

Mindfulness

a way to live life in the present tense

PETER MCINTYRE

“I have learned to shift from seeing myself as invulnerable to quite vulnerable – and to know that as not something to push away. There are good things about vulnerability. I have never felt so loved, supported, treasured... and have come to know some people in a way I think I never would otherwise.”

These were the words of June Robson one month after being diagnosed with an osteosarcoma. She was at first told this was “too large to remove”, but had surgery following a second opinion. She had time to think about how her life had turned upside down after her first dose of chemotherapy as an inpatient in Christie Hospital, Manchester, in northern England.

“I had fallen out with my body big time, to the point that I found it hard to look at myself in a mirror. What’s more, I now suddenly noticed that I used to really like my body. I’ve had the luxury of almost never being ill, being pretty fit for a young 60-something, and having a body that let me do pretty much anything I wanted. What things I had taken for granted!”

When first diagnosed, June was in a state of something close to panic. What helped her to cope with the psychological challenges was a technique for dealing with the reality of here and now rather than fearing for the future – the technique of mindfulness.

Mindfulness is currently suffering the curse of fashionable celebrity – presented as a kind of “chilling out”, which is more or less the opposite of what it is. Even the normally serious *Financial Times* ran a feature this September on “mindfulness” for home interiors. (“To turn on a light mindfully means being thoroughly caught up in what you are doing.”)

The psychological impact of cancer diagnosis and treatment is as far from this self-indulgent selfie ‘me-time’ as it is possible to get.

As June, now six months out of treatment, says: “My sarcoma had every bad news label attached to it apart from metastases. I am anxious when I go for follow up. When I went on holiday I was convinced something would go wrong when I was out of the country. I also have pain from the surgery – different amounts of pain on different days, but I am never pain-free.”

On the whole June is a fan of “good old-fashioned western medicine”, but she trained to teach mindfulness for people with chronic pain and brain injury when she was working as a psychologist in the NHS, before she had cancer. “It helps with letting go of all that wishing and hoping that things were different, that people spend their time and energy on.” It also helps to prevent the brain from endlessly



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“ruminating” on what caused the disease or the worst that might happen.

Applying it herself was instructive. “It helps with the two disabilities I have been left with – hearing loss and getting about on crutches. When the wretched crutches are really irritating, mindfulness brings you back.”

Focusing on what matters

Suzie H from London is in her 40s and was diagnosed two years ago with a uterine leiomyosarcoma that grew to the size of a small baby. She has faced three major operations including a radical hysterectomy and removal of ovaries and two rounds of chemotherapy. She puts her feelings more strongly. “It really is a bloody journey through all of this; it is treatment and life and death and looking forward and

looking back. You can’t stop yourself.

“I want to confront the issues of illness. I am more afraid of getting really ill again and being in this awful state of illness than I am of dying. But I also have to confront the fact that I might die – cancer can be very fast moving.”

Suzie attended a mindfulness course at the Penny Brohn Cancer Centre in Bristol. “I do it when I notice my head is racing into the future and I am becoming fearful of things that might happen, and when I recognise that I am worrying about something I cannot control. I try to make myself present. I will take some deep breaths. I might be walking around or I might go and sit down or lie down and concentrate or meditate.”

For Suzie, mindfulness means focusing on what matters. “In our modern

society there is some glorification of being busy all the time and rushing around. Everybody could do with pulling themselves into the present and stop worrying about what might happen in the future or has happened in the past and truly enjoy the moment you are in right now. It is really important to be present in our lives.”

Mindfulness-Based Stress Reduction (MBSR) was developed in the USA by Jon Kabat-Zinn out of the Buddhist practice of ‘sati’ (presence of mind), and has been adapted as Mindfulness-Based Cognitive Therapy (MBCT) for people with depression. Both have been used by cancer patients.

MBCT specifically for people with cancer (MBCT-Ca) was developed by Trish Bartley, one of the founding

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teachers at the Centre for Mindfulness Research and Practice in Bangor University, North Wales. She ran the first course in 2001 soon after she completed treatment for her own breast cancer. It continues to run three times a year at North Wales regional oncology units and around the UK – as a weekly class over eight weeks with a commitment to daily practice at home.

According to Bartley, the psychological impact of cancer can be even more difficult for some people than the physical disease. Cancer patients may deal with psychological trauma or distress by avoidance (pushing away unwanted experiences) or by rumination (caught in loops of negative thinking). The aim of the course is to help participants come back to the present experience and in time ‘turn gently towards’ what is happening with some level of kindness to themselves.

Bartley says: “Patients coming on a course are seeking some kind of release from their suffering. Many are desperately anxious, some are depressed or a number have been traumatised by their experience.

“If they benefit from the course, a participant no longer tightens around the anxiety or pushes it away, but is able to sit alongside it and breathe into it with a bit more kindness.”

Mindfulness also offers an opportunity to appreciate life more. “Because this is about being present to experience, we have more possibility of noticing and enjoying what is around us. You are more likely to see the

robin on the fence, or that the sky is a lovely blue or to feel the breeze on your face. The practice of mindfulness is to come back to your sensory experience. It might be a touch on the skin or a smell.”

The course involves hard work and a commitment to practice, including daily exercises such as a ‘body scan’, focusing on parts of the body in turn to notice what is happening. Some people call this ‘exercising the attentional muscle’ – rather like going to the gym to improve fitness, flexibility and stamina, but in this case training the mind.

Bartley says that this is not about trying to make everything lovely or change the experience, but simply to notice what is there and bring the mind back when it starts to wander. “When our mind wanders, we move into ‘automatic’, where habitual reactive patterns happen. And that is where all those horrible, negative, difficult thoughts are lurking: ‘This is my fault; I should have gone to the doctor earlier,’ or ‘Someone said something – she really meant that things are going badly’.”

Patients may be at their most vulnerable when their treatment is over and they lose the everyday support and reassurance from their health professionals. This may be the best time to start the course says Bartley.

“People quickly go back into work or if they are retired pick up on what they did before, looking after the grandkids or whatever, but are still recovering from the effects of radiotherapy or chemotherapy or ongoing treatment.

They often find they have not got the same energy, the same motivation. Friends and family congratulate them on ‘getting back to normal’, but the fears remain.”

There is growing evidence for the efficacy of mindful-based cognitive therapy in dealing with the psychological impact of a cancer diagnosis and treatment, but Bartley makes no claims for it extending life. “Cognitive therapy and counselling and mindfulness are undoubtedly going to reduce the psychological burden, but in terms of the actual life/death outcome I don’t think there is any evidence that a better psychological approach will improve your chances of living longer.”

No quick fix

She absolutely rejects mindfulness as a middle-class ‘me-time’ lifestyle choice. “It is just too easy to see mindfulness as some kind of flaky quick fix, ‘let’s all lie down and relax and be happy’. Mindfulness is a really gutsy approach to working with difficulty. It needs a lot of courage and intention and persistence and support. The four movements of mindfulness: intention, coming back, turning towards and kindness, are very profound and not to be learned in five minutes. Turning towards anxiety about what is going to happen to your children if you die, my goodness that is not pleasant.

“I have taught people across the socioeconomic spectrum in a rural and in some ways disadvantaged area of North Wales. People come feeling miserable, not sleeping, and waking at night with awful ruminations. They cry



Head-dress (duality): Suzie H created this self-portrait after going through chemotherapy following cancer surgery; using mindfulness to stop herself continually dwelling on bad things that might happen helps her stay engaged with the good things in her life

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very easily or their mood is dipping to the point where it is hard sometimes to get out of the house. People come because they want to feel better.”

Marguerite Wallis, who teaches people with chronic disease in Oxford agrees that “mindfulness is not zoning out, it is zoning in.” She sees it as a non-judgemental, loving kind consciousness of the present moment. “Often people’s thoughts go crazy because there is an underlying feeling that ‘This should not be happening to me.’ You are beating yourself up and miserable because you can’t do what you want, or you are running from yourself, keeping busy, getting exhausted, running on adrenalin or indiscriminate use of pain killers.”

Not all cancer patients practise mindfulness in the same way. Jean had half of her left lung removed after being diagnosed with bronchiolo-alveolar carcinoma in 2010, and had a bad time because of subsequent pain, infection and weight loss. “I was coughing up blood and I lost six stone while on steroids. I was being referred from one ‘ologist’ to another without getting answers. You cannot imagine how scary this gets.”

It was two years before she even saw a cancer nurse specialist and counselor through a cancer support network and was introduced to mindfulness.

Always a strong swimmer, Jean went back into the pool to build up her strength and to raise money for lung cancer research. She used mindfulness to keep her thoughts from straying and found the barriers to how far she could swim melting away.

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"I have found the swimming incredibly soothing – it energises me although it is a physical effort. I count the strokes and I am far more aware of what I am doing with my legs or arms and my breathing. Because of mindfulness and the concentration I have been able to break through most people's barrier. Each time I thought I could not do more, I just think I will push it another ten." She sometimes swims more than 300 lengths at a stretch raising money for the Roy Castle Foundation.

As a patient advocate Jean has now put mindfulness on the agenda of her local NHS Clinical Commissioning Group.

North America leads Europe in coverage. Linda Carlson has established Mindfulness-Based Stress Reduction courses at the Tom Baker Cancer Centre in Alberta, Canada, where she is director of research. In Europe, mindfulness for cancer patients is delivered in Cork and Dublin in Ireland,

and is increasingly popular in The Netherlands. Trish Bartley's course book is being translated into Spanish, French and Italian, and being adapted for use in Iran and India. She teaches courses in The Netherlands, Portugal, Belgium and Switzerland.

However, most cancer patients in Europe are never offered it. Trish Bartley would like to see referrals from general practitioners and through cancer centres: "It would be great if it was offered quite close to where they access support and treatment, because that would mean it was most likely to be picked up and known about, both by the professionals and by the patients. To get mindfulness into some sort of training in oncology and palliative care would be amazing and incredibly useful."

She and colleagues in Bangor and North West England are looking at setting up "low-dose" mindfulness courses for staff in hospices, to help

them with their own stress and potentially to benefit patients who may be nearing the end of life.

Sarah Bell, consultant in Palliative Medicine at the Garden House Hospice in Hertfordshire, England, is working with a colleague at Cambridge University to identify what research has been done on mindfulness in the hospice settings and has found very little outside North America. She supports the idea of shorter courses for patients and staff. However, those who fund services want to see evidence of effectiveness.

"Mindfulness in some guise in a modified course could be extremely useful for our patients receiving palliative care, and could be used in various forms, but there is no evidence that people are really using it and what we really need to do as a speciality is to start writing up what we are doing and try to get some evidence that it is benefiting our patients." ■



DEVELOPING THE EVIDENCE

The impact of mindfulness-based therapies on people with cancer is attracting a lot of research interest, but the evidence base is still quite limited.

- In 2013, the MINDSET trial led by Linda Carlson at the University of Calgary randomised 271 distressed survivors of breast cancer for mindfulness-based cancer recovery (MBCR), supportive-expressive group therapy (SET), or normal follow up (control group). Women who undertook MBCR showed the greatest reduction in stress symptoms and best quality of life. The women undertaking MBCR and SET both showed more stable cortisol levels than the control group. Researchers called for more investigation into the clinical implications (*JCO* 2013, 31:3119–26).
- The Australian National Health and Medical Research Council is funding a multi-centre trial of 190 men with metastatic prostate cancer who will receive mindfulness-based cognitive therapy or patient education to see the effect on levels of anxiety, depression and distress, quality of life and patient perceptions of outcomes (*BMC Cancer* 2013, 13:89).

- A 2013 review of studies conducted in November 2011 concluded that mindfulness-based stress reduction practice "shows a moderate to large positive effect size on the mental health of breast cancer patients and warrants further systematic investigation" (*Psycho-oncology* 22:1457–65).
- A 2011 review concluded "Mindfulness approaches are a promising intervention in cancer care, potentially across the cancer trajectory." Researchers recommended further research into different styles of mindfulness delivery (*Psycho-oncology* 20:681–697).
- In a 2010 study at the Helen Dowling Institute in Utrecht, The Netherlands, cancer survivors who undertook mindfulness-based cognitive group therapy showed significant improvements in fatigue and well-being (but not in functional impairment) compared with a control group (*Psycho-oncology* 21:264–272).
- A 2010 study from Australia of 115 cancer patients randomised to mindfulness-based cognitive therapy or a waiting list reported "clinically meaningful change" in depression, anxiety and distress (*J Consult Clin Psychol* 78:72–79).