About The Haven

The Haven is a unique charity that supports anyone affected by breast cancer, either from our three Haven centres in London, Hereford and Leeds, over the phone or via our website.

How we help

We provide a wide range of therapies to help people cope with the physical and emotional side-effects of breast cancer and its treatment. Our specialist cancer nurses and experts in emotional support, complementary therapies, nutrition, exercise and stress-reduction, provide each person who comes here with a tailor-made programme of one-to-one supportive care to help them feel better.

Who can come to a Haven?

Anyone affected by breast cancer is welcome and they can come before, during or after medical treatment for cancer. If family or friends need some emotional support too, they can also come to see our Haven counsellors.

What we offer

Complementary therapies to help relieve the physical and emotional side-effects of medical treatment. We offer over 30 therapies including acupuncture, hypnotherapy, herbal medicine and shiatsu (Japanese massage).

Emotional support for people with breast cancer and those close to them, including one-to-one and group counselling, support groups and stress-reduction programmes.

Advice on healthy eating from our nutritional therapists, tailored to each person’s individual needs.

Exercise, relaxation and meditation classes including yoga, mindfulness and qi gong, to help develop a healthier lifestyle.

Image workshops for advice on hair, make-up and clothing to help people feel good about their appearance.

Seminars and workshops on a wide range of subjects from body image and fertility through to journal writing and self expression.

Our in-house Haven Macmillan information and Support Manager and our Welfare, Benefits and Money Advisor help find useful information and secure financial support.

Our clinical credentials and how we work with the NHS

Each Haven centre is led by a specialist cancer nurse who manages a team of professional, complementary therapists. They are highly trained and experienced in treating people with breast cancer, so they know how to use the therapies we offer safely alongside a person’s medical treatment.

We correspond with each person’s medical consultant and GP to ensure that we provide care that is both safe and appropriate. We are recommended by many breast care nurses and medical teams.

Our commitment to research and service evaluation

Our Clinical and Research Director has a PhD in complementary cancer medicine and has many years of experience working in this field in the NHS. She leads our highly professional team of specialist nurses, therapists and researchers who are committed to evaluating the effectiveness of our support programme for people with breast cancer. Our Clinical and Scientific Advisory Board comprises 19 consultant breast surgeons, oncologists and other specialists who advise us on our clinical and research agendas.

Supporting people with breast cancer with their physical and emotional concerns and financial and information needs is central to the National Cancer Survivorship Initiative led by the Department of Health and Macmillan Cancer Support. With over 550,000 people in the UK living with a diagnosis of breast cancer, and with this figure expected to double by 2030, we are committed to expanding our network of centres so more people can benefit from our services.

“The patient experience can be a whirlwind of facts, and treatment. At The Haven, the patients’ holistic needs, often lost in the practicalities of hospital treatment, are carefully and sensitively restored. Having time to spend with each individual, the Haven picks up where the NHS lets go – to restore the whole being of the women coming to terms with her diagnosis and the lifelong effects of treatment.” Mr Rick Linforth, Consultant Oncoplastic Breast Surgeon, Bradford Hospitals
Haven attendances 2007-2012

Haven attendances record the number of appointments accessed by our Haven visitors. Combined number of appointments across our Havens accessed since 2007 shows a steady increase. (The decrease observed in 2010 was the result of a temporary reduction in the length of the Haven programme due to financial constraints at that time).

The Haven – Total Attendances Per Year

The number of people accessing our Havens continues to increase as we extend our services by opening new Havens.

Present Haven Research Team Members

Dr Caroline Hoffman, PhD, RN, BSW. Clinical and Research Director

Caroline has specialised in integrated healthcare for over 20 years both in the NHS and voluntary sector. Her last NHS role was as the first Nurse Consultant in Cancer Rehabilitation at the Royal Marsden NH&S Foundation Trust. Caroline’s long-standing expertise in psychosocial support, nursing and complementary therapies enables her to lead the teams of specialist nurses, therapists and researchers across all Havens. For her PhD she evaluated the effectiveness of a Mindfulness-Based Stress Reduction (MBSR) programme in a randomised controlled trial of 229 women who had been treated for breast cancer and attended The Haven. This rigorous study produced very positive results. She continues to teach MBSR at The Haven in London. These courses are open to all.

Dr Barbara Baker, PhD, BSc. Senior Research Fellow

Barbara graduated with a 1st Class BSc Honours degree in Biochemistry in 1977, and was awarded a PhD in Biochemistry/Microbiology in 1981. Barbara was a Lecturer at Imperial College, London for ten years, heading a small research group investigating the immunopathogenesis of psoriasis. After almost 23 years of research in the field of Immunodermatology, she has published 70 papers and written three books on the subject, two of which she has self-published. Barbara joined The Haven as Senior Research Fellow in April 2006. Barbara’s main interest is to understand, from an immunological perspective, the mechanisms involved in the improvement of the quality of life of women with breast cancer when complementary therapies are integrated with standard medical treatment. Barbara held the title of Visiting Honorary Research Fellow in the School of Healthcare, Faculty of Medicine and Health at the University of Leeds for a period of two years from March 2008 to 2010.
Published Haven research projects and service evaluations

Haven staff (past and present) are highlighted

1. **Baker, B.S., Harrington, J.E., Hoffman, C.J.**


3. **Hoffman, Caroline J., Ersser, Steven J., Hopkinson, Jane B., Nicholls, Peter G., Harrington, Julia E., Thomas, Peter W.**


5. **Baker, B.S., Harrington J.E., Choi B.-S., Kropf P., Muller I., Hoffman C.J.**


7. **Baker, B.S., Harrington, J.E., Hoffman, C.J.**


Executive Summary of Haven Research and Service Evaluation: 10 Year Report

The Haven, a registered charity is committed to evaluating its programmes for people with breast cancer in order to meet their needs most effectively and to improve the quality of the services we provide at our Havens, via the website and through our outreach programmes.

Listed below is an executive summary of the key findings from the different research studies and service evaluations, clinical audits and reviews that have been performed during the last ten years.

Haven Research Studies

Effectiveness of mindfulness-based stress reduction (MBSR) in mood, disease-related quality of life and wellbeing in stages 0 to III breast cancer: a randomized, controlled trial

Statistically significant improvements in overall mood, anxiety, depression, anger, vigour, fatigue and confusion, breast- and endocrine-related quality-of-life including hot flushes and other menopausal symptoms, emotional, physical and role functional wellbeing and general wellbeing were found in a large randomised controlled trial of women with breast cancer (N=229) following eight week MBSR programme, compared to controls.
Mindfulness-Based Stress Reduction in breast cancer: a qualitative analysis

Qualitative findings from 92 participants showed that the most positive experiences from MBSR were: 1) being calmer, centred, at peace, connected and more confident; 2) the value of mindfulness practice; 3) being more aware; 4) coping with stress, anxiety and panic; 5) accepting things as they are, being less judgmental of myself and others; 6) improved communication and personal relationships and 7) making time and creating space for myself. All participants who were asked said that they had become more mindful following MBSR training.

“The ‘Mindfulness’ course has helped me far more than I could have imagined. I have become calmer, more focused and more able to live in the present.” MBSR participant

A randomised controlled pilot feasibility study of the physical and psychological effects of an integrated support programme in women with breast cancer

Preliminary trends from a small, randomised pilot study (N=12) showed:

1. An improvement in confusion/bewilderment, cognitive and mental fatigue symptoms in the intervention group at 3 or 6 months. In the control group, total stress, anxiety and endocrine-specific symptoms improved. Emotional wellbeing improved in both intervention and control groups.

2. In the intervention group, an increase in the activity of Natural Killer (NK) immune cells was accompanied by an increase in peripheral blood arginase, and a moderate decrease in salivary cortisol (stress hormone) at 3 and/or 6 months, indicating an improvement in immune function. In contrast in the control group, NK cell activity and peripheral blood arginase decreased, at 3 and 6 months, suggesting decreased immune function.

A larger randomised study is needed to confirm these findings.

Haven Service Evaluations

Effect of an integrated support programme on the concerns and wellbeing of women with breast cancer: a national service evaluation using the Measure Yourself Concerns and Wellbeing Questionnaire

A self-evaluation by Visitors using the form Measure Yourself Concerns and Wellbeing (MYCaW) before and after the Haven programme. Findings were published online in 2011, and in print in February 2012.

Women with breast cancer found the Haven programme effective for addressing their key concerns and improving their wellbeing. The 2911 concerns presented by 1524 Visitors across London, Hereford and Yorkshire Havens were:

- 48% psychological and emotional
- 23% physical
- 17% related to wellbeing
- 11% related to hospital cancer treatment

The Haven therapies most commonly used to help with these concerns were acupuncture, nutrition, massage and aromatherapy, shiatsu, counselling and reflexology.

Statistically significant improvements were found in main concerns and wellbeing after the Haven Programme:

- Concern 1 (n=402) \( p < 0.0001 \)
- Concern 2 (n=372) \( p < 0.0001 \)
- Wellbeing (n=402) \( p < 0.0001 \)

After the Haven Programme, 91% of reported scores (n= 328) rated the concern as being a little better, much better or gone.

Service Evaluation of a Course of Individual Haven Therapy

Feedback from Visitors (N=341) in the London, Hereford and Leeds Havens following a course of an individual therapy. Overall, the most frequently listed reasons for receiving a course of individual therapy were:

- 50% physical
- 40% psychological/emotional

Of the physical issues, the most frequently listed were hot flushes/sweats and nutritional needs. Of the psychological/emotional issues, the most frequently listed was fear and anxiety. Over three quarters of the Visitors wanted help with general wellbeing.

Therapies used to address these concerns in descending order: nutrition; acupuncture; counselling; shiatsu; massage/aromatherapy; reflexology.
The number of Visitors reporting on the helpfulness of their course of therapy was as follows:

- 99% found it helpful
- 88% found it very helpful
- 87% found it essential for their recovery from breast cancer

Evaluation of a new model of care: is the outreach programme The Haven at Home helpful for breast cancer survivors?

The Haven at Home outreach programme was considered by approximately 80% (N=73) of users in the Yorkshire Cancer Network region to be very helpful and easy to understand.

All of the Yorkshire users who responded stated that they would recommend Haven at Home to others with breast cancer.

The Haven at Home was liked for its positive effects, usefulness at home, offer of companionship and specific therapies, despite some difficulty in accessing specific sections on the DVD by a few users.

“I think it is very good – it provides the emotional help I was looking for and I thought that was very good. When I was having chemotherapy, I didn’t want to travel and I think it is lovely that you have got something that you can look at and maybe when you do feel better or able to travel you can use the centre maybe.” Haven at Home user

Sara’s Group Mind-Body Programme

Haven Founder, Sara Davenport created a programme of a distinct combination of existing Haven therapies to see if it could better support people with longstanding problems in need of additional help. Selected Visitors (N=16) participated in the Sara’s Group Mind-Body Programme. Positive changes were found in the following areas:

- Statistically significant improvement in total stress scores (Symptoms of Stress Inventory), and anxiety and emotional subscale scores.
- A moderate, but non-significant increase in the number of natural killer cell numbers.

“During the year that I have spent on the programme at The Haven; it’s hard to measure how far I have grown in strength, confidence and wellbeing, the journey is so great. I was so fragile and lost when I began and now I feel a calmer, stronger and much better person than I was before I got breast cancer. I feel able to cope with the possibility of a recurrence with less fear than before and the knowledge that I have learnt skills to not only help me deal with health related issues but with many other areas of my life”. Sara’s Group participant

Emotional Freedom Techniques Service Evaluation

A service evaluation of 41 Visitors to the London and Yorkshire Havens who received a 3-week course of Emotional Freedom Techniques showed positive effects on menopausal symptoms associated with hormonal therapy:

- Significant decreases in the numbers of total hot flushes, numbers of moderate severity hot flushes and the perceived bothersome of hot flushes/night sweats.
- Significant improvement in fatigue severity and the degree to which fatigue interfered with normal activities.
- Significant improvement in mood scores - Total Mood Disturbance and the subscales Tension/Anxiety, Depression/Dejection, Fatigue/Inertia, Vigour/Activity and Confusion/Bewilderment.
- Significant decrease in the degree to which pain interfered with normal activities.

“Since doing the Emotional Freedom Technique I have found the hot flushes have become less severe and not so frequent”.

• Statistically significant improvement in total mood disturbance, and depression/dejection and confusion/bewilderment subscale scores of the Profile of Mood States.
Clinical Audit

Lymphoedema Clinical Audit

An audit of the presenting characteristics of all Visitors (N=263) seen in The London Haven’s former Lymphoedema Service (TLHLS) between 10th February 2000 and 4th June 2003 for treatment of breast cancer-related Lymphoedema. The reported outcomes of treatment were:

• A total of 70% of patients with breast/trunk oedema achieved complete resolution of swelling within 12 months following a course of Manual Lymph Drainage.

• Patients with moderate–severe and/or complicated arm swelling achieved a mean reduction of 40% in limb size over 12 months with a programme of intensive treatment and self-care measures.

• Patients with mild and uncomplicated arm swelling achieved a mean reduction of 30% in limb size over 12 months with self-care measures and minimal therapist input.

Reviews

Preliminary review of Visitor records at the London Haven to explore the feasibility of a 5-year survival study of women with breast cancer attending The Haven centres

We were interested to see whether preliminary data collected from our Visitor records (N=1569) could give us any indication of survival of women diagnosed with breast cancer who had attended The Haven in London from 2000 to 2005, compared to those who had not. Data from women who had attended The Haven within the first two years of diagnosis were included, with the following results, which appear to show a positive effect of The Haven programme on survival. However, the relatively small numbers of Haven Visitors compared to those from the cancer networks, and lack of matched controls, mean that these results should be viewed with caution.

Comparison of 5-year survival rates for the Haven Visitor cohort, London Cancer Networks (LCN) and London Strategic Health Authority

<table>
<thead>
<tr>
<th>Cohort</th>
<th>No. in cohort</th>
<th>No. of deaths</th>
<th>Relative survival rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haven Visitors</td>
<td>1,561</td>
<td>206</td>
<td>86.8%</td>
</tr>
<tr>
<td>South West LCN</td>
<td>4,686</td>
<td>1,178</td>
<td>84.5%</td>
</tr>
<tr>
<td>North West LCN</td>
<td>4,431</td>
<td>1,146</td>
<td>82.2%</td>
</tr>
<tr>
<td>London SHA Total</td>
<td>18,746</td>
<td>5,145</td>
<td>81.6%</td>
</tr>
</tbody>
</table>

Literature Review of Evidence Base underpinning the Haven Programme

Every two years, The Haven performs a literature review of the evidence underpinning the different therapeutic approaches offered at each Haven. Using the best available evidence, this review informs the evidence-base for the safe and effectiveness practice of therapies at The Haven.

Direction of future Haven research and why it is important

Research at The Haven is important because:

• The Haven is the only breast cancer charity that actually performs research in the field of complementary medicine (rather than funding it), which is a unique selling point. This is important as the charity is currently trying to differentiate what it offers from other breast cancer charities.
• The publication of high quality research provides an important marketing tool for the charity. For example, research published in high impact, peer-reviewed journals with a wide readership provides valuable PR opportunities and enables further collaborations with top researchers and clinicians. It also cements our presence as a high quality, credible organisation in the NHS and charitable sectors.

• The Haven is the only breast cancer support charity of its kind that keeps Visitor records. This unique, extensive resource is invaluable for contributing to ongoing research and service evaluation and recruitment to future research studies.

• Research into the effectiveness of the therapies offered by The Haven is essential for ensuring that the services provided meet the needs of its Visitors adequately, and also meet the criticism that is often levelled at complementary medicine, that there is an inadequate evidence base. It also helps us demonstrate that we are fulfilling our charitable aims and objectives.

• The National Cancer Survivorship Initiative reviewed the effectiveness of programmes that might help in cancer survivorship. The Haven at Home service evaluation was funded as part of this process.

• In order to have any future large-scale research collaborations at The Haven, there is a need to perform pre-pilot work so that we are in a strong position to receive any possible future NHS research funding. In any case, future research will need to be performed in collaboration with both a NHS consultant clinician as principle investigator and university-based researcher support for statistics etc.

• Funding for a large-scale research project would be obtained from a grant-giving body e.g. NHS Research for Patient Benefits or research funding charities. This would largely cover the cost of research staff salary.

Current area of new research

We are evaluating how a cutting-edge self-management technique, Emotional Freedom Techniques, could help the long term side effects of Tamoxifen and Aromatase Inhibitors and help with compliance to treatment.

Conclusions to Executive Summary

The Haven has embarked on an ambitious programme of research and evaluation for a small charity and this has shown that it is possible to achieve high standards. This can be judged by a number of successful publications in national and international peer-reviewed journals.

• The findings from research and service evaluations of programmes offered at The Haven are overwhelmingly positive, even when evaluated under the most rigorous conditions, e.g. the randomised controlled trial evaluating MBSR.

• Large numbers of Visitors from all Havens have given feedback to our unique programmes, which emphasises the value and support that they have received.

• Specifically, support programmes offered at The Haven have shown to be very beneficial for both psychological and physical problems:
  • Anxiety, depression, stress, mood disturbances, anger, fear, confusion, vigour,
  • Coping with loss and bereavement, relationship issues and emotional traumas
  • Common physical concerns including hot flushes and night sweats, fatigue, weight problems, sleep disturbance, aches and pains, nausea, side effects of radiotherapy and lymphoedema.

• From participating in our programmes people found that they:
  • were calmer, centred, at peace, connected and more confident
  • more aware of choices in their behaviour
  • more easily accepting of their life, less judgemental
  • had better personal relationships
  • made time and space to take care of themselves.
Preliminary measurement of immune mechanisms has been conducted in the evaluation of the Haven Programme and Sara’s Group programme. Some promising results suggest that this is an area for further development.

Preliminary findings from our service evaluation of Emotional Freedom Techniques in London and Yorkshire shows positive effects and warrants more rigorous research.

The Haven’s biennial performance of literature reviews of current evidence to underpin its clinical practice ensures safe and effective delivery of our services.

Research is important to demonstrate the value of the charity’s unique services to people with breast cancer. To continue this work in collaboration with NHS clinicians and academics is key to the future success of the charity.

Why does The Haven do research and evaluation?

Between 50 to 80% of people diagnosed with breast cancer turn to complementary therapies for help and support. Whilst in high demand by users, this area is not as well researched as medical treatments for cancer. The vast majority of money for cancer research goes into diagnosis and cure, however, improving quality of life is an important aspect for the growing number of people living with and beyond cancer. As we partner with the NHS, it is imperative that we are adding to the evidence base regarding the effectiveness of the therapies we provide. The aim of this research is to see how these approaches can enhance the lives of people living with cancer.

The Haven has been conducting research and evaluation of its services for people affected by breast cancer for over 10 years. The importance of evaluating the impact and potential benefits of our services to the Visitors we serve is a key part of meeting our aims and objectives, and also is a way of measuring the value of what we do. Some of the results obtained over the last 10 years have been published in peer-reviewed journals, whilst other reports and information are available online on The Haven website.

In order to share our findings from research and evaluation, we have produced this document, which is a summary of research projects and service evaluations carried out at the London Haven over the last 10 years.

What are the areas of research, service evaluation, clinical audit and reviews that The Haven has undertaken in people with breast cancer?

1. Research Projects
   - Evaluation of the effectiveness of the Haven Programme
   - Evaluation of the effectiveness of Mindfulness-Based Stress Reduction (MBSR)

2. Service Evaluations
   - Perceived concerns and wellbeing of Visitors before and after The Haven Programme using MYCaW
   - Individual courses of complementary therapies
   - The outreach Haven programme, Haven at Home
   - Sara’s Group Mind-Body Programme
   - Emotional Freedom Techniques for the side effects of hormonal therapy

3. Clinical Audit
   - Lymphoedema management for breast oedema

4. Reviews
   - Preliminary review of Visitor records at the London Haven
   - Literature review of Evidence Base
Chapter 1.
Research Projects

CJ’s story
“I picked up a leaflet about The Haven at hospital when I was first diagnosed. I was keen to try anything that might help, so I came in and met the nurse specialist who discussed what support might be most beneficial for me. I spoke to the nutritional therapist who analysed my diet and suggested practical ways that I could improve it; maintain a good weight and even out the peaks and dips in my energy levels. I also had acupuncture which helped me to stay on schedule with my chemotherapy appointments. Keeping to schedule was really important to us as a family because changes to the plan were very unsettling for my two adopted boys. I also knew that I needed some help in managing stress on a long term basis and this is where mindfulness based stress reduction (MBSR) really helped. I went to a class and could see how it would be really useful so I signed up for the Haven course to learn more and I can now practice it at home and it has become a part of my life. Coming to The Haven has been very good for me. Even just coming in for lunch, to read some books and have a chat with some of the other women going through the same thing is very restorative. You don’t have to explain your situation to everyone – they all just understand.”
1.1 Effectiveness of mindfulness-based stress reduction (MBSR) in mood, disease-related quality of life and wellbeing in stages 0 to III breast cancer: a randomized, controlled trial.


Research Team details: Dr Caroline J. Hoffman, The Haven; Professor Steven J Ersser, Dean and Professor, University of Hull; Professor Jane B. Hopkinson, Cardiff University; Dr Peter G Nicholls, University of Southampton; Julia E Harrington, The Haven; Professor Peter W Thomas, Bournemouth University. Date: 2004–2009

Key Findings

• To our knowledge, this is the largest adequately powered trial to date testing the effects of the MBSR programme in women with stages 0 to III breast cancer.

• Important findings from this study include statistically significant improvements following MBSR compared to controls in overall mood, anxiety, depression, anger, vigour, fatigue and confusion, breast- and endocrine-related quality-of-life including hot flushes and other menopausal symptoms, emotional, physical and role functional wellbeing and general wellbeing.

• Our study is the first to show significant benefits of MBSR on mood in cancer at three months.

Background

This randomised controlled study was carried out by Dr Caroline Hoffman (Clinical and Research Director) at The Haven in London as her doctoral work, in collaboration with professors and other academics from the Universities of Southampton, Hull, Cardiff and Bournemouth and is the largest randomised controlled trial in this field.

MBSR is a stress reduction programme, first developed by Professor Jon Kabat-Zinn at the University of Massachusetts Medical Centre 30 years ago, which is used world-wide for people with a variety of health problems. Only a few, very small, studies have been performed using MBSR with people with breast cancer prior to this research but its value in other health conditions suggested that rigorous evaluation in women with breast cancer was warranted. MBSR is an eight-week programme to reduce stress with the cultivation of mindfulness as its core tool. Mindfulness can be described as bringing attention and awareness to the present moment experience in a specific and non-judgemental way as a means of decentring, allowing the calming of physical and psychological symptoms and the building of resilience. A total of 229 women with breast cancer attending The Haven in London following hospital treatment were randomised into one of two groups, one of which received the MBSR programme, whilst the second formed a control group. Participants in the control group were able to participate in the MBSR programme following the study period. All participants completed questionnaires regarding mood, quality of life and wellbeing.

Abstract

Purpose

To assess the effectiveness of mindfulness-based stress reduction (MBSR) in women with stages 0 to III breast cancer following hospital treatment relating to mood, breast- and endocrine-specific quality-of-life and wellbeing.

Patients and Methods

A randomized wait-list controlled trial was carried out with 229 women following surgery, chemotherapy and radiotherapy for breast cancer. Patients were randomly assigned to the 8-week MBSR program or standard care. Profile of Mood States (POMS) (primary outcome), FACT-B and FACT-ES and WHO-5 Wellbeing scales evaluated mood, quality-of-life and wellbeing at weeks 0, 8 and 12.

Results

Repeated measures analysis of variance using outcome measurement at baseline as a covariate produced statistically significant interactions between measurement occasion and treatment group for POMS Total Mood Disturbance, subscales: anxiety, depression, anger, vigour, fatigue and confusion; FACT-B, FACT-ES and WHO-5 Wellbeing scales evaluated mood, quality-of-life and wellbeing at weeks 0, 8 and 12.
statistically significantly greater than at 8-weeks. Increased mindfulness practice predicted significant improvements in wellbeing at 8- and 12-weeks.

Conclusions
MBSR improved mood, breast- and endocrine-related quality-of-life and wellbeing more effectively than standard care in women with stages 0 to II breast cancer and these results persisted at three months. This provides novel evidence that MBSR can help alleviate long-term emotional and physical side-effects of medical treatments, including endocrine treatments. MBSR is recommended to support breast cancer survivors.

Funding
The Girdlers’ Company via The Florence Nightingale Foundation; Mr Harvey White, The Haven.

1.2 Mindfulness-Based Stress Reduction in breast cancer: a qualitative analysis


Research Team details: Dr Caroline J. Hoffman, The Haven; Professor Steven J Ersser, Dean and Professor, University of Hull; Professor Jane B. Hopkinson, Cardiff University. Date: 2004–2009

Key Findings

- This is one of the few qualitative investigations evaluating Mindfulness-Based Stress Reduction (MBSR) in breast cancer populations.

- Thematic analysis showed that the most positive experiences of 92 participants were:
  - being calmer, centred, at peace, connected and more confident
  - the value of mindfulness practice
  - being more aware
  - coping with stress, anxiety and panic
  - accepting things as they are, being less judgemental of myself and others
  - improved communication and personal relationships
  - making time and creating space for myself.

- All participants when asked (N=39) said that they had become more mindful following MBSR training.

Background
In the UK, the amount of physical and emotional support received, and the opportunity to learn self-management skills for breast cancer patients beyond medical treatment remains a postcode lottery. The UK’s National Cancer Survivorship Initiative is examining appropriate ways of helping people live well with and beyond cancer. The breast cancer charity, The Haven, seeks effective and novel ways to support the wellbeing of people through what is often a lengthy and unpleasant treatment and recovery period with uncertain outcomes. It provides free help in its day centres in the form of information, support and mind-body therapies to help people alongside and after their medical treatments; there is also support and complementary therapies available via their film and audio and web-based outreach programme called The Haven at Home.

Before commencing this research, there was no published qualitative MBSR data in cancer patients. Subsequently two studies have been published. In one study, five themes were found in cancer outpatients: opening to change, self-control, shared experience, personal growth, and spirituality, whilst in the second study of breast cancer patients, themes of acceptance, regaining and sustaining mindful control, taking responsibility for what could change, openness and connectedness were identified. The limited number of studies offered this opportunity to further research the qualitative experiences of women treated for breast cancer undergoing MBSR.

Abstract
Purpose
To explore the acceptability and perceived effects of participating in MBSR using qualitative data nested within an evaluative randomised controlled trial (RCT).

Patients and Methods
As part of a larger randomised controlled evaluative trial (see above), 92 participants with stages 0 to III breast cancer completed a short proforma following week 8 of a MBSR programme conducted at The Haven in 2005-2006. Semi-structured questions were used to explore the participants’ experience of MBSR. Data was analysed in a series of analytic steps using content and thematic analysis.
Results
Following thematic analysis, the most positive experiences from participants (N=92) were reported to be; 1) being calmer, centred, at peace, connected and more confident; 2) the value of mindfulness practice; 3) being more aware; 4) coping with stress, anxiety and panic; 5) accepting things as they are, being less judgemental of myself and others; 6) improved communication and personal relationships and 7) making time and creating space for myself. All participants when asked (N=39) said that they had become more mindful following MBSR training.

Conclusions
These qualitative results suggest that MBSR and mindfulness practice can enhance the quality of life in breast cancer survivors by teaching a way of being and coping that can be used in different aspects of their lives. A key new finding is that MBSR gives women time and space for themselves and permission to engage in self-care, thereby enhancing self-management.

Funding
The Girdlers’ Company via The Florence Nightingale Foundation; Mr Harvey White, The Haven.

1.3 A randomised controlled pilot feasibility study of the physical and psychological effects of an integrated support programme in women with breast cancer


Research Team details: Dr Barbara Baker, Julia Harrington and Dr Caroline Hoffman, The Haven; Dr Beak-San Choi, Dr Pascale Kropf and Dr Ingrid Muller, Imperial College, St Mary’s campus.

Date: Feb 2008 – Sept 2009

Key Findings
• Preliminary trends suggest that participation in The Haven Programme may be associated with an improvement in confusion/bewilderment, cognitive and mental fatigue symptoms, accompanied by an increase in immune function.

• A large multi-centre randomised trial to evaluate elements of The Haven programme is feasible, and would be worthwhile, provided that funding is available and recruitment is improved.

Background
Approximately half of women affected by breast cancer are turning to supportive and complementary therapies to help with disease symptoms, side effects of cancer treatment, or psychosocial issues that result from diagnosis, treatment and prognosis. However, the evidence base for the complementary therapies accessed by cancer patients is often lacking or of poor quality, highlighting the need for further research involving large numbers of participants in randomised, controlled trials, the so-called “gold standard” of clinical research.

Preliminary findings of the benefits of The Haven Programme suggest that a rigorous evaluation of its role as part of an integrated approach to treatment of women with breast cancer is warranted. The first step towards this goal is to carry out a small pilot feasibility study to test recruitment and outcomes to be used in a full scale, multi-centre randomised trial.

The pilot feasibility study was carried out from February 2008 to September 2009 at The Haven.
Abstract

Purpose
To perform a pilot feasibility study to evaluate recruitment and outcomes needed to measure the effectiveness of The Haven programme in women with breast cancer compared to controls.

Patients and Methods
The pilot feasibility study was a randomised study in which women with breast cancer either received The Haven Programme alongside standard medical treatments, or standard medical treatments alone. Recruitment for the study, carried out at Charing Cross and St Mary’s Hospitals in London, ran from February 2008 to the end of May 2009.

• Quality of life was measured using questionnaires that include factors such as mood states, menopausal symptoms, fatigue and stress.
• Blood and saliva samples were collected to measure immune cell function and levels of cortisol (stress hormone), respectively.
• To analyse the feasibility of evaluating the cost-effectiveness of The Haven programme, patients were asked to keep a cost diary in which they recorded the medications or medical supplies they had bought, and the number of visits they have made or received from healthcare professionals.

Results
Preliminary findings suggested that participation in The Haven programme may be associated with improvement in confusion/bewilderment, cognitive and mental fatigue symptoms, accompanied by an increase in immune function. In the control group, total stress, anxiety and endocrine-specific symptoms improved. Emotional wellbeing improved in both intervention and control groups.

Recruitment to the study was problematic and the number of participants low, with the result that the findings should be viewed purely as trends.

Conclusions
This study shows that it would be feasible to do a larger randomised controlled trial to more rigorously evaluate The Haven Programme. However recruitment was a major problem, which did not appear to be related to timing during cancer treatment and would need the support of dedicated hospital-based research nurses to address this in a future trial. However, the drop-out rate was low in both groups, and the amount of missing questionnaire data was small. The uptake of The Haven programme by the intervention group was variable; this could be improved by more careful monitoring. Although the numbers of participants were small, preliminary trends show promise and warrant further investigation with an adequately powered study.

Funding
GlaxoSmithKline generously donated £79,022.
Chapter 2.
Service Evaluations
of The Haven Programme

Elia’s story
“My medical treatment was second to none and The Haven was an absolute salvation too. They gave me with the equally important emotional support that I really needed. My emotions were a roller coaster and I was sensitive, moody and joyful in the space of about five minutes. Not only was I juggling breast cancer which included having ten operations, an infection and the effects of Tamoxifen, but I was also coping with my mum’s health problems, the final year of my studies and a new relationship. All together it proved quite a challenge. The love and support I received from my boyfriend, friends as well as the people at The Haven kept me going. I had acupuncture which helped with all sorts of things including stress, and my Mind Body sessions were really amazing – they helped me to think about what I wanted from life. Counselling has been such a help too. I now feel much more emotionally stable. I am looking forward with eagerness and hope for a bright future.”
2.1A Effect of an integrated support programme on the concerns and wellbeing of women with breast cancer:
a national service evaluation using the Measure Yourself Concerns and Wellbeing Questionnaire.

Research Team details: Julia Harrington, Dr Barbara Baker, Dr Caroline Hoffman, The Haven.
Date: April 2007 – Sept 2009

Key Findings

- Psychological and emotional concerns predominated in The Haven Visitors. This is a unique finding as emotional needs are sometimes not given as high priority as physical problems.

- Within the programme, in addition to the support of a specialist nurse, the one-to-one therapies most commonly used were acupuncture, nutrition, massage & aromatherapy, shiatsu, counselling and reflexology.

- Statistically significant results show that women with breast cancer find The Haven programme effective for addressing their key concerns and improving their wellbeing.

- After participating in The Haven Programme, 91% of reported scores rated the concern as being a little better, much better or gone.

- These effects are consistent across all three Havens—in London, Hereford and Leeds. This gives us confidence that our unique, in-depth and individually tailored mind-body programme can be successfully transferred to different locations around the country with consistent results.

Background

A new Haven centre was opened in 2008 in Leeds, Yorkshire. To investigate whether the Visitors to all three Haven centres (n=402) consistently perceived improvement in their main concerns and wellbeing after receiving the integrated Haven support programme, a service evaluation was conducted during the period April 2007 to September 2009 using the self-report MYCaW questionnaire. This was a follow-up to a previous evaluation carried out between September 2004 and January 2006, prior to the opening of the Yorkshire Haven, which is described below.

Abstract

Purpose
To carry out a national service evaluation of the integrated cancer support programme offered by The Haven using the Measure Yourself Concerns and Wellbeing (MYCaW) outcome questionnaire.

Methods
Breast cancer survivors who visited one of three Haven centres in the UK completed the MYCaW questionnaire, before and after six one-hour complementary therapy sessions.

Results
“When first diagnosed with breast cancer I found it hard to tell people, as I didn’t want to be treated any differently. So I tended to bottle everything up. This also put a lot of stress on my husband and family. Coming to The Haven helped me to think about everything and open up to others”. Jacqui

The 2911 concerns presented by 1524 visitors to the Haven centres were predominately psychological and emotional (48%), with 23% physical, 17% related to wellbeing and 11% to hospital cancer treatment.

Statistically significant decreases in mean baseline scores (indicating improvement) for concerns and wellbeing were observed after treatment: concern 1 (5.09 ± 1.04 vs 3.17 ± 1.60, p < 0.0001, n = 402), concern 2 (4.69 ± 1.08 vs 3.08 ± 1.56, p < 0.0001, n = 372), and wellbeing (3.30 ± 1.41 vs 2.63 ± 1.28, p < 0.0001, n = 402).

The therapies most commonly used were acupuncture, nutrition, massage and aromatherapy, shiatsu, counselling and reflexology. After therapy, 91% of reported scores (n = 328) rated the concern as being a little better, much better or gone.

Conclusions
These findings suggest that women with breast cancer find The Haven integrated support programme valuable for addressing their main concerns and improving their feeling of wellbeing.

Funding
The Haven
2.1B Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data using Measure Yourself Concerns and Wellbeing (MYCaW)


Research Team details: Dr Helen Seers, Penny Brohn Cancer Care; Dr Nicola Gale, University of Westminster; Dr Charlotte Paterson, University of Exeter; Helen Cooke, Penny Brohn Cancer Care; Dr Veronica Tuffrey, University of Westminster; Dr Marie Polley, University of Westminster (former Haven Research Fellow). Date: Sept 2004 – Jan 2006

Key Findings

• Measure Yourself Concerns and Wellbeing (MYCaW) was found to be a suitable tool for evaluating the problems and concerns of Haven Visitors.

• Psychological and emotional concerns predominated.

• After The Haven Programme, there were significant improvements in Visitors’ concerns and wellbeing.

• Visitors found that the most important aspects of coming to The Haven were:
  a) receiving complementary therapies on an individual or group basis
  b) support and understanding received from therapists
  c) time spent with other patients.

Background

The Haven has been using the self-report MYCaW questionnaire since 2004 to evaluate the effectiveness of its support programme. Using this tool, Visitors to The Haven can rate their two main concerns and level of wellbeing. In the first evaluation, data was collected from 421 patients at The Haven centres in London (n=268) and Hereford (n=153) between September 2004 and January 2006 using the MYCaW questionnaire, completed before and after a mean of six one-hour complementary therapy sessions. This data was then combined with similar MYCaW data collected from Penny Brohn Cancer Centre for the purposes of publication.

Abstract

Purpose

The widespread use of complementary therapies alongside biomedical treatment by people with cancer is not supported by evidence from clinical trials. We aimed to use combined qualitative and quantitative data to describe and measure individualised experiences and outcomes.

Patients and Methods

In three integrative cancer support centres (two breast cancer only) in the UK, consecutive patients completed the individualised outcome questionnaire Measure Yourself Concerns and Wellbeing (MYCaW) before and after treatment. MYCaW collects quantitative data (seven-point scales) and written qualitative data and the qualitative data were analysed using published categories.

Results

782 participants, 92% female, mean age 51 years, nominated a wide range of concerns. Psychological and emotional concerns predominated. At follow-up, the mean change (improvement) in scores (n=588) were: concern 1, 2.06 (95% CI 1.92–2.20); concern 2, 1.74 (95% CI 1.60–1.90); and well-being, 0.64 (95% CI 0.52–0.75). The most common responses to ‘what has been the most important aspect for you?’ were ‘receiving complementary therapies on an individual or group basis’ (26.2%); ‘support and understanding received from therapists’ (17.1%) and ‘time spent with other patients at the centres’ (16.1%). Positive (61.5%) and negative (38.5%) descriptions of ‘other things affecting your health’ correlated with larger and smaller improvement in concerns and wellbeing, respectively.

Conclusions

In a multicentre evaluation, the MYCaW questionnaire provides rich data about patient experience, changes over time and perceptions of what was important to each individual with cancer within that experience. It is unlikely that meaningful evaluations of this complex intervention could be carried out by quantitative methods alone.

Funding

£20,000 generously donated by GlaxoSmithKline.
Patients and Methods
People with cancer who use complementary therapies experience and value a wide range of treatment effects, yet tools are urgently required to quantitatively measure these outcomes. MYCaW is an individualised questionnaire used in cancer support centres providing complementary therapies, scoring ‘concerns or problems’ and ‘well-being’ and collecting qualitative data about other major events in a patient’s life and what has been most important to the patient. Content analysis on 782 MYCaW questionnaires from people at cancer support centres was carried out. The ‘concerns,’ ‘other things going on in their life’ and ‘important aspects of centre’ were thematically categorised and externally validated by a focus group, and the inter-rater reliability was calculated.

Results
Clinical information from a cancer patient’s perspective was collected that is not measured on standard quality-of-life questionnaires; furthermore, some themes acknowledge the multi-faceted aspects of complementary and alternative medicine provision, rather than information only relating to the therapeutic intervention. Categories for qualitative MYCaW analysis have been established providing a tool for future research and/or service delivery improvement within cancer support centres such as these.

Conclusions
The established themes provide a framework to aid analysis of qualitative aspects of complementary therapy care for people with cancer, thus improving our understanding of how such support can help the patient’s cancer experience.

Funding
£20,000 generously donated by GlaxoSmithKline to The Haven, and additional funding to enable publication from the University of Westminster Research Development Fund and Penny Brohn Cancer Care.
2.2 Service Evaluation of a Course of Individual Therapy (unpublished)

Research Team details: Dr Barbara Baker, Julia Harrington, Dr Caroline Hoffman. Date: June – Nov 2009 and May 2010 – June 2011

Key Findings

- Most frequent problems listed by the Visitors were physical (50%) and psychological/emotional (40%).
- The commonest physical problems were nutritional or hot flushes/sweats.
- The commonest psychological problems were fear and anxiety.
- Over three-quarters of the Visitors wanted help with general wellbeing.
- Three-quarters of the problems cited were addressed using nutritional therapy, acupuncture and counselling.
- 99% Visitors felt that their course of therapy had been helpful.
- 87% Visitors felt their course of therapy was essential for their recovery from breast cancer.
- 58% Visitors felt that they needed more therapy appointments.

Background

Each Visitor coming to a Haven is offered a personalised programme of one-to-one therapies and the opportunity to join various groups, classes and seminars. We offer a minimum of ten hours of individual therapy time in addition to assessments and reassessments conducted by our specialist nurses or senior therapists. In order to evaluate the perceived benefit of the individual therapies that Haven Visitors receive, each therapist gives the Visitor an evaluation form to complete at the end of the course of that particular therapy e.g. acupuncture, counselling, nutrition. This information is valuable for The Haven to assess how particular therapies can help our Visitors.

Abstract

Purpose

The purpose of this service evaluation was to determine how beneficial the Visitors found courses of individual therapies offered at The Haven.

Course of Individual Therapies Service Evaluation

Two evaluations were carried out in the periods from 1 June to 30 November 2009, and 1 May 2010 to 30 June 2011, and the data combined. Subsequent to the first evaluation, the feedback form was revised to remove the questions relating to payment for additional appointments; this data has been omitted from the report. A total of 341 Visitors to The Haven in London, Hereford and Leeds completed a feedback form on completion of a course of therapy. Just over half of the forms were completed at the Leeds Haven, a third at the London Haven, and only a small proportion (14%) at the Hereford Haven.

Results

Overall the therapies most frequently evaluated by Visitors, in order of frequency, were: nutrition; acupuncture; counselling; shiatsu; massage/aromatherapy; reflexology. The majority of Visitors (64%) received 2-4 appointments of an individual therapy (mean 3.43; range 1-14, n= 321). Just over half (58%) of Visitors felt that they needed more therapy appointments, whilst around one-third (36%) did not. Almost all (99%) of the Visitors felt that their course of therapy had been helpful (88% very helpful), and 87% that it was essential for their recovery from breast cancer. The most frequent problems listed by the Visitors were physical (50%) and psychological/emotional (40%), with some wellbeing issues (9%). The commonest physical problems were nutritional or hot flushes/sweats, which were treated mainly with nutritional therapy and acupuncture. The commonest psychological problems, fear and anxiety, were treated most often with counselling and acupuncture; wellbeing was addressed using nutritional therapy. Overall, three-quarters of the problems cited were addressed using nutritional therapy, acupuncture and counselling.

Conclusions

Haven Visitors reported having received significant benefits from the individual Haven therapies to help with their individual concerns.

Funding

The Haven and Simply Health.
2.3 A service evaluation of The Haven at Home as a support programme for breast cancer survivors


Research Team details: Dr Barbara Baker, Julia Harrington, Dr Caroline Hoffman, The Haven.
Date: April 2009 – Feb 2010

Key Findings

- The Haven at Home programme was considered to be very helpful (79%) and easy to understand (81%).

- Seven of the 13 DVD sections (getting emotional support, about breast cancer, Emotional Freedom Technique, Tai Chi movement, yoga stretches, nutrition and creating a healthier environment), were considered to be very helpful by 60-70% of the participants.

- All 4 sections on the audio CD (mindfulness meditation, hypnotherapy, breathing, relaxation and healing visualisation and essence of meditation) were considered to be very helpful by 60-70% of the participants.

- The Haven at Home was liked for its positive effects, usefulness at home, offer of companionship and specific therapies, despite some difficulty in accessing specific sections on the DVD by a few users.

- All who responded stated that they would recommend the programme to others with breast cancer.

Background

It is the aim of The Haven to make its programme accessible to anyone affected by breast cancer throughout the UK. To this end an outreach programme called Haven at Home, consisting of a DVD, CD and web-based information, has been developed to complement the existing three Haven centres in Leeds, London and Hereford, and extend the availability of The Haven Programme to those who cannot reach a centre in the UK. It was officially launched on 29th January 2009 in Leeds. Haven at Home includes many of the different elements from the in-house Haven Programme to support mind and body that are known to be helpful from Visitor feedback. To determine whether this outreach resource is helpful for breast cancer survivors, a service evaluation was started in April 2009, with recruitment completed at the end of February 2010.

Abstract

Purpose

The aim of the study was to evaluate whether the outreach programme Haven at Home is helpful for breast cancer survivors.

Methods

Women living with breast cancer in the region covered by the Yorkshire Cancer Network were given a copy of The Haven at Home programme by breast care nurses at the hospitals they attended, and asked to complete and return a feedback questionnaire. To increase the return of feedback questionnaires, the study was extended to 206 women who had attended the Haven centre in Leeds. 73 completed feedback questionnaires were returned. In addition, telephone interviews were conducted with ten of the responding participants to obtain further detailed views and comments.

Results

- The majority of the participants found the DVD (80%; n=58) and audio CD (66%; n=49) very helpful. For the website, the proportion who found the resource very helpful was lower (55%; n=40), but the level of missing responses was higher than for the DVD and audio CD.

- Seven of the DVD sections were considered to be very helpful by 60-70% of the participants (getting emotional support, about breast cancer, Emotional Freedom Technique, Tai Chi movement, yoga stretches, nutrition and creating a healthier environment). All the sections on the audio CD (mindfulness meditation, hypnotherapy, breathing-relaxation-healing visualisation, and the essence of meditation) were considered very helpful by 60-70% of participants.

- 81% of participants found the DVD, audio CD and/or website easy to understand, and all participants who responded stated that they would recommend The Haven at Home to other people with breast cancer.

The three main aspects of The Haven at Home that were liked by the participants were the positive effects of the programme, (described as enjoyable,
relaxing, informative, reassuring, calming, supportive, encouraging, caring, thoughtful, friendly, helpful, sensitive, inspiring), the ability to use the programme when unable or unwilling to go to a Haven centre or if they preferred the privacy of their own home, and the feeling that they were not alone and could hear from others in the same situation.

62% stated that they had no dislikes about the programme or did not complete this section. Thirteen participants expressed the view that access to the different Mind, Body and Life sections on the DVD was confusing and that problems were encountered when negotiating through the menu.

Other comments were made by 62% of participants, the majority of which could be divided into four main categories; the Haven at Home programme, the Haven centres, The Haven as an organisation and charity, and earlier access to the resource.

**Quote from Haven at Home user:**

“I think it is very good – emotional help I was looking for and I thought that was very good. When I was having chemotherapy, I didn’t want to travel and I think it is lovely that you have got something that you can look at and maybe when you do feel better or able to travel you can use the centre maybe.

“CD is really good – there are times when you think I am fine, I am fine, but then you have a blip – you think that I have got something here and you can sit down quietly and get things back in perspective, start again. You might only want to listen to 20 minutes of it, but you can pick. I thought it was very, very good.

“Overall, even though I am five years on, I was grateful to have these. Good thing to have because you don’t know when it is going to happen to you, and when it does happen, if you can’t get referred quickly it is a tool you can use – I felt I was on the right track doing the right things”.

**Conclusions**

The Haven at Home programme was considered to be both very helpful and easy to understand by the majority of breast cancer survivors who used it. They liked Haven at Home for its positive effects, usefulness at home, offer of companionship and specific therapies, despite some difficulty in accessing specific sections on the DVD, and would recommend the programme to others with breast cancer. Most comments made by the breast cancer survivors emphasised the benefit and support they had received from the Leeds Haven, the Haven at Home programme and The Haven as a charity. Suggestions were made as to additional features to be included on the DVD.

**Funding**

Yorkshire Cancer Network generously donated a grant of £18,207.
2.4 Sara’s Group Mind-Body Programme (unpublished)


Date: Jan 2010 – April 2011

Key Findings

- Clinical assessment by the therapy team suggested that more than two-thirds of participants had benefited to some extent from the programme.

- Significant improvement in total mood disturbance, and depression/dejection and confusion/bewilderment subscale scores (POMS).

- Significant improvement in total stress scores (SOSI), and anxiety and emotional subscale scores.

- A moderate increase in natural killer cell numbers over the course of the study.

- Significant worsening of the endocrine-specific and physical wellbeing quality of life scores measured by FACT.

- Adrenal hormone levels were chronically suppressed in most participants at the start of the programme; there was no overall improvement on completion.

- Nearly half of the participants had lymphocyte levels below the normal range at the start of the programme; there were no consistent improvements on completion.

- No consistent changes in vitamin D, C-reactive protein, albumin, IFN-γ and TNF-α levels, or in white blood cell numbers were observed at the end of the study compared to baseline.

- All of these findings should be viewed as preliminary as only 13 Visitors out of 16 completed all the evaluations.

Background

Reasons for disharmony in the body and the mind may or may not be known consciously and may be due to many factors including past traumatic events. Removing mental and emotional trauma from the body, mind and energy system, and cultivating a calm and balanced state between the mind and body, may help to improve general health and wellbeing. This combined with the development of the necessary skills to take control of one’s life and play a part in one’s own recovery can lead to a happier and healthier life in the future. Sara’s Group mind-body programme was designed specifically for women with breast cancer to help remove these causes of disharmony in the body and mind, helping to restore balance and enable the participants to live in a more calm and confident way. This is a new intensive, in-depth approach involving a combination of various mind/body therapies; this approach has not been tested before at The Haven (or elsewhere). If beneficial, it is planned to develop and expand the programme more widely to Visitors to The Haven.

Abstract

Purpose

1. To see if removing mental and emotional trauma from the body, mind and energy system can help improve the general health and wellbeing of women with breast cancer.

2. To investigate whether any changes in hormonal and/or immune function are associated with response to the programme.

Sara’s Group Programme

A service evaluation of Sara’s group programme was carried out involving 16 women with breast cancer selected to take part. Self-report questionnaires to assess quality of life (FACT-B plus ES; Functional Assessment of Cancer Therapy-Breast and Endocrine Symptom subscale), stress (SOSI: Symptoms of Stress Inventory) and mood states (POMS; Profile of Mood States), and blood and serial saliva samples for immunological and hormone analysis, respectively, were collected at baseline, 15 weeks and 12 months. Hair mineral tests were also performed at baseline and at 12 months. Participants were asked to complete home practice record sheets of their use of techniques such as meditation, relaxation etc, taught to them as part of the programme.
Findings
Clinical assessment of the Visitors by the therapy team suggested that more than two-thirds had benefited to some extent from the programme. This was reflected in a statistically significant improvement in total mood disturbance, depression/dejection and confusion/bewilderment subscales (POMS), and in total stress, anxiety and emotional subscales (SOSI). In contrast physical wellbeing, including endocrine and menopausal symptoms, was statistically significantly worse at the end of the programme. There were no consistent changes in the hormonal and immune factors measured during the programme, with the exception of a moderate increase in natural killer cells.

Conclusions
Statistically significant improvements in psychological and emotional wellbeing supported the aims of Sara’s Group mind-body programme to improve the general health and wellbeing of women with breast cancer attending The Haven. A moderate increase in the activity of natural killer cells was associated with these improvements. However, physical wellbeing including menopausal symptoms was not improved and in some cases worsened. This is in contrast with results from our previously conducted large randomised controlled study of Mindfulness Based Stress Reduction (see page 10), which showed a statistically significant improvement in endocrine symptoms. This suggests that the negative physical and endocrine findings reported here might be due to the small numbers of women who undertook the Sara’s Group programme.

These findings are preliminary as this was a pilot evaluation of a new programme involving only 16 Haven Visitors. The valuable information obtained from this work will be used to inform the future development of The Haven Programme.

Publication
This service evaluation has not yet been written up for publication.

Funding
The Haven.
Abstract

Purpose
1. To develop a self-EFT protocol for women with breast cancer with Tamoxifen or Aromatase Inhibitor-associated menopausal symptoms, such as fatigue, hot flushes, joint pains and mood disturbance.
2. To test the effectiveness of the self-EFT protocol for addressing menopausal symptoms.

Service Evaluation
A service evaluation was carried out on a total of 41 Visitors to the London and Leeds Haven centres, who were invited by email to take part. Participants received three weekly EFT sessions in which they were taught how to use the tool. They were asked to complete a 7-day hot flush diary and the following questionnaires before the start of the course and at 6 and 12 weeks: Profile of Mood States (POMS), Brief Pain Inventory (BPI), Brief Fatigue Inventory (BFI), Functional Assessment of Cancer Therapy- Endocrine Symptom subscale (FACT-ES) and Hunter HFNW Scale. They were also given home practice sheets to complete during the first 6 weeks to assess self-EFT practice, and invited to attend a follow-up focus group at 8 weeks.

Findings
There were statistically significant decreases in the numbers of total hot flushes, numbers of moderate severity hot flushes and the perceived bothersome of hot flushes/night sweats at 6 and 12 weeks compared to baseline. However, the FACT-ES score, which includes menopausal symptoms, did not show a significant change.

Fatigue severity and interference with normal activity scores were also significantly decreased at 6 and/or 12 weeks compared to baseline, as were Total Mood Disturbance and the subscales Tension/Anxiety, Depression/Dejection, Fatigue/Inertia, Vigour/Activity and Confusion/Bewilderment.

EFT shows potential as a self-help tool to manage the side effects associated with hormonal therapies in women with breast cancer.

Background
Adjuvant hormonal therapy significantly improves the long-term survival of women with hormone-sensitive breast cancer, but is associated with debilitating side effects including hot flushes, joint pain, nausea, mood disturbance and fatigue. These side effects are one of the main reasons why only 41-72% of breast cancer patients finish their recommended courses of hormonal therapies. This lack of adherence to Tamoxifen and Aromatase Inhibitors is of significance as randomized trials have shown higher recurrence rates and worse survival with less than 5 years of treatment.
Comments from EFT participants recorded in the Hot Flush Diary:

“Definitely the flushes have reduced in number and severity since I have attended and been practising the EFT course”.

“Still tapping each morning and very few flushes now. Trying to tap more for pain”.

“Whilst I still suffer from bouts of depression they haven’t escalated to a severe, hopeless bout since I began EFT”.

Conclusions
This service evaluation has shown that Emotional Freedom Techniques show considerable potential as a self-help tool to manage the side effects associated with hormonal therapies, specifically hot flushes/night sweats, fatigue and mood changes, in women with breast cancer.

Publication
This service evaluation is currently being written up for publication. The findings were presented at the CAMSTRAND 2013 conference and the conference abstract published: Baker, B.S., Hoffman, C.J. European Journal of Integrative Medicine 2013; 5:572.

Funding
The Haven.
Chapter 3. Clinical Audit

Hannah’s story
“I was originally misdiagnosed at 22 years old, so I had been living with a cancerous tumour inside me for nearly two years. Knowing only a little about cancer and its progression I was sure that it would have spread to other areas of my body but tests and scans later showed that fortunately this was not the case, although it had spread to my lymph nodes. I began to focus on the surgery and treatment ahead. Emotionally I started to struggle and physically I was suffering from fatigue, difficulty sleeping and anxiety. I went to The Haven in Leeds who put together a programme of support for me. It included Shiatsu massage and reflexology which both helped hugely with the physical symptoms and helped me to relax. Just getting out of the house and having somewhere to go at a time when I was at risk of infection was good for me. The Younger Women’s support group was really helpful and beneficial. It was so good to meet other people in a similar situation, who understood what I was dealing with.”
3.1 Treating breast cancer related lymphoedema at the London Haven: A clinical audit.


Key Findings

• 70% of patients with breast/trunk oedema achieved complete resolution of swelling within 12 months following a course of Manual Lymph Drainage.

• Patients with moderate–severe and/or complicated arm swelling achieved a mean reduction of 40% in limb size over 12 months with a programme of intensive treatment and self-care measures.

• Patients with mild and uncomplicated arm swelling achieved a mean reduction of 30% in limb size over 12 months with self-care measures and minimal therapist input.

Background

Lymphoedema is recognised as a significant management problem for both patients and clinicians. Around 25% of those undergoing axillary intervention as treatment for breast cancer will go on to develop some degree of lymphoedema, which will impact their everyday life and wellbeing.

The Haven in London provided a full lymphoedema treatment service between 2000 and 2004. Led by Eunice Jeffs, one of the few senior clinical nurse specialists in lymphoedema treatment at the time, Eunice provided a full treatment protocol for people with breast cancer related lymphoedema during this time.

An audit of all 263 patients seen in The London Haven Lymphoedema Service (TLHLS) between 10th February 2000 and 4th June 2003 for treatment of breast cancer-related lymphoedema was carried out in the summer of 2003.

Abstract

Purpose
To carry out an audit of all 263 patients seen in The London Haven Lymphoedema Service (TLHLS) between 10th February 2000 and 4th June 2003 for treatment of breast cancer-related lymphoedema in order to:

1. Identify effective and ineffective treatment programmes.

2. Inform the decision-making process regarding where to focus future efforts and funding.

3. Provide a report to the Smith’s charity who had substantially funded TLHLS.

Methods

The records were examined of each patient who had attended the TLHLS between 10th February 2000 and 4th June 2003 and information including onset and duration of swelling, severity (size and extent) of swelling at first presentation, lymphoedema treatment received and changes in severity over time were collected.

Results

A total of 70% of patients with breast/trunk oedema achieved complete resolution of swelling within 12 months following a course of Manual Lymph Drainage. Patients with moderate–severe and/or complicated arm swelling achieved a mean reduction of 40% in limb size over 12 months with a programme of intensive treatment and self-care measures. Patients with mild and uncomplicated arm swelling achieved a mean reduction of 30% in limb size over 12 months with self-care measures and minimal therapist input.

Conclusions

Healthcare professionals need to be particularly alert to identify swelling during the cancer treatment and follow-up period as, although 59% had developed swelling during this time (i.e. within 12 months following their original axillary surgery or radiotherapy), only 31% accessed treatment within three months of developing swelling, which is the time period when the oedema is considered most easily treated.

The results highlight the key issues around current practice at the London Haven and the need for further research in promising areas in lymphoedema management.

Funding

Smith’s Charity.
Chapter 4. Reviews

Hayley’s story
“Life has been a bit of a rollercoaster since I was diagnosed, but The Haven has been such a Godsend. I couldn’t have got through my chemo without them. When I was first diagnosed it was a massive shock. My first instinct was to worry about my three children and how long I was going to be around for them. I had a lumpectomy and mastectomy which was OK but the chemotherapy was awful. It made me feel the lowest I have ever felt. I heard about The Haven both through a friend who had been and also through my breast care nurse. I first came after my mastectomy, but it was during my chemo when I felt so down and de-motivated that I needed their support the most. I had Aromatherapy sessions which I found it very relaxing but Hypnotherapy was the thing that kept me going. I was having such a struggle with the chemo and at points just felt like giving it up but the hypnotherapy helped so much. I also really enjoyed the yoga group, it helped me to relax and having a regular place to go where I could have a chat with other women in the same situation was such a relief. The Haven has helped me to get where I am now. I now feel really good and have gone back to Leeds University to finish my midwifery course.”
4.1 Preliminary review of Visitor records at the London Haven to explore the feasibility of a 5-year survival study of women with breast cancer attending The Haven centres (unpublished)

Research Team: Dr Barbara Baker, Julia Harrington, Dr Caroline Hoffman. Date: Aug 2009 – Mar 2011

Key Findings

• Of the Visitor cohort (N=1561), just over half were less than 50 years of age at diagnosis; this group had a lower survival rate compared to that of the 50-69 year age group, which is consistent with national breast cancer survival figures and may be related to differences in severity of disease.

• Classification of the stage of the disease of the Visitors showed an increase in deaths with disease severity. This again is consistent with current knowledge about breast cancer.

• The relative 5-year survival rate of the Haven Visitors was 86.8% (N=1561) compared to 84.5% (N=4686) in South West LCN, 82.2% (N=4431) in North West LCN and 81.6% (N=18,746) in the London SHA, which includes all London regions.

• No consistent change in the proportion of deaths was observed with increasing numbers of therapy appointments suggesting that the quality (reassurance that support is always available) rather than quantity of time spent at The Haven may be of more benefit to the Visitor during and after medical treatment.

• At all stages of breast cancer Haven Visitors had a better five year survival rate, but the Haven Visitor numbers were much smaller than the London SHA figures, so interpretation of these findings must be viewed with caution, and more research is needed.

Background

At The Haven, the focus of our research and evaluation has always been emotional support, quality of life, symptom management and improvement of wellbeing. Whilst, due to small numbers, it will not be feasible to conduct a rigorous randomised controlled trial evaluating survival in people affected by breast cancer, we were interested to see whether preliminary data collected from our Visitor records could give us any indication of survival of women diagnosed with breast cancer who had attended The Haven in London from 2000 to 2005, compared to those who had not.

Abstract

Purpose

To determine the 5-year survival rate of visitors to The London Haven during the period February 2000 to February 2005 and to compare with that of breast cancer survivors attending hospitals in the five London Cancer Networks during the same period.

Methods

The clinical records of 2,116 Visitors to The London Haven during the 5-year period from its opening in February 2000 until February 2005 were reviewed. Only those Visitors who were diagnosed up to 24 months on their first visit to The Haven were analysed (n=1,569). Age at diagnosis, and clinical data concerning the size of tumour, involvement of lymph nodes and medical treatment (needed to classify disease stage), were extracted from the Visitor notes. Dates of death were obtained from two historical websites, Ancestry.co.uk and FindmyPast.co.uk, and in some cases from Visitor records, and checked against the Thames Cancer Registry database, which contained 80% of the Visitor cohort. Five-year survival rates, and their association with age and disease stage at diagnosis, and number of Haven therapy appointments were analysed.

Results

Visitors who had been diagnosed for up to 24 months at first visit were selected for survival analysis (n=1569). There were 313 deaths, 68% of which were within 5 years, whilst 31% survived 6-10 years after diagnosis.

The overall 5-year relative survival rate for the Visitor cohort was 86.8% compared to 84.5%, 82.2% and 81.6% for the South West and North West London Cancer Networks, and London SHA, respectively (Table 1).
The proportion of deaths gradually increased from disease stage 0 (<4%) to stage IV (>50%). The relative 5-year survival rates for stage I, II/III and IV were 96.8%, 82.6% and 42.9%, respectively, compared to 89.0%, 76.2% and 23.0%, respectively for the London SHA. (Table 2).

No consistent change in the proportion of deaths was observed with increasing numbers of Haven therapy appointments. However, the proportion of deaths amongst Visitors receiving <12 therapy sessions was moderately higher than for those receiving 13-24 therapy sessions (13.5 ± 3.2% vs 10.5 ± 3.7%). This group tended to have more severe disease suggesting an explanation for the moderately higher death rate observed. These results must be viewed with caution as the number of Haven Visitors is relatively small compared to that of the wider breast cancer population figures.

### Conclusions
This study was intended as a preliminary analysis of 5-year survival in Visitors to the London Haven. The lack of matched controls prevents the conclusion that the increased survival observed was due to the programme offered at The Haven. However, the findings suggest that a large-scale randomised, controlled trial to investigate the effect of an integrated approach to breast cancer treatment may be warranted.

### Funding
The Haven and Simply Health.

### Table 2. Comparison of 5-year survival rates by stage at diagnosis for The Haven Visitor cohort and London SHA

<table>
<thead>
<tr>
<th>Stage of disease at diagnosis</th>
<th>Number in cohort</th>
<th>Number of deaths (% of total)</th>
<th>5-year survival rate</th>
<th>Number in cohort</th>
<th>5-year survival rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>106</td>
<td>4 (3.8)</td>
<td>96.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage I</td>
<td>282</td>
<td>9 (3.2)</td>
<td>96.8%</td>
<td>8,824</td>
<td>89.0%</td>
</tr>
<tr>
<td>Stage II/II</td>
<td>215</td>
<td>8 (3.7)</td>
<td>96.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage II</td>
<td>172</td>
<td>26 (15.1)</td>
<td>84.9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage II/III</td>
<td>616</td>
<td>107 (17.4)</td>
<td>82.6%</td>
<td>5,496</td>
<td>76.2%</td>
</tr>
<tr>
<td>Stage III</td>
<td>81</td>
<td>26 (32.1)</td>
<td>67.9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage IV*</td>
<td>35</td>
<td>20 (57.1)</td>
<td>42.9%</td>
<td>1,797</td>
<td>23.0%</td>
</tr>
<tr>
<td>Total</td>
<td>1507</td>
<td>200</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Includes 2 Visitors who were stage III/IV
4.2 Literature Review of Evidence Base underpinning The Haven Programme

Research Team: Dr Barbara Baker, Julia Harrington. Date: Every 2 years from 2007

Key Findings

- In cancer care, high quality research studies have been performed on only a limited number of complementary therapies such as acupuncture, mindfulness meditation and nutrition.

- In some less commonly used complementary therapies, currently there is no published research in cancer and evidence is based on case studies.

- Further high quality, rigorous research studies are needed to strengthen the evidence base for complementary therapies in cancer.

Background
The practice of complementary therapies are frequently criticised for lack of evidence. A literature review process was commenced to help counter this claim and ensure best standards of clinical practice at The Haven. This process was started in 2007 and, in accordance with the Information Standard certification, this review is updated every two years.

Findings from this review inform the safe and evidence-based practice of therapies at The Haven. In the review process, the best available evidence is considered as guidance for the practice and effectiveness for each therapy. Where possible meta-analyses, systematic reviews, randomised controlled trials and high quality qualitative research are used for this process.

Abstract
Purpose
To update the review of literature on the evidence underpinning the range of different therapies offered at each of The Havens.

Methods
The following databases were searched from September 2009 to date: Cochrane Database of systematic reviews, Centre for Reviews and Dissemination (CDR) Databases: Database of Abstracts of Reviews of Effects (DARE), MEDLINE/PUBMED, EMBASE, CINAHL, PsycINFO, NHS National Library for Health – Complementary and Alternative Medicine, National Center for Complementary and Alternative Medicine (NCCAM). Other sources included: National Cancer Institute (NIH), Memorial Sloan-Kettering Cancer Centre (MSKCC), Wikipedia, InteliHealth, therapy-specific websites.

The search terms used included: therapy name (e.g. acupuncture), breast cancer, cancer, herb or food name, safety, symptom name (e.g. hot flushes).

To obtain the highest research quality available, databases were searched firstly for meta-analyses, then systematic reviews, unsystematic reviews, randomised controlled trials (RCT), non-randomised controlled trials, and lastly, when no other data was available, uncontrolled trials, case studies and other research methods. High quality qualitative research studies were also included. Research papers selected for their quality and suitability were summarised and included in the Research Evidence-Base document, which is available on the Haven website.

Results
In cancer care, good quality research meta-analyses or reviews were only available for the more common therapies such as acupuncture, mindfulness meditation and nutrition. In some less commonly used complementary therapies, currently there is no published research in cancer and only limited research reports of other diseases. Evidence in cancer is therefore currently based on smaller research studies and case studies.

Conclusions
Further high quality, rigorous research studies are needed to strengthen the evidence base for complementary therapies.

Funding
The Haven.
Lesley’s story

“The Haven was repeatedly and strongly recommended early on, by friends who have had cancer, by my breast care nurse at the hospital and by my GP. I first visited soon after starting chemotherapy, and was so reassured by the calm atmosphere, the kindness of everyone I met, and the knowledge that everyone there was either being treated for breast cancer themselves, or was a professional who understood it. In my first consultation, we discussed what therapies and sessions would be most helpful alongside my hospital treatment plan. These included nutritional advice, acupuncture, craniosacral therapy and massage. I left after that first visit feeling very relieved, and calmer and safer than I had since the initial diagnosis. Massage was a real treat and comfort, a caring touch after being poked, prodded, drugged and radiated! Acupuncture was particularly helpful during chemotherapy, when it seemed to balance my body and my emotions by both calming and re-energising, and craniosacral therapy worked for me in a similar way. The nutritional therapist gave some sensible and manageable ideas for improving my diet, and suggested supplements to boost my immunity at the end of the formal hospital treatments. The Haven has given me an important, caring space away from day to day medical matters to reflect and recharge, it has really lived up to its name and I now recommend it to others as enthusiastically as it was suggested to me.”
5.1 A study of MBSR for the treatment of fatigue, anxiety and depression in patients with metastatic breast cancer with The University of Southampton

Research Team details: Professor George Lewith, Dr Gerry Leydon and Dr Caroline Eyles, Department of Primary Care and Population Sciences, University of Southampton; Dr Caroline Hoffman, The Haven.

Date: Jan 2011 – Dec 2011. Results awaiting publication.

Background
Cancer related fatigue is one of the most common symptoms experienced by those with persistent or advanced cancer and may be related to treatments, the cancer itself, menopausal symptoms and anxiety and depression. Fatigue has been poorly investigated and there are few effective treatments. Mindfulness-Based Stress Reduction (MBSR) has been shown to help people manage chronic pain and fatigue and also anxiety and depression. Although MBSR has been investigated in women with early stage breast cancer it has not been explored in advanced or metastatic breast cancer.

Following on from the success of Dr Caroline Hoffman’s research at The Haven evaluating MBSR in women with earlier stages of breast cancer, Professor George Lewith and Dr Gerry Leydon were awarded funding for around £250k by the National Institute for Health Research (NIHR) (UK), Research for Patient Benefit (RfPB) programme to conduct a study investigating the effects of MBSR on fatigue, anxiety and depression in women with metastatic breast cancer. Dr Hoffman is a collaborator in this research and is teaching the MBSR to the participants in the study.

“MBSR has improved my life beyond measure, and I cannot thank you enough for your support and instruction”. Lisa Jones

Abstract
Purpose
To assess both the impact of MBSR on fatigue, anxiety and depression in women with metastatic breast cancer, and the feasibility of conducting a possible future randomised controlled trial.

Patients & Methods
This is a predominately qualitative feasibility study, designed in collaboration with The Haven. Patients, identified as eligible by their oncologists and recruited onto the study, took part in one of three 8 week mindfulness courses taught by Dr Caroline Hoffman, the Clinical and Research Director of The Haven. There were 19 participants recruited onto the study and MBSR teaching was completed in December 2011.

Funding
A proportion of the RfPB grant was paid to The Haven for Dr Hoffman’s involvement in the study.
5.2 Acupuncture Research Study (ACU.FATIGUE) with The University of Manchester (completed Dec 2010)


Research Team details: Professor Alex Molassiotis, University of Manchester; Professor Alison Richardson, King’s College, London; Dr Jacqueline Filshie, Royal Marsden Hospital; Dr Peter Mackereth and Jo Bardy, Christie Hospital, Manchester. Date: Mar 2009 – Dec 2010

Background
Fatigue is a common and often under-reported problem experienced by breast cancer patients; it can be distressing and negatively impacts on patients’ quality of life. As many as 90% of breast cancer patients receiving chemotherapy may experience considerable fatigue, and as many as 40% of women may also experience moderate to severe levels of fatigue, even several years after treatment has been concluded. Preliminary evidence suggested that acupuncture might help in the management of this complex condition. Professor Alex Molassiotis at the University of Manchester obtained funding from Breakthrough Breast Cancer to carry out the world’s largest and most advanced clinical trial (ACU.FATIGUE study) to investigate the effectiveness of acupuncture for managing cancer-related fatigue in breast cancer patients.

Abstract
Purpose
To investigate the effectiveness of acupuncture and self-acupuncture in the management of cancer-related fatigue in women with breast cancer.

Patients & Methods
This was a pragmatic randomised controlled trial comparing acupuncture with enhanced usual care. Women with breast cancer who had completed chemotherapy treatment (N= 302) were recruited from the Christie Hospital, Manchester, the Royal Marsden Hospitals and Guy’s & St Thomas’ Hospital in London, and at The Haven centres in London, Leeds and Hereford. Treatment was delivered to 227 patients by acupuncturists (including experienced acupuncturists at The Haven centres) once a week for 6 weeks through needling three pairs of acupoints. The usual care group (n=75) received a booklet with information about fatigue and its management. Primary outcome was general fatigue at 6 weeks, measured with the Multidimensional Fatigue Inventory (MFI). Other measurements included the Hospital Anxiety and Depression scale, Functional Assessment of Cancer Therapy-General quality-of-life scale, and expectation of acupuncture effect.

Results
Two hundred and forty six of 302 patients randomly assigned provided complete data at 6 weeks. The difference in the mean General Fatigue score, between those who received the intervention and those who did not, was -3.11 (95% CI, -3.97 to -2.25; P < .001). The intervention also improved all other fatigue aspects measured by MFI, including Physical Fatigue and Mental Fatigue (acupuncture effect, -2.36 and -1.94, respectively, both at P< .001), anxiety and depression (acupuncture effect, -1.83 and -2.13, respectively, both at P < .001), and quality of life (Physical Well-Being effect, 3.30; Functional Well-Being effect, 3.57; both at P < .001; Emotional Well-Being effect, 1.93; P = .001; and Social Functioning Well-Being effect, 1.05; P < .05).

Conclusions
Acupuncture is an effective intervention for managing the symptom of CRF and improving patients’ quality of life.

Funding
Payment was made from the study grant for both the Haven researchers’ time in the recruitment of Visitors to the study, and for the Haven acupuncturists’ services.

“Acupuncture was one of the treatments recommended. At first I thought I didn’t want any more needles near me but it was amazing. The chemo was a totally different experience after it. I didn’t feel so sick; I felt more in control and full of energy. It was magical.” Debbie
Chapter 6. Conclusions and the way forward

Maggie’s story
“I was seeing an NHS nutritionist who recommended The Haven. She said, “They have the fullest information for dealing with all areas of breast cancer care,” so the day after my first radiotherapy session I phoned and spoke to the Haven Programme Manager. At my first appointment we discussed what was available. I wanted to have aromatherapy which had been helping with my ME symptoms for a while and also nutritional advice. I also needed help with my emotional upset and stress. The individual counselling sessions really helped to get to the roots of my emotional problems and have given me effective techniques for dealing with strong negative feelings and stress. Group sessions such as Emotional Freedom Technique and Mindfulness taught me how to quiet my mind when things are stressful. I feel more secure in my ability to choose the right nutrition to keep me healthy and the aromatherapy sessions were blissful and calming. All the advice I was given helped greatly and it was all given with calm reassurance and empathy. The Haven is aptly named. It has been my lifeline for almost a year now and I know will continue to be there for me.”
6.1 Conclusions to The Haven Research and Service Evaluation: 10-year Report

The Haven has embarked on an ambitious programme of research and evaluation for a small charity and this has shown that it is possible to achieve high standards. This can be judged by a number of successful publications in national and international peer-reviewed journals.

- The findings from research and service evaluations of programmes offered at The Haven are overwhelmingly positive, even when evaluated under the most rigorous conditions, e.g. the randomised controlled trial evaluating MBSR.

- Large numbers of Visitors from all Havens have given feedback to our programmes. Their feedback emphasises the value and support that they have received which is not available elsewhere:
  - Specifically, support programmes offered at The Haven have shown to be very beneficial for both psychological and physical problems.
  - Anxiety, depression, stress, mood disturbances, anger, fear, confusion, vigour.
  - Coping with loss and bereavement, relationship issues and emotional traumas.
  - Common physical concerns including hot flushes and night sweats, fatigue, weight problems, sleep disturbance, aches and pains, nausea, side effects of radiotherapy and lymphoedema.

- From participating in our programmes people found that they:
  - were calmer, centred, at peace, connected and more confident.
  - more aware of choices in their behaviour.
  - accepting their life more easily, less judgemental.
  - had better personal relationships.
  - made time and space to take care of themselves.

- Preliminary measurement of immune mechanisms has been conducted in the evaluation of The Haven Programme and Sara’s Group programme. Some promising results suggest that this is an area for further development.

- Preliminary findings from our service evaluation of the Emotional Freedom Techniques in London and Yorkshire shows positive effects and warrants more rigorous research.

- The Haven’s biennial performance of literature reviews of current evidence to underpin its clinical practice ensures safe and effective delivery of our services.

6.2 Why research at The Haven is important

- The Haven is the only breast cancer charity that actually performs research in the field of complementary medicine (rather than funding it), which is a unique selling point. This is important as the charity is currently trying to differentiate what it offers from other breast cancer charities.

- The publication of high quality research provides an important marketing tool for the charity. For example, research published in high impact factor peer-reviewed journals with a wide readership provides valuable PR opportunities and enables further collaborations with top researchers and clinicians. It also cements our presence as a high quality, credible organisation in the NHS and charitable sectors.

- The Haven is the only breast cancer support charity of its kind that keeps Visitor records. This unique, extensive resource is invaluable for contributing to ongoing research and service evaluation and recruitment to future research studies.

- Research into the effectiveness of the therapies offered by The Haven is essential for ensuring that the services provided meet the needs of its Visitors adequately and also meet the criticism that is often levelled at complementary medicine, that there is an inadequate evidence base. It also helps us demonstrate that we are fulfilling our charitable aims and objectives.

- The National Cancer Survivorship Initiative reviewed the effectiveness of programmes that might help in cancer survivorship. The Haven at Home service evaluation was funded as part of this process.
In order to have any future large-scale research collaborations at The Haven, there is a need to perform pre-pilot work so that we are in a strong position to receive any possible future NHS research funding. In any case, future research will need to be performed in collaboration with both a NHS consultant clinician as principal investigator and university-based researcher support for statistics etc.

Funding for a large-scale research project would be obtained from a grant-giving body e.g. NHS Research for Patient Benefits or research funding charities. This would largely cover the cost of research staff salary.

6.3 Current area of new Haven Research

We are evaluating how a cutting-edge self-management technique, Emotional Freedom Technique, could help the long term side effects of Tamoxifen and Aromatase Inhibitors and help with compliance to treatment.

Please contact our research team
Clinical and Research Director:
caroline.hoffman@thehaven.org.uk
or 020 7384 0007 or visit our website for more details of our research programme.

www.thehaven.org.uk
020 7384 0099