

BREATHWORKS
LIVING WELL PROGRAMMES
MINDFULNESS BASED APPROACHES
TO PAIN AND ILLNESS
executive summary 2010

breath
works



for living well

Executive Summary

Why should I read this?

Many medical professionals are frustrated by the limitations in helping those suffering from long term pain and other chronic conditions. Others are anxious to implement cost effective methods of helping patients whether they are reliant on drug based approaches, on waiting lists or simply wanting to take control of their own well-being. This document and the related links, describe some of the evidence supporting the effectiveness of mindfulness based approaches both for the patient and potentially for your practice or authority. It builds on existing evidence of effectiveness used in NICE guidelines of mindfulness based cognitive therapy for the treatment of depression (which frequently accompanies many pain and chronic conditions) and illustrates how your patients can benefit.

The evidence

The evidence base is expanding concerning the effectiveness of a mindfulness based approach to the management of pain and chronic illness. (For more details see *Associated Article 1: The Evidence Base for Mindfulness Based Interventions for Chronic Pain*, on research page of Breathworks website: www.breathworks-mindfulness.co.uk) Evidence deriving from randomised controlled trials, longitudinal studies and service evaluation provide positive indications of the benefits of this approach. The Breathworks Foundation research agenda, in collaboration with academic institutions, medical and other health professionals, critically evaluates the clinical significance of the Breathworks approach for patients, practitioners and service commissioners.

What next?

After seeing the evidence and understanding the implications for your practice of mindfulness skills and techniques, if you want to know more about how mindfulness approaches can work for you and your patients, simply call the Breathworks Foundation on +44 (0) 161 834 1110 or email info@breathworks.co.uk and our experienced team can help you develop your own programmes. Alternatively attend one of our special training courses for health care professionals, which are held regularly throughout the UK. (Full details at www.breathworks-mindfulness.co.uk)



mindful movement



contemplation



body awareness

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Mindfulness Based Approaches

From its origins over 2,500 ago to the forefront of modern medical and education practice, mindfulness is recognised as being key to quality of life.

In recent years, mindfulness approaches have been influenced by the work of Dr. Jon Kabat Zinn who founded the Center for Mindfulness at the University of Massachusetts Medical School. His work and the original Mindfulness Based Stress Reduction (MBSR) programme he developed have formed the foundation for research and development of other mindfulness based approaches across the world.

What is mindfulness?

Many of us are familiar with definitions of mindlessness; pictures of violent, inconsiderate or out of control behaviour often dominate the headlines of our daily news. But mindfulness is more than simply the opposite of such behaviour. It involves the development of skills and attributes, ways of thinking and living, that improve well-being and help us to live an effective life.

Mindfulness is a way of engaging with whatever is happening in your life, a way of taking charge, a way of being, that enables you to face the challenges and demands of everyday life, whether simply working or bringing up a family or coping with pain, stress and chronic illness.

Mindfulness, or mindful awareness, is a state of present moment attention where you can clearly perceive thoughts, physical sensations, emotions and events at the moment they occur, without reacting in an automatic or habitual way. This means you can make choices as to how you respond to things and have a rich and fulfilling life, even when experiencing difficult circumstances. (For more details see *Article 2: detailed descriptions of mindfulness as used in a therapeutic context*, on research page of Breathworks website: www.breathworks-mindfulness.co.uk)

How is mindfulness used in health, education and business?

Mindfulness is being used in many different settings. From National Institute of Clinical Excellence (NICE) approved interventions for the treatment of depression to leadership programmes for executives, many thousands of organisations and individuals are seeing the benefits of mindfulness based approaches.

There are many intervention acronyms used, including Mindfulness Based Stress Reduction (MBSR), Mindfulness Based Cognitive Therapy (MBCT) and Mindfulness Based Pain Management (MBPM). Most programmes take fundamental mindfulness practices and include additional components for specific conditions, circumstances or issues. At Breathworks™ our core services are referred to as 'Living Well' programmes as we know from experience that this is what mindfulness practice allows people to do regardless of their situation. This core is then developed for key areas such as our 'Living Well with Pain and Chronic Illness', 'Living Well with Stress' and 'Living Well in Schools' programmes.

Is it simply meditation?

No. While incorporating a range of meditative practices, the Breathworks programmes involve a wide range of activities, skills and techniques from mindfulness in daily life to body awareness, mindful movement and improving relationships with others, all based on the fundamental principle of learning how to make choices – to respond rather than react. It is this special combination that allows mindfulness practice to have a real impact on our daily lives, on our ability to live well.

(To read more about how mindfulness differs from other psychological therapies in the treatment of chronic pain see *Article 3: The distinction between mindfulness and other psychological therapies for the treatment of chronic pain*, on research page of Breathworks website: www.breathworks-mindfulness.co.uk)

Breathworks

Who are Breathworks™?

'Breathworks' is the everyday name of a family of organisations, all working to alleviate suffering. The original Breathworks company was established as a not for profit business in 2004 following the success of the 'Peace of Mind' project funded by the Millennium Commission in 2001. This project, developed and led by the founder of Breathworks, Vidyamala Burch, was the first to specifically work with patients suffering from chronic pain, using mindfulness techniques.

Our mission statement

- Breathworks exists to alleviate human suffering
- We help people who are living with pain or other long term conditions
- We help people living with stress
- We teach people to help themselves and others using mindfulness based techniques

How we started

Our pain management programme was developed primarily by Vidyamala Burch who has used the practice of mindfulness to manage her own chronic pain for over 20 years. In 2003, she was joined by Gary Hennessey and Sona Fricker to form Breathworks, a not for profit organisation which now has trainers throughout the UK and Europe as well as further afield in countries such as New Zealand and Brazil. Vidyamala Burch is the author of *Living Well with Pain and Illness* (published by Piatkus an imprint of Little, Brown Book Group). Foreign rights have already been sold to six countries.

What do we do?

- **Research and innovation:** we work with other experts to continue to deepen our understanding of how practising mindfulness can help people living with pain, stress or long term conditions.
- **Promotion:** we promote the use of mindfulness based techniques and share our research and experience with the world so that more people can benefit from what we have learned.
- **Training and education:** we train health professionals and others in mindfulness based techniques; we provide educational products that help people living with pain or stress to help themselves.
- **Support the Breathworks community:** we nurture and support an international community of people who want to use mindfulness based techniques to help both themselves and others to improve their quality of life.

The 'Living Well' Programmes

At the core of our services are eight week 'Living well' programmes which develop effective self management skills for daily living.

The following research evidence demonstrates the success of the programmes based on service evaluation across a range of programmes and client groups.

The Evidence

What we've gathered

The evidence that follows is based on both qualitative and quantitative data collected as part of specific studies and in service evaluation of our programmes. Collecting such data is part of our commitment to evidence based practice. We are indebted to Dr Amanda C de C Williams, University College London; Dr Natasha Doran, University of Manchester and Dr Elaine Weatherley Jones, Centre for Mindfulness Research and Practice, Bangor University, Gwynedd, North Wales; for their assistance in the collection and interpretation of data.

Qualitative

In a longitudinal study funded by the Medical Research Council through the School of Primary Care at the University of Manchester, participants in a 'Living Well with Pain and Illness' programme were interviewed over a number of years and results compared to others taking part in a hospital based programme. These in-depth interviews explored how the different management and treatment approaches affected the subjective experience of long term back pain sufferers.

Participants who attended the Breathworks programme, both male and female, aged between 28 - 66 years old, had all suffered lower back pain for between 4–28 years. The study clearly showed the significant and lasting benefits of the 'Living Well' programme over time, including the participant's ability to manage flare-ups of their condition.

- All participants reported an increased ability to 'accept' the pain rather than attempting to block or be fearful of it.
- Even though some reported an increase in pain due to their deteriorating condition, all reported increased quality of life.
- Participants all reported incorporating the skills and techniques taught on the programme in to their everyday lives.

Participant Comments

Many participants reported specific benefits including:

Reduction in pain – "Over the course my pain reduced because, something in my mind was able to reduce the pain threshold and also by that pain lessening, my back not being as inflamed, I got more mobility in my back".

Changing relationship with pain – "I realised I might not be able to change the pain or the external reality of living with the pain - but I could change how I related to the pain and the way that I thought about it... a lot of my stress was not the pain itself but the added emotional impact that I put on myself because of the pain".

More pain, but better quality of life – "I am actually in more pain than I have ever been. Over the last couple of years it has got more wide spread and has got worse; but even now I am putting into practice all the things I have been taught. I think I've got a good quality of life".

Non resistance – "To take pain, you know don't try to push it away... I found if you give pain space it's a lot better than trying to get rid of it, 'cos then you build emotions up and things tense and this brings more pain on".

Pain as a door to empathy – "I think the biggest thing for me being on the course was recognising that my pain didn't isolate me, in fact it was my pain that made me human... and I was able to accept that everybody experienced pain to some degree and some level ... and that it wasn't unique to me, and instead of feeling isolated and apart I could use it as a way of engaging with other people".

Quantitative

On Breathworks programmes we ask participants to complete a range of pre and post-programme questionnaires. We use widely validated and accepted models that relate to the condition of participants. These include:

Pain Questionnaire

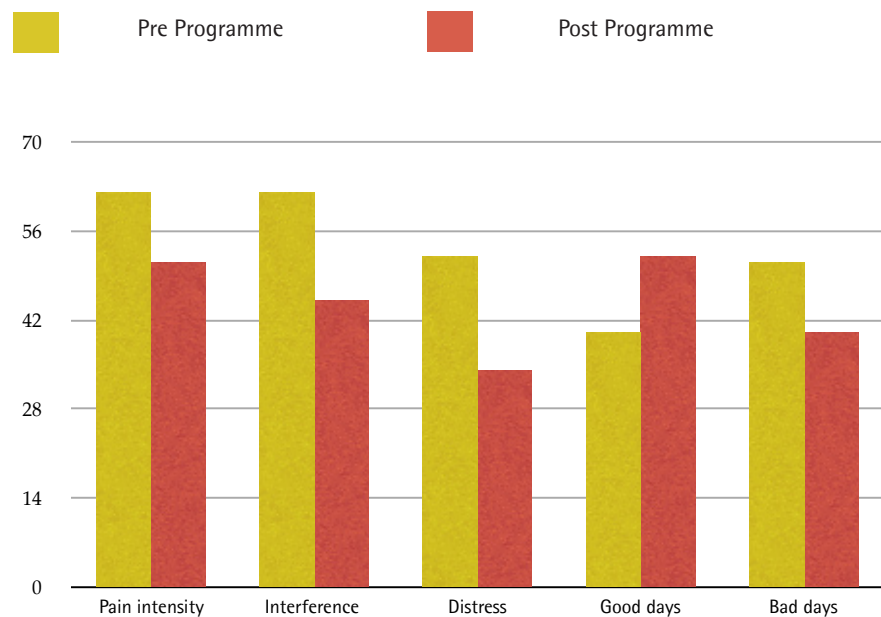
- Pain Catastrophising Scale (PCS)
- Freiburg Mindfulness Questionnaire
- Pain Self Efficacy Questionnaire (PSEQ)
- Chronic Pain Acceptance Questionnaire(CPAQ)
- SF 36 Quality of Life
- Depression, Anxiety and Positive Outlook Scale (DAPOS)
- Self compassion scale

Results

Results are shown for a sample of questionnaires. All the results shown are statistically significant, providing clear indication of the efficacy of Breathworks' Living Well programmes. For clarity, some information has been omitted but full details of participant numbers, statistical significance and effect sizes are available on Article 4: Table of full results of *Breathworks Quantitative results August 2009*, on research page of Breathworks website: www.breathworks-mindfulness.co.uk)

Pain Questionnaire

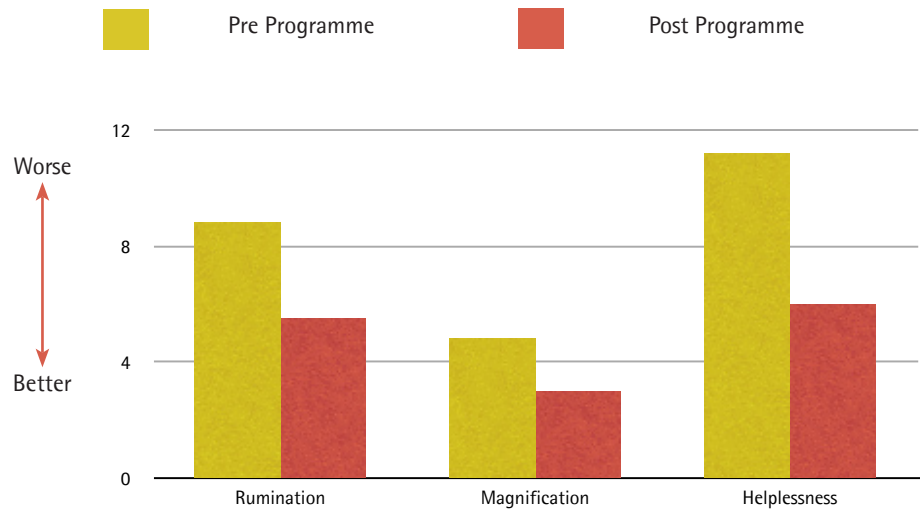
The Pain Questionnaire responses clearly demonstrate reductions in pain intensity, in the interference with daily life, and in distress caused by pain following the programme. In addition, participants experienced more good days and fewer days when they felt overcome by their pain (bad days).



Pain Catastrophising Scale

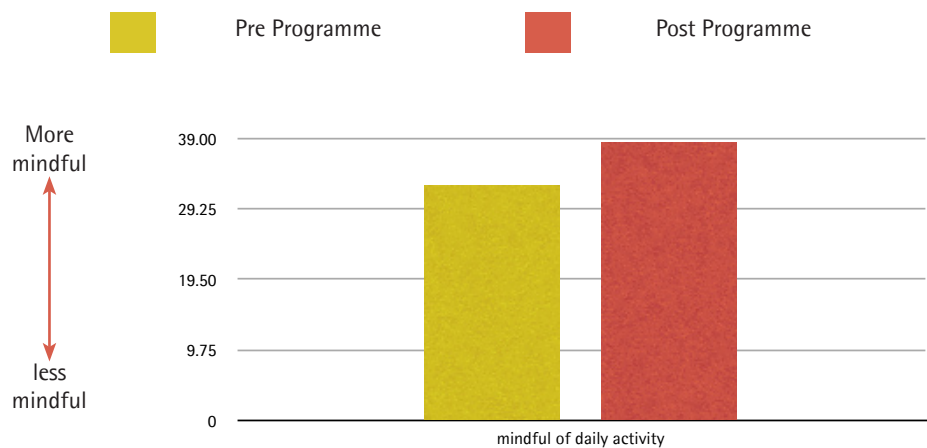
In measuring the way people reflect on their pain (rumination), how problems can increase in the patient's perception (magnification), thereby taking over their lives and limiting ability to cope (helplessness) we are exploring the day to day impact pain can have, examining not just the medical but the personal and social impact pain can have.

The results clearly show how programme participants benefit meaning they are less overwhelmed by their pain and more able to enjoy a better quality of life.



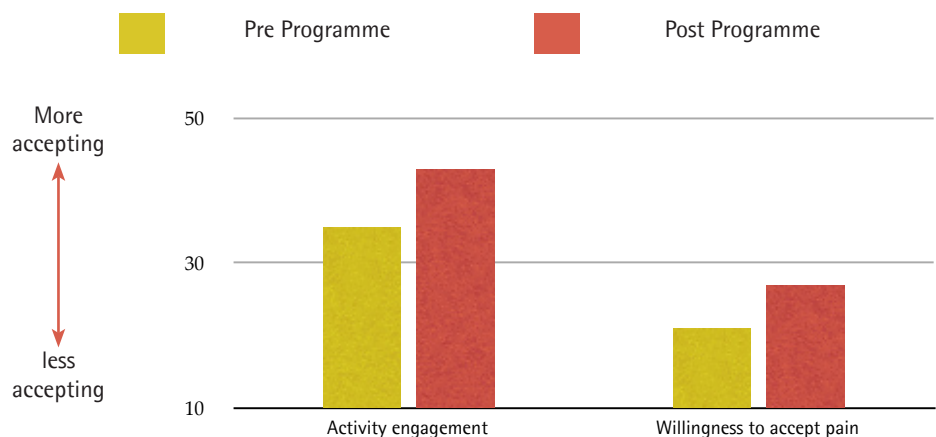
Freiburg Mindfulness Questionnaire

In measuring mindfulness of daily activity we are able to see how pain can overtake the lives of sufferers. Programme participants showed clear improvements in day to day mindfulness of activities. They were in pain but still had the ability to participate and appreciate what is going on around them.



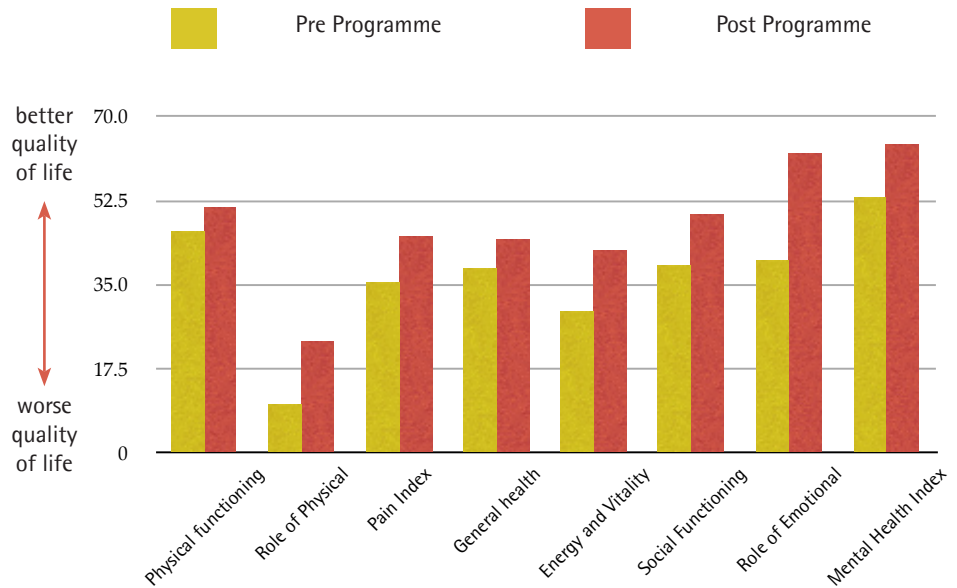
Chronic Pain Acceptance Questionnaire

Results show how programme participants have been able to improve their ability to work with their pain engaging in day to day activities more fully.



SF-36

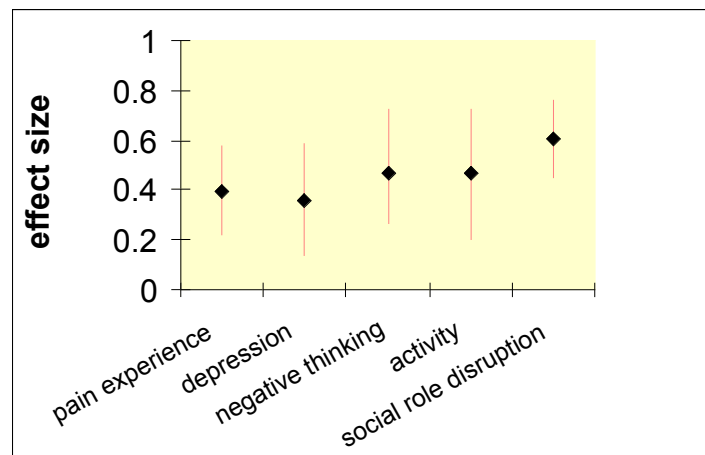
Measuring a range of characteristics as part of overall quality of life indicators, all areas show clear improvement, particularly people's ability to be more physically and emotionally engaged with life.



Effect Sizes

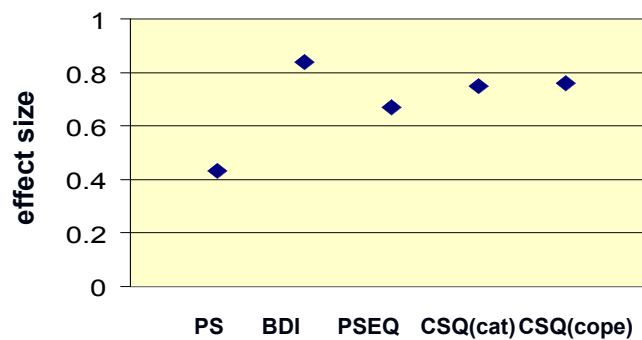
Use of Cognitive Behavioural Therapy (CBT) for patients on waiting list for in-patient pain management programmes

The chart shows that the use of CBT has clear benefits for patients on a waiting list, helping them cope with a range of pain issues from depression through to the disruption in their everyday lives. While the effect sizes in the study were good, Dr. Amanda C de C Williams, one of the authors of the study compared and contrasted them to data from the Breathworks Living Well Programme, producing a similar chart of effect sizes when examining similar domains of pain experience (lower chart right).



Morley, Eccleston and Williams, 1999

The Breathworks data shows higher effect sizes. Even allowing for the fact that this is not an exact comparison in terms of patient groups and methods of research, we can see that the Living Well programme is not only an effective intervention for patients, but compares very respectably to traditionally used methods.

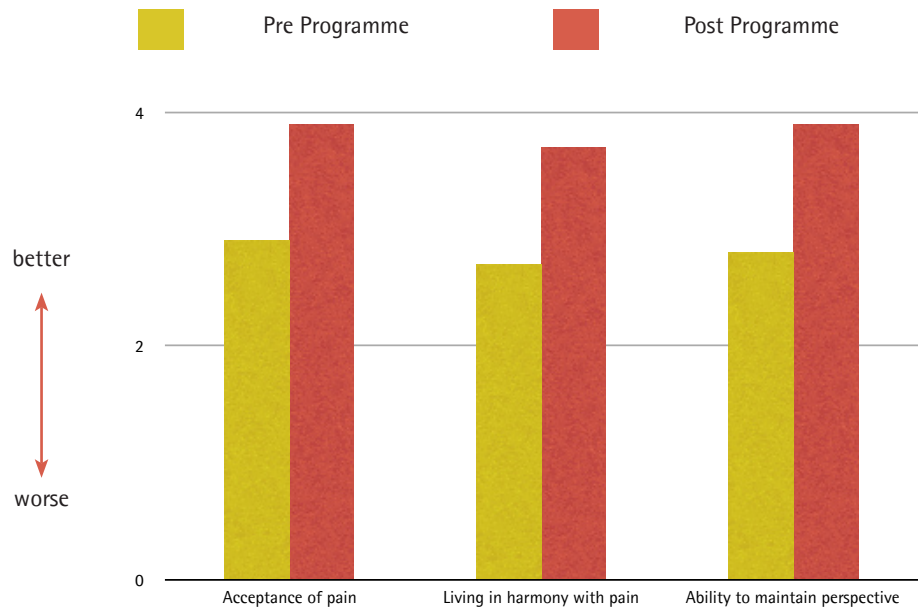


Breathworks Evaluation Questionnaire

While the widely used evaluation methods highlighted above show the effectiveness of the 'Living Well' Programmes, the processes involved, skills taught and style of delivery and participation produce valuable effects not measured with these traditional tools. We have therefore developed our own assessment and evaluation questionnaire to measure areas relating to the quality and depth of a participant's engagement in everyday life, during and after the programme. Awaiting validation the questionnaire was developed in conjunction with Dr Amanda C de C Williams of University College, London, to make it as accurate and informative as possible for our own evaluation purposes. These results are shown below:

Living With a Painful Body

The results illustrate the increased ability of programme participants not only to have greater acceptance of their pain but to have greater ability to maintain perspective when in pain, living in harmony with it rather than fighting or blocking it, no longer living in fear of it.



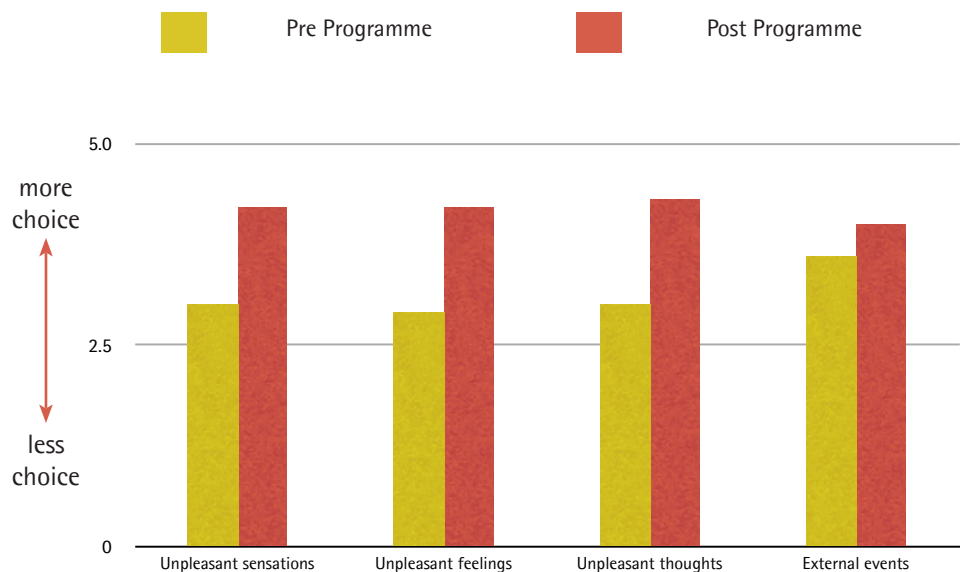
Choice

The following results show responses in relation to the question:

How much choice do you feel you have in response to....?

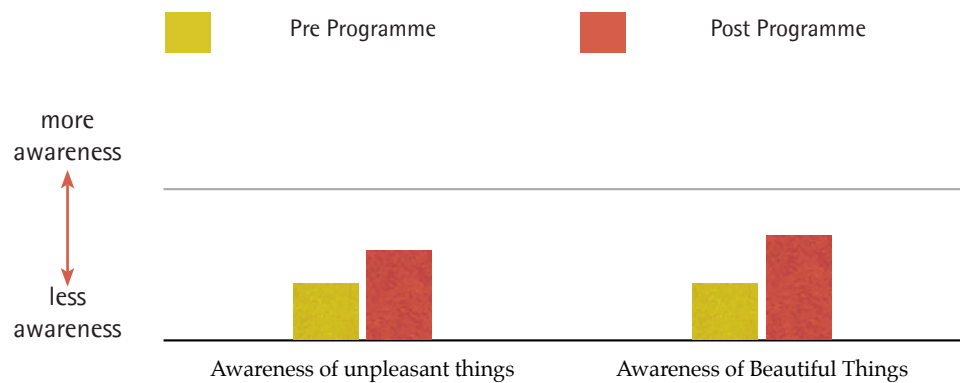
(Similar results were obtained in relation to pleasant sensations, thoughts etc. These have been omitted to aid clarity on the chart.)

As can be seen participants felt they had significantly more choice in their ability to respond, including the ability to respond to unpleasant external events outside their control. Such increases in choice reflect the long term improvements in quality of life seen in the earlier qualitative study.



Awareness of the World

In asking participants how much more aware they are of the world around them, obviously increased mindfulness or awareness means they notice the unpleasant aspects of life more, even though they are now less affected by them. More importantly there is also a significant and greater increase in awareness of the beautiful in the world around them.



The real life experience behind the data

"Incorporating what I have learnt from the 'Living Well with Pain' course has literally changed my life. I've learned that listening to my body and taking regular rest periods is not the same as 'giving in' as I'd feared. In fact I can actually do a lot more and enjoy what I am doing. I've also learned to accept help rather than stubbornly battling on which has made life a lot easier, both for me and others – I am a much nicer person to be around now I am practising mindfulness!"

Sharon O'Brien 46, Rheumatoid Arthritis & Multiple Sclerosis (MS)

"Following a diagnosis of Hodgkin's lymphoma in 2003, I underwent four years of chemotherapy, radiotherapy, a stem cell transplant and deteriorating health. I felt as though my life was spiralling out of control. Last year I was informed of more complications and told I needed further treatment followed by a bone marrow transplant later this year. Having encountered mindfulness and the Breathworks approach as taught by Vidyamala and her colleagues, I am amazed at how I am coping with this new round of treatment. Now that I am more able to be present with my experience as it is, I feel more peaceful, more confident, and can enjoy being alive right now. My attitude is profoundly different. In fact, I would say I am no longer waiting for light at the end of the tunnel. Thanks to Breathworks the tunnel has fallen away."

Anu Gautam, 32, cancer and ME/chronic fatigue syndrome

"Since learning of my kidney disease in my twenties, I tried to forget about it and 'get on with my life'. However, when infection after infection kept coming along and hitting me in the face (or abdomen!) I realised it couldn't be ignored and wanted to find a pro-active way to 'do' something about it. I feel very grateful to have come across Breathworks and attended a course. This has helped me learn how to manage my stress, energy and pain levels in ways that allow me more balance in my life. I experience much wider gaps between hospital admissions, less reliance on orthodox drugs to stay well, decreased stress levels and don't have the high blood pressure often associated with, and a risk factor of, my condition. Now, in my thirties, I actually see doing a body scan and practising pacing as acts of kindness towards myself, that will, I believe, help me live longer, or at least delay the onset of end-stage renal failure, through kindly self-management."

Amitasuri, chronic renal failure (polycystic kidney disease), intracranial aneurysms

"I discovered the 'Living Well with Pain' course two years ago. Although referred by my GP I was wary at the beginning having no understanding of mindfulness or meditation. The course was great; it has given me tools to help me manage pain and associated anxiety much more effectively. I get so much more out of life now and the continuing support of the Breathworks community, through the web, meditation days and retreats, is a lifeline. Vidyamala is speaking from personal experience as well as using her understanding of meditation and mindfulness to live a full and enjoyable life; she is an inspiration."

Cate, 58, hyper mobility and fibromyalgia

"I had been meditating for some years before learning about Breathworks. The 'Living Well with Pain' programme opened my eyes to how I was managing and being 'managed by' my illness. The programme and continued practice and use of the tools, techniques, and insights gained has changed my life. I am more active and feel more in control, responding better to day-to-day difficulties, which also benefits my family and work. A key part of the programme for me is also the attitude and example set by Vidyamala Burch herself. That someone can take her own pain, experience and condition and use it to help others in a practical and sustainable way is an inspiration to anyone with a chronic condition or involved in helping others."

S J, 54, diabetes and peripheral neuropathy;

"Although I didn't have physical illness, I booked on the Breathworks course because I hoped it would help me deal with the myriad of physical effects I experienced as a result of stress and anger difficulties. It has enabled me to take hold of the reins of my life again and make a new start – to live again. I was angry, self-absorbed and in constant conflict with the world around me. I believed that I was usually right and others were usually wrong. On this course I have learnt to challenge these perceptions of myself and disarm the thought processes that were behind my inability to cope with situations. I have learned to like and look after myself as well as developing compassion for others. I now feel a profound and reassuring peace is starting to blossom in my life."

Andy Scott, anger and stress management

"I have been living with back pain since a lifting accident (aged 16), followed by a diagnosis of spondylolisthesis and a spinal fusion operation (aged 18). I have tried many therapeutic approaches, both medical and complementary, to help manage my symptoms over the years. Having been told by one consultant that my pain was 'normal given my abnormal spine' and that I would 'never work', I have since completed three academic degrees and am looking to build a career in teaching and research. The Breathworks course has been very instrumental in my recovery and in my ability to cope with the pressures and deadlines of academia, as it has provided me with a set of tools such as pacing and meditation which I have integrated fully into my life. What made the course unique was its philosophical stance towards pain and suffering being less about 'resisting', 'fighting', or 'removing' the pain and instead to foster an awareness and acceptance of the pain in any given moment. Having attended the Breathworks courses both as a researcher and a fellow participant, I have seen that through adopting a 'moment to moment' approach to chronic illness and pain, the grief or panic which can all too often attend the fear that one may be in pain for life, can be reduced if not removed entirely. Rather than feeling all consumed by pain, the methods and approaches which this course provides, can be positively utilised as a means of coping in one's everyday life."

Dr N. J. Doran, 34, spondylolisthesis and post-operative pain

"I did the Breathworks pain management course which helped me cope with the problems of having an arthritic spine. The skills and insights I learnt really came to the fore when I had a stroke. They helped me deal with the shock and trauma of having a stroke and to adjust to the life changes a stroke brings."

Frank Rowlands, 65, arthritis and stroke victim

Background Information and Glossary

A. The Breathworks Foundation

The Foundation undertakes research and development activities, working with our own teams and other experts to continue to deepen our understanding of how practising mindfulness can help people living with pain, stress or long-term conditions. We share our research and experience across the world so that more people can benefit. In the last few years Breathworks has run workshops and given talks at events including:

- Annual Scientific Conference of the British Pain Society (2006)
- International Conference on Mindfulness and Acceptance, University of Wales, Bangor (2006)
- Annual Congress of the Chartered Society of Physiotherapists (2006)
- 5th Annual International Scientific Conference: Integrating Mindfulness-Based Interventions into Medicine, Health Care and Society (Centre for Mindfulness in Medicine, Health Care and Society, University of Massachusetts 2006)
- Karolinska Institutet, Sweden (2007)
- 2nd Annual Conference of the North East Branch of the British Psychological Society (2009)
- Meditation in Health Care Conference, Bristol (2009)

The Foundation nurtures and supports the Breathworks Community, an international gathering of people who want to use mindfulness-based techniques to help both themselves and others to improve their quality of life

B. Breathworks CIC

As a not-for-profit organisation that helps people living with pain, long term illness or stress to manage their condition and improve their quality of life, Breathworks CIC is responsible for the training of Living Well programme trainers. It also provides a range of mindfulness programmes for health care and education practitioners, from those simply establishing their personal practice to those seeking to use mindfulness based approaches within their existing work. Breathworks CIC has rapidly gained international recognition as experts in the field of mindfulness based pain management and currently provides training programmes throughout Europe, Scandinavia and Australasia.

C. Living Well Programmes

The generic product of Breathworks. Delivered by regional Breathworks 'not-for-profit' companies and highly trained and accredited independent trainers around the world.

D. Community Interest Companies

Community Interest Companies (CICs) are limited companies, with special additional features, created for those who want to conduct a business or other activity for community benefit, and not purely for private advantage. This is achieved by a 'community interest test' and 'asset lock', which ensure that the CIC is established for community purposes and the assets and profits are dedicated to these purposes. Registration has to be approved by the Regulator, who also has a continuing monitoring and enforcement role.

E. Vidyamala Burch

Breathworks founder, Vidyamala sustained a spinal injury at just 16 and has spent over 20 years using mindfulness based techniques to ease her own suffering and that of others around the world.

F. Jon Kabat Zinn

The founder and former Executive Director of the Center for Mindfulness in Medicine, Health Care, and Society at the University of Massachusetts Medical School. He is also the founder (1979) and former director of its renowned Stress Reduction Clinic and Professor of Medicine emeritus at the University of Massachusetts Medical School. Recognised for his role in promoting the use of mindfulness in medicine.

G. Qualitative research

Within the social sciences, qualitative research places an emphasis on process and context. It provides a way of assessing the validity of social interactions or theory and is often used to explore smaller, focused samples rather than large, randomised trials

H. Quantitative research

Originally the 'gold' standard in health research but now also being supported by qualitative methods. Focuses primarily on the scientific investigation and measurement of phenomena and their relationships.

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Useful Contacts

The Breathworks Foundation

The Breathworks Foundation is the research and community arm of the 'Breathworks' movement, hosting and facilitating research activities throughout the UK and communicating the results of research to professionals.

Research Contacts: Vidyamala Burch – vidyamala@breathworks.co.uk
Elaine Weatherley Jones – elaine@breathworks.co.uk
Community Contact: Steve Johnson – steve@breathworks.co.uk

Breathworks CIC and National enquiries

For all training courses and general enquiries regarding Breathworks operations in the UK and elsewhere.

Finance & Operations Contact: Sona Fricker – sona@breathworks.co.uk
Training Contact: Gary Hennessey – gary@breathworks.co.uk

Breathworks Manchester CIC

For Breathworks services in Greater Manchester and Merseyside including the boroughs, towns and cities of Ashton-Under-Lyne, Bolton, Bury, Liverpool, Manchester, Oldham, Salford, Stockport, Trafford, Warrington and Wigan.

Information Contact: Colin Duff – colin@breathworks.co.uk

Breathworks in Cumbria

For Breathworks programmes in Cumbria, and for specialist programme development including schools programmes and mindfulness in nature activities.

Contact: Steve Johnson – steve@breathworks.co.uk

Breathworks in Lancashire, West and North Yorkshire

For Living well with Pain and Chronic Illness and Living Well with Stress Courses in Leeds and Blackburn.

Contact: Lorna Megan – lorna@breathworks.co.uk

Breathworks in London

For Breathworks programmes in London

Contact: John Linney – info@bodywisehealth.org

Breathworks in Scotland

For Living Well with Pain and Chronic Illness and Living Well with Stress courses in Glasgow, Edinburgh and Breathworks programmes throughout Scotland.

Contact: Jyotipakshini – erica@sangha.com
Taradakini – taradakini@breathworks.co.uk

Breathworks in Wales

For Breathworks services in Cardiff and across Wales.

Contact: Atapani – info@breathworkscardiff.co.uk

Breathworks in Birmingham and Midlands

For Breathworks services in Birmingham and Midlands

Contact: Ann Bruton or Richard Hawkins – birminghambreathworks@googlemail.com