has immediate and long-term benefits for participants in their health-related quality of life, particularly spiritual, emotional and functional wellbeing.

This mixed methods approach has now been adopted as the gold standard for the Penny Brohn UK Bristol Whole Life Approach. It enables patient needs to be identified and addressed at different stages of their cancer experience, so appropriate interventions can be planned as a tailored package of care, alongside conventional treatments.



References:

- ¹ 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; 15(4): 435–445
- ² Jolliffe R, Polley M, Jackson S, Caro E, Weeks L, Seers H. The responsiveness, content and convergent validity of the Measure Yourself Concerns and Wellbeing (MYCaW) patient reported outcome measure. *Integrative Cancer Therapies*, 2015; 14(1): 26–34
- ³ Yost KJ, Eton DT. Combining Distribution- and Anchor-Based Approaches to Determine Minimally Important Differences: The FACIT Experience. *Evaluation & the Health Professions*, 2005; 28(2):172–191

The Penny Brohn UK Bristol Whole Life Approach at GenesisCare

We currently provide the Penny Brohn UK whole life approach across nine of our UK centres. We are the only private provider to embed this in care pathways. It is based on the evidence-based service developed by Penny Brohn UK and includes:

The holistic caring approach by Penny Brohn UK staff is part of an integrated cancer treatment package within the GenesisCare pathway

- A Wellbeing Consultant appointed to each patient
- The patient will undertake a holistic needs assessment with their Wellbeing Consultant using the MYCaW assessment tool, enabling them to highlight the specific concerns that are troubling them at that time
- Through this comprehensive assessment the Wellbeing Consultant will be able to suggest a bespoke package of interventions to help support the patient's resilience
- The wellbeing service may include reflexology, acupuncture, counselling, relaxation and mindfulness meditation sessions, group-based wellbeing sessions, telephone counselling service and centre-based cancer support groups as defined in the Bristol Whole Life Approach

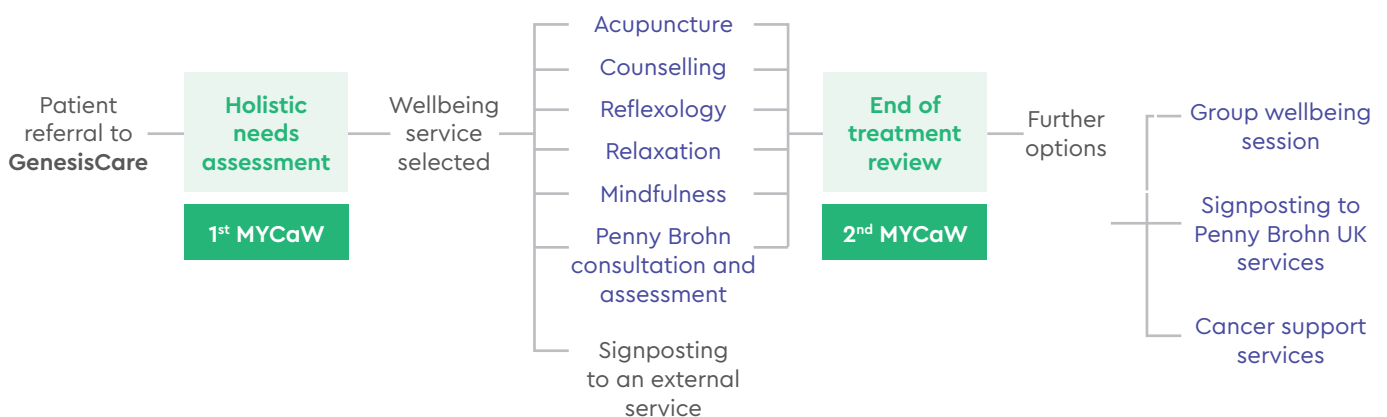
This will be delivered as part of the patient's overall care pathway (see fig. 4).

As well as offering the therapies, the Wellbeing Consultant will refer the patient to appropriate local services and other sources of support.

After the course of therapy sessions, the patient will be reassessed using PROM (MYCaW) and Patient Reported Experience Measure (PREM) tools.

Fig. 4

Penny Brohn UK treatment support at GenesisCare



95% of patients choose to access Penny Brohn UK services whilst undergoing treatment in our centres¹

Reference:

¹ GenesisCare. Data on File. May 2019

Evaluation of the Penny Brohn UK wellbeing service at GenesisCare

In conjunction with the Penny Brohn UK Research and Evaluation team, we have been conducting an ongoing evaluation of patient-reported and clinical outcomes for patients undertaking the wellbeing programme.

In this evaluation, data was collected between 2016 and 2018, from over 700 patients following an integrated Penny Brohn UK care pathway using the MYCaW validated questionnaire.

This questionnaire asks people to rate their two most pressing Concerns on a scale of 0–6 (6 being the worst). MYCaW also rates Wellbeing from 0–6.

Respondents are then asked to re-rate their Concerns and Wellbeing after completing a course of Penny Brohn UK therapies at a GenesisCare centre.

Results PROMS (patient reported outcome measures)¹

Average Concerns and Wellbeing ratings **improved after a course** of Penny Brohn UK therapies.

67% had clinically significant improvement in their main cancer Concerns.*

49% had a clinically significant improvement in their Wellbeing.*

Improvement is measured as an increase of + 1 point or more.

PREMS (patient reported experience measures)²

Data collected from nearly 715 patients attending Penny Brohn UK/GenesisCare Services from 2016–2018.

Out of 677 respondents between 2016 – 2018, 662 (98%) said "yes" the Penny Brohn UK services had made a difference to them²

Wellbeing Consultant appointments rated 4.9/5.0 for satisfaction²

Average satisfaction ratings out of 5 for therapies:

Reflexology	4.8
Meditation	4.7
Relaxation	4.7
Acupuncture	4.7
Counselling	4.6

*P ≤ .05

References: 1 GenesisCare. PROM Data on File. May 2019 2 GenesisCare. PREM Data on File. May 2019

"We believe the Penny Brohn approach is the future for how cancer care will be delivered to everyone. We are proud to be the first to offer this to all of our patients"

James McArthur,

UK General Manager, GenesisCare

To ensure your patients are supported throughout their treatment journey with a whole life approach, refer them to GenesisCare for world-class diagnostics, chemotherapy, radiotherapy and wellbeing.

08083 019 753

REM@genesiscare.co.uk

Referral form: genesiscare.com/uk/refer-for-oncology



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