# MINDFUL HEROES

stories of journeys that changed lives



Edited by

Terry Barrett, Vin Harris and Graeme Nixon

Everyone loves a good story. This book tells the stories of a constellation of Mindful Heroes: ordinary people just like us, who followed the path of mindfulness and went on an inner journey that would change their world.

They engaged with an in-depth study and courageous exploration of mindfulness practice. Having experienced for themselves the benefits of mindful awareness, compassion and insight, they then wanted to give others the opportunity to discover their own potential. These 26 Mindful Heroes from 10 countries creatively applied mindfulness to a variety of settings across Education, Health, Business, Sport, Creative Arts and Community work. Now they share the moving stories of their personal and professional journeys of transformation with you.

"As the old saying goes, 'It is not what happens on the cushion, it is what we take out into the world.' Mindful Heroes exemplifies this notion, exploring the lives of those who have not only experienced the personal benefits of meditation, but those who have gone on to make it their passion and purpose in life, planting the seeds of awareness and compassion for the benefit of us all."

**Andy Puddicombe** author of *The Headspace Guide to Mindfulness & Meditation: 10 minutes can make the difference.* Co-Founder http://www.headspace.com

"This is a wonderful book. It reminds us that we are all heroes, due to the power of our own minds. The living examples presented in these pages help to make the mindful path accessible and relatable. I am so happy that works like this are emerging, bringing mindfulness into the heart of our modern culture."

**Gelong Thubten** Buddhist monk, mindfulness teacher and author of *A Monk's Guide to Happiness*. http://www.gelongthubten.com

"This book is an inspiration as we follow the journeys of heroic people who integrated mindfulness into their way of life in a creative and transformative way."

**Sr. Stanislaus Kennedy** is founder of the Sanctuary Meditation Centre and Focus Ireland and the author of several bestselling books on spirituality including *Awakening Inner Peace, Mindful Meditations for Everyday and Gardening the Soul.* http://www.sanctuary.ie/

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# MINDFUL HEROES: STORIES OF JOURNEYS THAT CHANGED LIVES

Edited by Terry Barrett, Vin Harris and Graeme Nixon

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Terry Barrett, Vin Harris and Graeme Nixon (Editors).

# **DEDICATION**

We dedicate this book that it may inspire individuals and groups to develop their mindfulness and compassion. The royalties of this book are going to the Everyone Project which supports groups who may not otherwise have the opportunity to participate in mindfulness courses.

www.everyoneproject.org

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# CHAPTER 24

# TURNING EMPATHIC DISTRESS INTO COMPASSION - A HERO'S JOURNEY FOR FAMILY CARERS



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# INTRODUCTION

We have learnt from other rich contributions to this book that the mind can be trained to respond more positively to stressful life events by using mindfulness techniques. After conducting a small research study into the impact of mindfulness training on the well-being of unpaid family carers, I am now convinced that showing carers how to adopt an attitude of kindness and compassion towards themselves and others plays a key role in alleviating the stress of individuals who find themselves in long-term caring roles.

This chapter not only presents the findings of my research study. It also covers my own journey over many years as I travelled from the painful depths of being an unsupported and unmindful full-time mother and carer, through learning mindfulness and self-compassion, to finding myself flourishing even when facing pretty stressful life events.

The greatest - and totally unexpected - gift I received on this exceptionally rewarding journey came about when I began to share the juicy, sweet fruits of my training in mindfulness and compassion with a small group of highly stressed family carers. The very act of opening my heart to these unsung caring heroines and then extending heartfelt compassion to them contributed so much to my own long-term healing and overall sense of wellbeing and fulfilment in life.

# MY HERO'S JOURNEY

Vin Harris describes the 'departure', 'descent', 'initiation' and 'return' phases of the hero's journey in Chapter two of this book. The 'departure' indicates the moment in life when a crisis launches the hero into a journey of new realisation. The 'descent' is the next stage of the journey where the hero uncovers teachers and new skills to help him with the challenges that he will face on his journey of self-discovery and change. The 'initiation' represents the ultimate challenges to be faced and overcome on the journey, culminating in the 'return' where the hero arrives safely back having conquered his dragons and demons. He is now ready to share his story and knowledge to help others. This is my hero's journey.

Having babies didn't come easily for me. 35 years ago, it took four miscarriages before my plight was taken seriously by my doctor who put me forward for a trial treatment for recurrent miscarriage at St Marys Hospital in London. This controlled clinical trial involved identifying the presence of an antibody created during early pregnancy which immunises the mother against rejecting the foreign body of an embryo in her body. Despite my four pregnancies I had never created this antibody. The active treatment on this trial took the form of an injection of the prospective father's white blood cells. If you were in the control group however, you received just your own cells.

When I received the treatment, my arm swelled up as though someone had planted large eggs beneath my skin and so I was convinced I had received my partner's blood cells. Following the treatment, my next pregnancy was successful, and I carried the baby full term.

Following the birth, I was shocked to learn that I was in the control group. I was convinced that my strong belief that I had received the active treatment had enabled my body to create the necessary antibody. I also believed that the compassion, kindness and support I received from those running this trial in an exceptionally caring manner contributed to the positive outlook I adopted. Since then, I have firmly believed in the power of the mind, positive thought and the power of compassionate care. Looking back on my own path through life, I can now see that it was at this point that my 'departure' on my own hero's journey began. My first baby was extremely ill from birth, and so I cared for her intensely and with great stress until her death at 4 months. Years later, I became a full-time unpaid carer once again as I looked after my youngest daughter day in and day out after she developed severe anorexia as a teenager. At both these highly stressful times in my life, I didn't realise that my intense caring role went way beyond the normal demands and experience of being a mother. At neither time did I ever think of myself as a family carer in desperate need of some effective support.

Some years later a yearning for some kind of relief from my own troubled thoughts and feelings led me to train in Taoist meditation, Qigong, Tai Chi and Yoga. This is where the 'descent' into my hero's journey began. It took years for me to even understand 'letting go' and 'going with the flow of life'. But after several years of steady progress, I deepened my practice by training to teach mindfulness and compassion while completing the MSc Studies in Mindfulness with the University of Aberdeen. It was only when I began studies in mindfulness that I truly began the 'initiation' as all the pieces of the jigsaw were before me ready to be pieced together into a whole picture. Learning and practicing compassion practices in the first year of the MSc completely changed how I responded to life. I finally realised that it was time to become my own best friend so that I could keep soothing my troubled self with self-compassion and unconditional respect. This is such an important key to wellbeing as highlighted by Gilbert (2009) who states that most human beings spend too long in a destructive threat and drive system caused by the very nature of our reptilian brains.

2016 saw the spark of my 'return' ignite when I was inspired to bring mindfulness, compassion and mindful movement training to family carers. With the support of Carers in Hertfordshire, the setting up of this final research project for the MSc flowed effortlessly as I experienced the amazing phenomenon of 'wu wei'. In the Tao Te Ching, Lao Tzu (Zi, 1939) explains that 'wu wei' is a mental state in which our actions are quite effortlessly in alignment with the flow of life.

Everything had come full circle. My initial Taoist practices with meditation, Qigong and Tai Chi were now fully aligned with my mindfulness and self-compassion training. At last, I was able to pass on the fruits of my own training and practice to others with the core intention of empowering them as I had been empowered.

#### Pause and Reflect

Are there any profound moments in your life which come into your mind which you feel changed you? Are you able to see the path your life took since those times? Sit quietly and reflect on the journey. Notice how it feels.

# **CARING COSTS**

Mindfulness and compassion develop at the same pace. The more mindful you become, the easier you'll find it to be compassionate. And the more you open your heart to others, the more mindful you become in all your activities (Mingyur Rinpoche 2009, Location 3465)

At some point in most individuals' lives, there is a good chance that a close relative, such as spouse, child or parent, will suffer from some kind of long-term illness or disability. This not only turns life completely upside down for the family, but changes the relationship dynamic, as one member of the family takes on the role of unpaid carer – a role that over time often becomes all consuming.

At first, family carers don't usually define themselves as a 'carer'. As a mother, a woman often sees the care of their sick or disabled child as just an integral part of their parenting role. Similarly, when a spouse needs extra care due to a disabling disease or injury, a caring partner may see all their extra caring duties as just part of the normal role of a spouse who has vowed to care for the other 'in sickness and in health'.

It was only when I conducted my own research into the plight of family carers for the MSc Studies in Mindfulness that I realised that much earlier in my own life I had become a 'family carer' for two of my own daughters. At the time, I certainly did not identify myself as a caring heroine, but I do remember hoping that I could use these difficult experiences to help others someday. Miraculously, my training in mindfulness has finally provided me with that golden opportunity as part of my own hero's' journey.

As the caring demands on an inadvertent family carer increase over time, they tend to become subject to great stresses and strains that then have a seriously negative impact on their own emotional, mental and physical wellbeing. From my own experiences as a family carer and from supporting several groups of family carers with Mindfulness Courses, I now know that the impact of caring for a sick relative can be a complex cocktail of devastating emotions which can then have a devastating impact on carers' long-term health and wellbeing.

According to Carers UK (2015) 1 in 8 adults in the UK (around 6.5 million people) are carers. Furthermore:

- There are approximately 700,000 young carers aged 16-24. On average, young carers miss 48 days of school a year as a result of their caring role. It is also reported that they experience bullying at school and diminished health (Tubb, 2018).
- By 2037, it's anticipated that the number of carers will increase to 9 million.
- Carers save the economy £132 billion per year.
- People providing high levels of care are twice as likely to be permanently sick or disabled.
- 625,000 people suffer mental and physical ill health as a direct consequence of the stress and physical demands of caring.

In a study conducted by Carers UK (2012 p.6), carers reflected on their increased levels of stress, hopelessness and fatigue. One carer stated that they "did not realise how much stress caring puts on the carer and the effect it can have on your own health". 84% of respondents in this study reported increased physical and mental health problems due to their caring role. 91% reported increases in anxiety and stress and 53% reported that they were suffering from depression.

The detrimental effects of being immersed in a professional caring role have long been researched in some depth. The concept of compassion fatigue for example emerged in the 1980s when states of heightened stress, exhaustion and physical conditions were observed amongst nursing staff in a hospital emergency department (Joinson,1992). Compassion fatigue has been defined as a "deep physical emotional and spiritual exhaustion accompanied by acute emotional pain". (Pfifferling and Gilley, 2000, p.39). This can occur as a result of caring for others who are suffering, and/or through the absence of self-care and the lack of emotional support for the carer (Figley, 1995).

Lynch and Lobo (2012, p.2125) conducted one of the few existing studies into the instance of compassion fatigue amongst family carers and concluded that,

Compassion fatigue occurs when a caregiving relationship founded on empathy potentially results in a deep psychological response to stress that progresses to physical, psychological, spiritual and social exhaustion in the family caregiver

Further distressing consequences of caring for a sick relative include isolation, becoming lost and engulfed in the caring role and feelings of grief or guilt (Wada and Park, 2009). Grief can manifest from losing a loved one to the illness or from the carer's life not unfolding as they hoped or expected. Family carers can also feel guilty every time they do something for themselves, which can prevent them finding time for self-care (Gilbert, 2009).

When family carers are continually faced with the suffering and sometimes negative moods of their sick or disabled relative, the feelings of empathy the carers experience may lead to burnout, even amongst the most devoted caregivers. Symptoms of burnout include having no energy, having disturbed sleep, depression, irritability and a decrease in quality of life (Marriott, 2003). Compassion fatigue appears to be common amongst long-term family carers. But why should a positive emotion such as compassion have such a negative effect on carers in the long run? Klimecki and Singer (2012 p.369) have proposed that,

rather than compassion fatigue it is empathic distress that underlies the negative consequences faced by caregivers who are exposed to others' suffering

Therefore, it has been suggested that the condition of compassion fatigue should be renamed 'empathic distress fatigue' (Ricard, 2009).

Neuroscientist Tania Singer and team set up an extensive study to identify how individuals' responses to empathising with others' suffering can play a significant part in damaging their own sense of personal wellbeing. For example, 'suffering with' another can cause caring individuals to feel the other person's pain as though it were their own pain. This in turn can then lead to caring individuals suffering more stress and poorer health. Singer argued that if carers simply accept that it is the other person that is in pain not them, and if carers then cultivate feelings of compassion for the person suffering, carers can end up feeling more positive and in better overall health than if they continue to go on suffering with the person in pain or distress. See Figure 1 below.

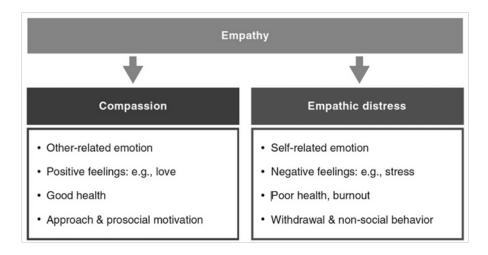


Figure 1: - Compassion (Singer and Klimecki, 2014, p.875)

This concept is supported by Perry, Dalton et al., (2010, p.3) who encourage a self-care strategy for family carers by emotionally "distancing themselves from their relatives' suffering". This inspired my study in which I encouraged participants to shift from 'suffering with' their sick or disabled relative, to aiming to attain a state of compassion in which they had sympathy for, and a desire to help, their loved one, without moving into empathic distress. The results of my study indicated that this shift had occurred.

# THE ALCHEMY OF MINDFULNESS, COMPASSION AND QIGONG

The benefits of mindfulness-based interventions, compassion and Qigong are well reported and include symptomatic relief to stress and depression as illustrated in Figure 2 below.

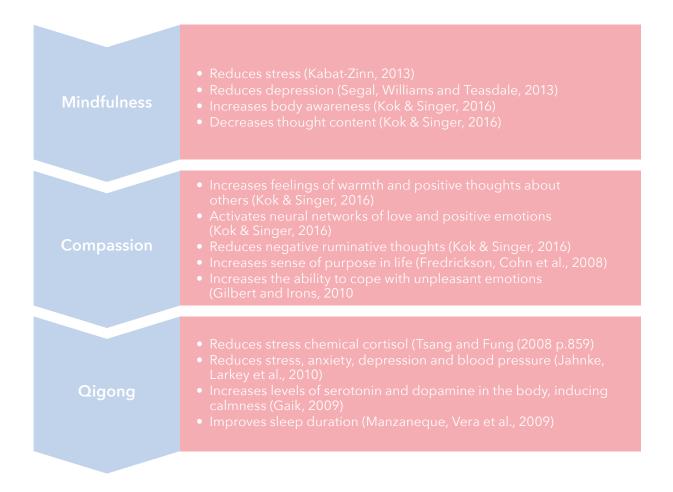


Figure 2: Evidence of benefits

Hoppes and Bryce et al., (2012, p148) claim that "Training in mindfulness has shown to be effective for individuals under stress and has intriguing potential for caregivers". There are many other studies which have found a positive impact of mindfulness on specific groups of family carers, for example, those who are caring for relatives suffering from specific conditions such as dementia (Waelde, Thompson et al., 2004) and parent carers of sick children (Bögels, Lehtonen et al., 2010).

The Dalai Lama was said to have asked neuroscientists to rise to the challenge of identifying the positive qualities of compassion (Jinpa, 2015, location 261). Singer rose to that challenge and investigated the impact of 'the loving kindness meditation' in comparison with the three mindfulness practices of breath awareness, observing thought and the body scan, which are typically included in an 8-week mindfulness course. In a study involving the use of psychometric tests and MRI scanners,

researchers were able to analyse behaviours and activity in the brain as a direct response to specific types of mindfulness meditation practices. The results of this study are summarised and illustrated in Figure 3 below. Whilst all four practices led to increased awareness of body and decreased the tendency to become distracted by thoughts, the compassion practice of loving kindness was the only practice to increase positive thoughts in a statistically significant way.



Figure 3: Phenomenological Fingerprints of Four Meditations (Kok, Singer, 2016, p.9).

The Loving kindness (metta) practice, derived from Buddhism some 2500 years ago, is a practice which focuses on cultivating a heartfelt wish that others may be free from suffering. Recent research has found that the loving kindness practice "activates neural networks of love and positive emotions, even in the light of distress stimuli" (Klimecki and Singer, 2012, p.370). Hutcherson, Seppala et al., (2008) found that just 7 minutes of loving kindness meditation induced positive feelings for self and others. These key findings influenced the design of my course for carers. I realised that this practice and short meditations could help transform the carers' stressful responses to their caring role and in particular the suffering of their relative to a much healthier positive response.

Whilst most research into the stress suffered by family carers has focussed on the impact this stress may have on their mental and emotional wellbeing, stress can also result in negative physical symptoms. For example, Behnke (1997) claims that suffering in the body can occur as a result of tension and emotional stress. Family carers can be said to be living in a fight or flight zone, where repeated demands from the relative they are caring for and the emotional trauma experienced from the loss of self in the caring role, may cause them pain and tension in the body. Practices which involve becoming bodily aware can help shift the experience of one's body into one of softness and ease and thus be of real benefit to stressed, tense carers.

Qigong is a system of healing medicine founded in China. The psychological and physiological health benefits of Qigong have been recognised for over five thousand years (Gaik, 2009). Qigong is known to improve mood and quality of life, whilst decreasing stress, anxiety and depression, and can thus

be seen to have similar benefits to practices such as mindfulness meditation. Over a longer period of time a regular Qigong practice can strengthen the organs, nervous system and cardiovascular system as well as balancing emotions.

#### Pause and Practice

Take 10 minutes or so out of your daily life to practice this simple Qigong sequence - available at http://www.mindbodyone.co.uk/butterflysweepingqigong

### RESEARCH

In my research study I came up with the following key questions designed to explore the plight of family carers and to see what types of mindfulness training would benefit them.

- 1. What symptoms of stress and emotional distress in response to their caring role are present in family carers that negatively affect their wellbeing and flourishing?
- 2. What would be the impact of a specifically designed 10-week Mindfulness, Compassion and Qigong Course (MCQC) on the overall wellbeing and flourishing of family carers?

With any desired transformational outcome there is a process that needs to be followed. The problem, solution, process and goal are highlighted in Figure 4 below.

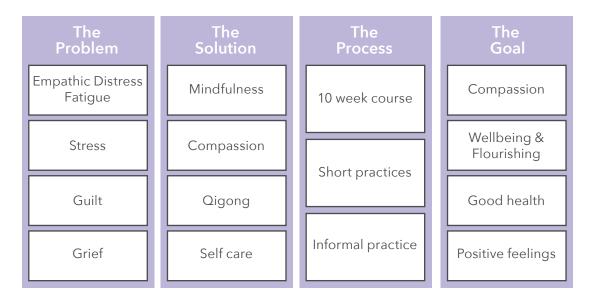


Figure 4: The process for transforming empathic distress to compassion and wellbeing

# THE MINDFULNESS COMPASSION AND QIGONG COURSE

Carers in Hertfordshire kindly volunteered to support my study by recruiting twelve family carers, all women, to undertake my course. Participants had a range of caring roles including caring for sick husbands, parents and children. The course was held in a beautiful location at an old priory which provided a sense of sanctuary for the carers for their two-hour session for ten weeks.

The Mindfulness Compassion and Qigong course (MCQC) was developed using the 8-week Mindfulness Based Living Course (MBLC) as its base (Mindfulness Association, 2011). The course was extended to 10 weeks to allow for additional practices to be included from the Compassion Based Living Course (CBLC) (Mindfulness Association, 2017), Qigong movement and space for group discussion and sharing.

From my experience, family carers do not feel they have time to include a formal mindfulness practice into their lives, so in my course I emphasised informal and 'daily life' practices that would be easily achievable day by day. To encourage a regular formal practice, I recorded short 10-minute audio files of each guided practice in the MBLC course and the compassion practices for the participants to practice with at home. I taught the carers about taking comfort in small things, similar to the practice of Hygge in Denmark. Hygge (meaning wellbeing) takes its origins from Norway in the 19th Century, and means to find comfort, rest and safety whilst regaining energy and courage (Søderberg, M.T., 2016).

#### Pause and Reflect

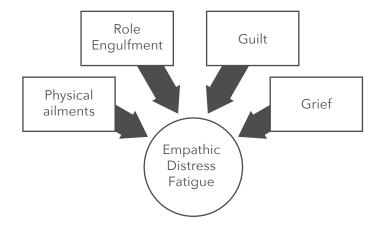
Think of a pleasant event - such as the feel of sunshine, the smell of the flowers, the smile from a stranger. It could even be a simple activity you enjoy, such as drinking hot chocolate by the fire or taking a walk in a park. Notice how this activity makes you feel - the sensations in your body, your mood and your thoughts. Reflect on how you can change how you feel by changing your thoughts (energy follows focus).

One of the most important aspects of the training I provided to family carers was an emphasis on the importance of looking after themselves first and foremost. To begin with it was clear that the carers were not used to doing this. To convey this key idea, I used the analogy of the safety instructions on a flight to put your own life jacket and oxygen mask on before helping others. I also integrated Qigong into every session as a stress relieving practice. As a basis I taught them butterfly sweeping Qigong and movements from the traditional 18 move Qigong. I also taught them a further practice which involves using imagery and movements to clear out negative emotions. I showed the carers how to visualise a bubble of positive energy around themselves from which they can pour out their love and care. At the same time, I emphasised that this positive energy bubble could protect them from any negative environments and people including the negative energy of their sick loved one. I also included here the negative energy of 'the authorities' with whom most of the carers seemed to do battle on a pretty regular basis.

In order to understand how the carers were feeling and the impact of the course on their health and wellbeing I needed to collect information from them. I did this by collecting data through four questionnaires which examined the carers state of stress using the Perceived Stress Scale (Cohen, Kamarck, 1983); resilience using the Brief Resilience Scale (Smith, Dalen et al., 2008); overall wellbeing and flourishing using the Flourishing Scale (Diener, Wirtz et al., 2010) and self-compassion using Neff's (2003) Self Compassion Scale, before and after the course. Whilst the data I collected this way was revealing, the most important aspect of my research turned out to be capturing the carers' 'lived experience' through their stories, poems, paintings and heartfelt sentiments from focus groups, weekly observations and interviews. Evidence of carers' wellbeing before, during and at the end of the course came tumbling forth in a torrent of heartfelt emotion and experience. The rich narrative which emerged later formed the essence of a carer's journey from empathic stress fatigue to wellbeing, from grief to acceptance and from role engulfment to a positive self.

# EMPATHIC DISTRESS TO WELLBEING

The main findings from my study confirmed that there is a big physiological and psychological 'cost of caring' for a sick relative, illustrated below in Figures 5 and 6.



Physical illness
Chronic stress
Exhaustion
Depression
Chronic fatigue
Poor sleep
Isolation
Anger
Emotional exhaustion

Figure 5: Symptoms of Empathic Distress Fatigue

Figure 6: Physical ailments experienced by participants pre-course

Anne shared a poem with the group, which aptly reflects the dark depths one can reach as a family carer;



By analysing the words used to describe how participants were feeling I created a word cloud below in Figure 7, which highlights emotions and ailments experienced before the course.



Figure 7: Pre-Course Emotions & Ailments

#### Pause and Practice - 3-minute breathing space

I now invite you to do a practice that the carers found very beneficial in their daily lives. Sit comfortably and close your eyes. Bring your awareness to your body sensations, thoughts and feelings. Expand your awareness to your senses to include sounds, smell and touch. Now allow your focus to rest only on the sensation of breathing. How you breathe, where you can feel it. Explore the whole sensation of breathing as if noticing it for the very first time. Do this for about a minute or so. Next allow your awareness to spread to the rest of your body and become aware of any sensations in the body, noticing contrasts of tension and warmth, tingling etc. Expand your awareness to your emotions and thoughts. Allow your senses to reengage with sounds, smells touch and sight as you open your eyes.

Check in with how you are feeling now.

# **TRANSFORMATION**

One of the most exciting findings from my small study was that when the results from the questionnaires were analysed for the group after the course, a 32% increase in self-compassion was seen. Perceived stress levels were reduced by 32%, feelings of wellbeing and flourishing increased by 26% and resilience increased by 26%.

Six key themes became apparent which had contributed to the carer's transition from one of empathic distress to one of flourishing and improved health. I observed and recorded the unfolding process using weekly notes. The transformation represented a journey starting with mindful awareness to self-compassion and self-care, acceptance, the emergence of a more positive sense of self, improvements in carer/relative relationship and concluding with psychological and physiological wellbeing.

The word cloud in Figure 8 below, represents the positive words extracted from the carers' narrative data indicating the transformational impact of their commitment to the course and their practice.



Figure 8: Post course experience

The results of my study indicated that an important shift in response to empathy had occurred as described in Figure 1. For example, one participant in my study describes:

The turning point was when I said to him, I know you are feeling crap. I've always said - yes, I know you are in pain etc - but I have never put it to him that I am not going to take that pain on board. It's not my pain and I can't take it away for you

# MINDFUL AWARENESS

The carers in my study became more mindfully aware as a result of the course. It provided them with new insights into their behaviours, thoughts and feelings and assisted them to realise that they have a choice about how they respond to stressful situations. One participant reflected;

It's the awareness that makes the difference. I didn't realise the destructive path I was travelling down. The course has given me to the opportunity to be allowed to be aware

An awareness of how their minds worked and their usual patterns of behaviour enabled most of the participants to gain some insight into how they might be able to change their reactions to stressful triggers:

I now realise I can change things. Whereas before I would have got annoyed by my father but this time I decided not to get annoyed. It has changed me

One participant became aware of how her mind created stories that caused her to suffer:

I've been making up stories as I have been going along. I used to worry about what people think but now I am different. I realised I didn't need to make up a story

# SELF-COMPASSION AND SELF-CARE

Self-care is not selfish or self-indulgent. We cannot nurture others from a dry well. We need to take care of our own needs first, so that we can give from our surplus, our abundance. When we nurture others from a place of fullness, we feel renewed instead of taken advantage of (Jennifer Louden 2004, p.2)

Prior to the course, several participants described how they would forgo their own concerns and go along with the desires of others in an attempt to make them happy. But at the end of the course, they described how they had become more protective of their own wellbeing and were more self-accepting and self-compassionate. Clare stated, "I am more inclined to say I deserve a break and do something for myself". Others stated that they were doing things they wouldn't have done before, felt empowered, and that they were taking back control of their lives. Many of the participants started taking short breaks from caring and doing things for themselves like exercise and creative classes.

Joy shared her experience.

Realising that you are only human and accepting that sometimes you are pushed to your limits and can't cope any more - that's the thing. Thinking you are a bad person because you have yelled at someone but recognising that you are only human. Recognising that it isn't an issue - it's big.

Mary stated that she was more compassionate with herself:

I actually say to myself - you have been through an awful lot over four years and not many people I know would be able to handle that without getting to breaking point.

# **ACCEPTANCE**

Acceptance and acknowledgment of feelings of grief were unprompted key themes which arose in the narrative from the interviews and focus groups. One participant described her grief as being paralysing:

The course helped ground me and not allow the grief to keep taking over. Trying to let everything be, as I cannot change what has happened.

Another participant acknowledged: "Life wasn't what I expected of life. It's really a loss".

The RAIN practice is included in the MBLC course. Developed by Tara Brach (2003), the practice involves inviting a difficulty into a meditation and going through a process of 'Recognising' the difficulty, 'Allowing' it in, 'Investigating' into how this difficulty makes us feel and finally seeing if we can let it go through a process of 'Nurturing'. As a result of practicing 'RAIN' one participant shared some of her deep insights which she felt resulted from a new awareness of her thoughts and reactions:

Looking at things from a different angle helped me to break through. I didn't realise what my undercurrent of thoughts was about. Then I realised the undercurrent was anxiety. I suppose once you know what something is, you can deal with it, realise there is no substance to it. So, let it go or at least let it pass through and go. Before I was overwhelmed, too scared to address any of it. Now it is nice to sit there and not pretend. To be authentic, true to myself, allowing it to be there

Clare reported learning how to:

accept things as they are. The course helped me to stand back and not worry myself sick. Its major to be able to do that. I notice how I am feeling and then say - Let's cope, let's not worry if things might go wrong

### **Pause and Practice**

Explore the RAIN practice for yourself by visiting Tara Brach's practice page https://www.tarabrach.com/selfcompassion1/

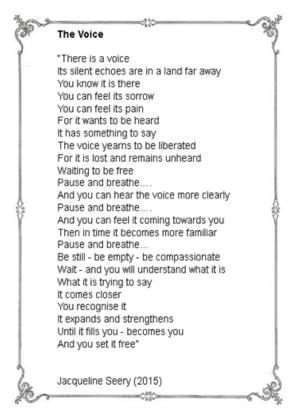
#### FINDING POSITIVE SELF

As part of my unfolding journey, I wrote a poem in my journal during the first year of MSc Studies in Mindfulness. I realised that I had found my voice and a more positive sense of self.

One of the most remarkable findings that emerged from my research was that my small group of family carers had also begun to find their voices.

The finding of their voice was integral to the emergence of a 'positive-self' which compared favourably to carers' pre-course states of role engulfment, guilt and grief. My research has revealed that a positive-self can emerge through a combination of increases in self-compassion, self-esteem, self-confidence and social-self, as represented in Figure 12 below.

In my study, as participants' feelings of isolation were alleviated, other positive changes in their mood and emotional state followed. As the carers' self-compassion and self-confidence increased, so their self-esteem improved. Participants stated, "I started doing things for myself", and "I feel empowered. I feel I am taking back control".



# **IMPROVED RELATIONSHIPS**

Generally, my carers reported that their relationship with those they were caring for was more relaxed and had improved throughout the course. Some attributed this change to their own improved sense of calm and happiness. Some participants shared that they were no longer taking things so personally or feeling like a victim of their role. One participant said that,

The relationship with my husband was as if we turned the clock back 20 years. My husband says he has seen a change in me and I have seen a change in him

Some of the participants said that they practiced mindfulness with their relative which had a positive effect on them both.

# PSYCHOLOGICAL AND PHYSIOLOGICAL WELLBEING

Before the course, participants described being stressed, anxious and depressed. After the course, their levels of stress had dropped significantly. In particular one participant reflected:

I felt really alone, really depressed and I wasn't in a very good place. The difference now is that when things happen to me, okay I am really upset about it, but I don't let it affect me as much as I did before. I think that is because I am more mindful of not letting it consume my whole being. I can feel it, live with it and know that feeling is going to pass

Participants described how they were sleeping better, feeling calmer, more relaxed and coping better. One participant described the change in how she felt thus: "I used to get angry and short tempered, but now I am more back to my philosophical self." Mary described how her body used to

be in so much pain that she ended up in hospital with high levels of stress. She explained:

My physical body, stress, anxiety and depression is better. The way I handle situations are all better. Everything is much better than it was

Another participant described how she used to feel snappy and stressed. She says, "Now I don't feel angry or stressed. The mindfulness took it to another level in how I feel about myself".

# **DEPARTURE**

My small study revealed evidence of the symptoms of empathic stress amongst family carers. These symptoms included high levels of stress, depression, anxiety, ill health, sleep problems, grief, guilt, frustration, isolation, exhaustion and feelings of helplessness and hopelessness. My findings strongly suggested that maintaining a short daily formal practice and integrating brief moments of mindfulness and self-compassion into daily life are sufficient to bring about greater overall wellbeing in stressed family carers. All of the participants commented that the course was highly appropriate and beneficial to them and three reported that it had changed their lives.

Two of the participants described the course as 'brilliant' and that it was important that the compassion and Qigong had been a part of it. Others recognised the particular value of the compassion element within the course;

I can see the value of the compassion element of the course. You have to have it tailored correctly for the people it's for. That's where a lot of people have a negative view of mindfulness. How you altered the course for us was brilliant

I think this is amazing. you have given us a gift. That's how I feel about it

It had become apparent that that the carers had begun their 'departure' into hero's' journeys of their own.

# THE HERO'S RETURN

Anne shared a poem she had written with the group. Her descent into her own hero's' journey had begun:

# Seasons "I have lived in Winter for too long. Burdened by the weight of responsibility I have grown cold and lonely. Mindfulness, you have shown me Spring. You have touched me with the soft breeze of change. You have cleansed me with bitter sweet tears of rain. You have shown me a glimpse of sunshine. But it will be me who steps into Summer, alone, Head held high to catch the warmth. It will be my Summer. Others may choose to follow and that will be their Summer. Winter will come again But I will have Mindfulness at my side, my companion for life" 'Anne' - Family carer in Hertfordshire, 2017.

As I conclude this story about the awful stress experienced by a small group of family carers, and their extremely positive responses to the course I ran for them, I realise the impact of my own empathic response towards their pain. Sharing their pain made me acutely aware of my own feelings as I cried along with them. I shared their journeys from suffering to glimpses of transformation, as bodies relaxed, smiles appeared, and they finally began to become much more empowered and accepting of their unavoidable caring roles.

I lived and breathed these carer's stories for twelve months. In Ricard's (2015 p.60) words I feel a "profound, heart-warming courage linked to limitless love" for the family carers in my study. I salute these unacknowledged heroines of our contemporary rather uncaring society. Spending quality time with these incredibly courageous and generous women felt to me like coming home. I

had returned to a place of unconditional love and compassion for all suffering human beings, but particularly for all those amazing carers who - like my past-self - courageously keep going under the most stressful circumstances.

As I write this chapter, in June 2018, Britain is commemorating the end of WW1 and saluting all the heroes of that dark time in our history. But as well as saluting these 20th century heroes, I would like to salute here the thousands upon thousands of unsung caring heroes of the 21st Century.

I feel so privileged to have been able to hold a warm, compassionate space for these caring heroines. I feel so blessed that I was able to share with them all that I have learnt on my own heroine's journey through life. I am now so incredibly grateful that my own challenging life journey, during which I have met, and been supported by, so many incredibly wise, generous and empowering mindfulness teachers, has enabled me to offer these vulnerable, stressed carers a set of effective tools and insights to initiate them into their own heroine's' journey home to unconditional love and wholeness.

#### REFERENCES

BEHNKE, E.A., (1997). Ghost gestures: Phenomenological investigations of bodily micromovements and their intracorporal implications. Human Studies, 20(2), pp. 181-201.

BRACH, T., (2003). Radical Acceptance

Awakening the love that heals fear and shame within us. London: Ebury Press. BRANDEN, N., (Undated). Brainy Quote. Available: https://www.brainyquote.com/quotes/ nathaniel\_branden\_163773?src=t\_acceptance [Date Accessed: 23rd June 2018]. CARERS ŪK (2012). Īn Sickness and in Health. Available: https://www.carersuk.org/forprofessionals/policy/policy-library?task=download&file=policy\_file&id=208. London: Carers UK [Date Accessed 30th November 2016].

CARERS UK., (2015). Facts about carers. Available: https://www.carersuk.org/news-andcampaigns/press-releases/facts-and-figures [Date Accessed: 23rd June 2018]. COHEN, S., KAMARCK, T. and MERMELSTEIN, R., (1994). Perceived stress scale. Measuring stress: A guide for health and social scientists.

COVEY, S.R., 2006. Servant Leadership Use your moral authority to serve. Leadership

Excellence, 23(12), p.5.

DIENER, E., WIRTZ, D., TOV, W., KIM-PRIETO, C., CHOI, D., OISHI, S. and BISWAS-DIENER, R., (2010). New Well-being Measures: Short Scales to Assess Flourishing and Positive and Negative Feelings. Social Indicators Research, 97(2), pp. 143-156.

FIGLEY, C.R., (1995). Compassion fatigue: Toward a new understanding of the costs of

FREDRICKSON, B.L., COHN, M.A., COFFEY, K.A., PEK, J. and FINKEL, S.M., (2008). Open hearts build lives: positive emotions, induced through loving-kindness meditation, build consequential personal resources. Journal of personality and social psychology, 95(5), pp. 1045.

GAIK, F., (2009). Managing Depression with Qigong. Singing Dragon.
GILBERT, P. and IRONS, C., (2004). A pilot exploration of the use of compassionate images in a group of selectrical people. Memory, 12(4), pp.507-516.

GILBERT, P., (2009). The compassionate mind: A new approach to life's challenges.

London: Constable and Robinson Ltd (Kindle edition).

HOPPES, S., BRYCE, H., HELLMAN, C. and FINLAY, E., (2012). The effects of brief mindfulness training on caregivers' well-being. Activities, Adaptation & Aging, 36(2), pp. 147-166.

HUTCHERSON, C.A., SEPPALA, E.M. and GROSS, J.J., (2008). Loving-kindness meditation increases social connectedness. Emotion, 8(5), pp. 720.

Ivtzan, I. and Lomas, T. eds., 2016. Mindfulness in positive psychology: The science of meditation and wellbeing. Routledge.

JAHNKE, R., LARKEY, L., ROGERS, C., ETNIER, J. and LIN, F., (2010). A comprehensive review of health benefits of gigong and tai chi. American Journal of Health Promotion, 24(6), pp. e1-e25.

JINPA, T., (2015). A Fearless Heart. Why compassion is the key to greater wellbeing.

London. Little, Brown Book Group (Kindle edition).

JOINSON, C., (1992). Coping with compassion fatigue. Nursing, 22(4), pp. 116, 118-9, 120.

KABAT-ZINN. J., (Undated). 76 Most Powerful Mindfulness Quotes: Your Daily Dose of Inspiration. Positive Psychology Programme. Available: https://

positivepsychologyprogram.com/mindfulness-quotes/[Date Accessed:23rd September 2018].

KABAT-ZINN, J., (2005). Coming to our senses: Healing ourselves and the world through mindfulness. Hachette UK (Kindle edition).

KABAT-ZINN, J., (2013). Full Catastrophe Living, Wherever You Go There You Are. London: Piaktus (i-book version)

KLIMECKI, O. and SINGER, T., (2012). Empathic distress fatigue rather than compassion fatigue? Integrating findings from empathy research in psychology and social

neuroscience. Pathological altruism, pp. 368-383. KOK, B.E. and SINGER, T., (2016). Phenomenological Fingerprints of Four Meditations: Differential State Changes in Affect, Mind-Wandering, Meta-Cognition, and Interoception Before and After Daily Practice Across 9 Months of Training. Mindfulness, pp. 1-14.

LOUDEN, J., (2004). The woman's comfort book: A self-nurturing guide for restoring balance in your life. HarperSanFrancisco.

LYNCH, S.H. and LOBO, M.L., (2012). Compassion fatigue in family caregivers: a Wilsonian

concept analysis. Journal of advanced nursing, 68(9), pp. 2125-2134. MANZANEQUE, J.M., VERA, F.M., RODRIGUEZ, F.M., GARCIA, G.J., LEYVA, L. and BLANCA, M.J., (2009). Serum cytokines, mood and sleep after a qigong program: is qigong an effective psychobiological tool? Journal of Health Psychology, 14(1), pp. 60-67. MARRIOTT, H., (2003). The selfish pig's guide to caring. Polperro Heritage Press. MINDFULNESS ASSOCIATION, Ltd., (2011). Mindfulness Based Living Course - 8-week

Programme - Course Manual. Mindfulness Association Ltd.

MINDFULNESS ASSOCIATION, Ltd., (2017). Compassion Based Living Course - 8-week Programme - Course Manual. Mindfulness Association Ltd.

NEFF, K.D., (2003). The development and validation of a scale to measure self-compassion. Self and identity, 2(3), pp. 223-250.
PERRY, B., DALTON, J.E. and EDWARDS, M., (2010). Family caregivers' compassion fatigue

in long-term facilities. Nursing older people, 22(4), pp. 26-31. PFIFFERLING, J. and GILLEY, K., (2000). Overcoming compassion fatigue. Family practice

management, 7(4), pp. 39-39.

RICARD, M. and SINGER, W., (2017). Neuroscience Has a Lot to Learn from Buddhism, A scientist and a monk compare notes on meditation, therapy, and their effects on the brain. The Atlantic. Available: https://www.theatlantic.com/international/archive/2017/12/ buddhism-and-neuroscience/548120/ [Date Accessed 4th January 2018].

RICARD, M., (2009). Empathy and the Cultivation of Compassion. Matthieu Ricard. Available: http://www.matthieuricard.org/en/blog/posts/empathy-and-the-cultivation-ofcompassion. [Date Accessed 24th July 2017]. RICARD, M., (2015). Altruism: The power of compassion to change yourself and the world.

Hachette UK.

RINPOCHE, Y.M., (2009). Joyful wisdom. Random House (Kindle edition).

SEGAL, V.Z., WILLIAMS, J.M.G. and TEASDALE, J.D., (2013). Mindfulness-Based Cognitive Therapy for Depression. Second edn. New York: The Guildford Press (Kindle edition). SINGER, T. and KLIMECKI, O.M., (2014). Empathy and compassion. Current Biology, 24(18), pp. R875-R878. SINGER, T., KOK, B.E., BORNEMANN, B., ZURBORG, S., BOLZ, M. and BOCHOW, C.,

(2016). The ReSource Project: Background, design, samples, and measurements. SMITH, B.W., DALEN, J., WIGGINS, K., TOOLEY, E., CHRISTOPHER, P. and BERNARD, J., (2008). The brief resilience scale: assessing the ability to bounce back. International Journal of Behavioral Medicine, 15(3), pp. 194-200.

SØDERBERG, M.T., (2016). Hygge: The Danish Art of Happiness. Penguin UK. TSANG, H.W. and FUNG, K.M., (2008). A review on neurobiological and psychological mechanisms underlying the anti-depressive effect of qigong exercise. Journal of Health

Psychology, 13(7), pp. 857-863. TUBB, G., (2018). "Young carers face loneliness and isolation in summer holidays". Sky News. Available: https://news.sky.com/story/young-carers-face-loneliness-and-isolation-in-summer-holidays-11456375 [Date Accessed: 23rd June 2018]. WADA, K. and PARK, J., (2009). Integrating Buddhist psychology into grief counselling.

Death studies, 33(7), pp. 657-683. WAELDE, L.C., THOMPSON, L. and GALLAGHERTHOMPSON, D., (2004). A pilot study of a yoga and meditation intervention for dementia caregiver stress. Journal of clinical psychology, 60(6), pp. 677-687. ZI, L., (1939). Tao te ching. Lulu. com.