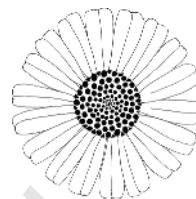

Chapter One

Mindfulness and Cancer



Mindfulness practice is really a love affair with what we might call truth, which includes beauty, the unknown and ... how things actually are, all embedded here in this very moment.

(Kabat-Zinn, 1990)

Mindfulness practice is central to my own experience of being with cancer. In the previous section, I write about this and the ways that cancer and mindfulness have impacted on me personally.

Now, in this first chapter, we ponder questions, such as:

What is mindfulness?

What does a mindfulness-based course involve?

What might a mindfulness practice offer someone with cancer?

After suggesting some basic descriptions of mindfulness, we look through the eyes of three different people with cancer, all of whom made their way to a Mindfulness-Based Cognitive Therapy for Cancer (MBCT-Ca) course in North Wales. Their stories will help to orient us towards what mindfulness offers those who are living with cancer.

Introduction

Being mindful is to be fully present with your direct experience, whatever you are doing, thinking or feeling – here and now.

Mostly, we are *not* aware. We are rarely fully *with* the experience we are having *now*. We tend to wander back, dwelling in the past – or run forward, anticipating the future. We can be driving a car, but functioning on automatic and only partly aware, whilst worrying about something about to happen, or thinking about something someone said earlier.

When we practise being mindful, we do something and know that we are doing it – like eating and actually tasting the food – or going for a walk and noticing the full scope of the view – or turning on the radio and actually hearing the programme. Becoming more mindful offers us many possibilities. It helps us to become more aware, centred and balanced. We may find more to appreciate in the ordinary experiences of our day.

Mindfulness also helps us learn to respond differently to difficult situations. Instead of reacting, in a knee jerk way, immediately imagining the worst – we learn to stop, and come back to the direct experience we are having now. This changes things and gives us an opportunity to find other ways of managing what is challenging us.

We now turn to the experience of three people. Their stories will help us begin to understand what mindfulness might offer people with cancer.

Will Mindfulness Help Me?

Jane was only 32 when she was told that she would probably not survive breast cancer. A single parent with three young children, she tolerated nearly twelve months of an aggressive treatment regime and seemed to manage pretty well. After it was all finished, her doctor told her that she might be fine after all.

Almost immediately, Jane started feeling awful. ‘My head is all over the place’, she told me. ‘I’m angry – not sleeping well – and horrible with the kids’.

Family and friends had withdrawn, assuming she was alright now that treatment had finished and her prognosis was so much better. In reality, Jane was only just beginning to get in touch with her feelings and finding them hard to manage. She could not understand what was happening and thought she was being ‘really stupid’.

After a clinic appointment with her oncologist, she was referred to a mindfulness course.

When Jane heard that what she was experiencing was entirely normal, and that others also get in touch with strong emotion after the end of treatment, she immediately felt a bit better.

On hearing about mindfulness and the course, she could see that it might help her to be more ‘present’, although just talking about it did not give her much of a clue as to how she could do that. However, she was well aware that she was spending a lot of the time anxiously brooding on what might happen – worrying about the children, and fretting over every twinge of pain thinking it might be the beginning of the cancer returning.

In describing persistently critical thoughts, ‘that do my head in’, Jane can connect with the possibility that learning to stop and be more aware of the habits of her mind, might be a first step in helping her to develop ways of being kinder to herself. She knows that she blames herself for everything – getting cancer, losing patience with the children, and even for feeling so awful. She would love not to do that and feel more herself again. It is a long time since she has felt happy.

‘Count me in’, she tells me ‘I can’t wait to start’.

What Does Mindfulness Offer? Is It Safe?

David is a retired professional man in his sixties with incurable cancer. He finished a recent round of treatment last year and is currently in remission. He is a fairly cautious person, who does not easily engage with new people or situations. His doctor referred him for a mindfulness course, because he is not sleeping well, and is feeling low and lethargic.

David meets me to hear about the course. He is not sure it will help him, but he says he thinks he ought to give it a go. 'I haven't much to lose', he says 'I wonder if it will work for me'.

What might mindfulness offer someone like David? And how could he be helped to commit to the vital home practice involved. On the face of it, he is very different to Jane. He is a lot older, more set in his ways, and clearly sceptical about the approach.

David was not much interested in hearing about learning to be more present. It did not sound like his sort of thing, and anyway he did not understand. He became a bit more engaged when he was told about some research, which demonstrated evidence of the benefits of mindfulness. This was more his line.

The first mindfulness-based course was developed by Jon Kabat-Zinn in Massachusetts over thirty years ago, for groups of people with a wide range of different health conditions. Since then, Mindfulness-Based Stress Reduction, (MBSR for short) has spread to many parts of the world (Kabat-Zinn, 1990). Part of that development includes some research undertaken by a leading psycho-oncology team with cancer patients in Calgary, Canada over the last ten years. They are getting some good outcomes from MBSR. Evidence is building that mindfulness holds much promise for cancer patients (Shennan et al., 2010).

David was relieved to hear this. He had already decided to take the course, because his doctor advised it, but if mindfulness was not the flaky, touchy feely approach that he first assumed, it might have something genuine to offer him. The news got better the more he heard. A form of mindfulness for people with depression, known as Mindfulness Based Cognitive Therapy

(MBCT) has been found to significantly reduce the risk of relapse in people with a history of depression (Segal et al., 2002). NICE (the National Institute for Clinical Excellence), the UK health standards body, explicitly recommends MBCT for people who have had three or more depressions.

David was currently on medication for depression. He heard that the mindfulness course he would be going on had been adapted directly from MBCT for Depression, and targeted to the needs of people with cancer. It had been running for over ten years. Regular evaluations of course outcomes suggest that participants experience improved levels of sleep and wellbeing after attending. ‘I could do with that’, said David wistfully ‘I wonder if it will work for me’.

What is Involved on the Course?

The last person we meet is Sheila. A married woman in her early 40s, with two children, she was traumatized by a diagnosis of ovarian cancer, eighteen months earlier. She has never forgotten the look on her mother’s face when the doctor told them.

After treatment, her prognosis was said to be fairly good, but she did not believe it. Sheila is convinced that she is going to die, but can’t bear to think about it. She dreads going to bed at night. As soon as she closes her eyes, everything crowds in – especially that expression on her mother’s face.

She broke down when she last saw her specialist nurse. Sheila admitted to be feeling terribly tense. ‘It is as if there is a dark cloud blocking out the light’, she said ‘I know I can’t go on like this. It is making me ill. Even my husband, who is very laid back, is really worried’.

When Sheila met me, we discussed how she was feeling and touched on what she had been through. It was hard for her to talk about it, but she said that she was desperate to feel better. She had been referred to counselling but had not chosen to continue. ‘Talking about it doesn’t help’, she told me.

Like David, she would have to develop some confidence in mindfulness before she could commit to the course. Unlike David, hearing about research findings would not be much help to her. Sheila needed to make a personal connection with me, her teacher, and feel that she could trust the course. It helped her to hear about practical details, such as what to expect, and how the sessions were structured.

I told her that the course ran for eight weeks, with a session every week lasting for two and a half hours, with about ten people in the group. Sheila admitted that she was quite nervous with people she did not know. I explained that it was not a self help support group. We practise a mindfulness-based exercise, guided by me, the teacher, and then we explore our experience of it. Then we experience another practice or exercise and discuss that. 'There is no need for you to say anything unless you want to', I told her. At times the group breaks into pairs or small groups to discuss the mindfulness exercise, and sometimes we stay in the larger group.

Sheila quickly appreciated that she would have to commit herself to the home practice. I was clear that whatever she got out of the course was mainly up to her – and the home practice was an important ingredient in it all. She said that she was so desperate to feel better that she would do whatever was needed. I explained that she would follow one of the thirty minute practices every day at home using a CD.

There are also a number of short practices which she would learn to weave into her day. Some of these could be helpful to turn to when things felt tough. It seemed very important to explain to Sheila that mindfulness involves having the courage to turn towards what is difficult little by little, with sense of friendliness and kindness for herself. She said that 'turning towards' sounded scary, and she was not sure she could do that, but something inside told her that learning to be kinder to herself was probably exactly what she needed.

As she left the room after our exchange, she looked a little brighter.

Developing Course Themes

Jane, David and Sheila all decided to join an MBCT-Ca course. They were not told about the themes that would build through the course. It was too

soon for that and would not have made sense to them. Mindfulness is best learned through direct experience.

However, over the weeks that follow the start of the course, they all became more familiar with awareness of sensations in the body. Jane found this naturally much easier than David and Sheila, but they all engaged in the practice of scanning the body. They were learning to be curious about their physical sensations.

Sheila got on well with practices involving the breath. She found she was able to bring her focused attention to sensations of breathing quite easily. This helped her feel less tense and gave her something to concentrate on at night. Jane liked to focus on the sensations of the contact of her feet on the floor. This helped her to feel more settled and steady. David said he particularly enjoyed the practice of mindful movement. He was rather surprised by this, as he was not a particularly active person, but he found he felt better after doing the gentle stretching postures. In different ways, they were all learning to bring their attention back to the 'anchor' of their present moment experience, in the body and the breath.

The movement practices helped Sheila come closer to awareness of her body and helped her to practise gentleness. She found the body scan hard and struggled with the stillness of it, but she noticed that it was possible to open into the intensity of a stretch, by breathing into it. She could be aware of strong sensations in her body, without feeling so frightened. David also found it was easier for him to be mindful when moving and stretching. His mind seemed to wander much less and he felt more alive and alert after the practice.

These and other practices helped them to develop:

- The intention to step out of automatic reacting and come back to the anchor of present moment in the body and the breath.
- The practice of turning towards what is difficult little by little.
- The possibility of bringing kindly, curious and gentle attention to their experience.

As time passed, and their practice developed, it became easier for them to become aware of the way their minds wandered. They began to notice when judging, worrying or despairing thoughts crept in and were less likely to be swept away by them. Through the building momentum of their mindfulness practice, it was sometimes possible to respond to these troubling moments

with one of the short practices they were learning. They were becoming more mindful in their everyday lives. This offered them choices that enabled them to live more fully, and manage difficulties with more kindness and compassion.

A Cognitive Model of Cancer Distress

About half way through the course, we share a cognitive model of cancer distress with participants. It is known as a vicious circle of anxious preoccupation (Moorey & Greer, 2002). Jane and Sheila immediately recognized it from their own experience. David's patterns were a bit different, but he knew that he too could be swept up like this.

The vicious circle starts with some general anxiety, which is often present in the background experience of people with cancer. This inevitably triggers tension in the body, which is felt as an ache or a pain. Attention is drawn to these feelings and because they are unpleasant and not wanted, negative interpretations soon start forming. 'It is getting worse'. 'It might be a recurrence'. 'Maybe it will kill me'. These thoughts are added to the feelings of anxiety and 'not wanting', fuelling the tension and physical pain. This simply increases the negative interpretations making them more and more apparently convincing. A vicious circle of anxious preoccupation quickly builds.

Individuals have different patterns in their adjustment to cancer. Unlike a mental health condition such as depression, there is no one cognitive model that comprehensively explains the mechanisms that fuel distress in everyone with cancer. However, the vicious circle of anxious preoccupation comes closest to offering a cognitive model of cancer distress that applies to the people who find their way onto a mindfulness-based course for people with cancer. This is discussed in much more detail in the next chapter. Other relevant cognitive models that contribute to cancer distress are also explained.

Through practising mindfulness, participants learn to notice and interrupt the cycle of anxious preoccupation. Thoughts may still arise, anxiety may still be felt, interpretations may even start to build – but it may be possible to recognize the thoughts, feelings and body sensations for what they are – not necessarily true facts. Once noticed, it is always possible to come back to the

‘anchor’ of the breath in the body. This offers connection to present moment awareness and an opportunity to choose what to do next, rather than be at the mercy of overwhelming thoughts and feelings.

Jane, David and Sheila

We conclude this first chapter by returning to our three participants.

By the end of the course, Jane had relaxed a fair bit. She continued to feel anxious, especially around clinic times, but she used her own versions of some of the short practices most days, came to mindfulness follow up sessions now and again, and used a longer practice when she felt she needed to. She said she felt a lot happier, and was definitely steadier at home with her children. When I last heard from her, she was well and hoping to start work again soon.

David was surprised at how much he gained from the course. Of the three, he probably benefitted the most. He continued to do the movement practice and also followed a short sitting practice regularly. He joined a choir, which he loved, and reported that he was sleeping better and feeling pretty good much of the time. Last heard, he was still in remission, no longer depressed and continuing to practise.

Sheila was less troubled by flash backs by the end of the course. She used some short breathing practices, when thoughts and feelings were troubling her. She said that she could see more chinks of light at the end of the tunnel. Her specialist nurse was impressed with these changes, and subsequently regularly referred other patients to courses. Sheila wrote a poem, which she posted to me some time after the end of the course, praising mindfulness for giving her back her life.

Not everyone who participates on MBCT-Ca courses is necessarily as motivated or gains as much as these three. However, they are by no means unusual.

What Comes Next

In the next chapter, Stirling Moorey and Ursula Bates draw out the psychological implications of having a cancer diagnosis and of receiving

treatment. They present a clear picture of the mechanisms that perpetuate the distress experienced by cancer patients. Then in the following chapter, Nicholas Stuart describes the medical implications of cancer and treatment. This might be especially relevant to those of you who are unfamiliar with the world of oncology and treatment for cancer. We conclude this first section with a circle diagram that summarizes the patterns of suffering for people with cancer. In later chapters, other circles will be added that draw out the development of mindful awareness, from the picture of suffering with cancer, to learning to practice mindfulness through the eight week course, and finally to living mindfully and being with cancer.

From Blossoms

From blossoms come
this brown paper bag of peaches
we bought from the boy
at the bend in the road where we turned toward
signs painted *Peaches*.

From the laden boughs, from hands,
from sweet fellowship in the bins,
comes nectar at the roadside, succulent
peaches we devour, dusty skin and all,
comes the familiar dust of summer, dust we eat.

O, to take what we love inside,
to carry within us an orchard, to eat
not only the skin, but the shade,
not only the sugar, but the days, to hold
the fruit in our hands, adore it, then bite into
the round jubilation of peach.

There are days we live
as if death were nowhere
in the background; from joy
to joy, to joy, from wing to wing,
from blossom to blossom to
impossible blossom, to sweet impossible blossom.

Lee Li-Young (1986)