

This is a pre-publication version of the following article: Campbell, M. & A. Bendijk. 2016. Post-traumatic growth and spirituality: Insights and experiences in and after high dependency intensive care stay and the role of mindfulness in recovery, *Transpersonal Psychology Review*, 18(2), 18-25.

Post-traumatic growth and spirituality

Maya Campbell in conversation with Anna Bendijk.

Maya has been recovering from a heart attack and coma, she shares some of her experiences of the period after she woke up, her recovery and her personal mindfulness practice and teaching since then.

At first we 'listen' to some of Maya's experiences from when she was in intensive care....

"I am running through a corridor I don't know where I am. My keepers are running behind me. There are so many turns, I don't know which one to take, I don't know my way out. I need to find a phone. ... all these corridors look the same, it's a maze, a labyrinth, they are going to get me, I need to keep running to find a way out and get help. I look down at myself and see pyjamas and slippers. The corridor is grey, walled and barren; institutional. People brush past me, vacant in gaze, not looking at me as I run past. I am too afraid to ask anyone the way out. I am lost."

"I don't know where I am..... I don't know who they are, I only know I need to get out of here. Suddenly I get to an open room that leads to doorways with sunshine outside. I hurry forward to the exit, a way out. As I look at the vista in front of me I freeze. I do not recognize anything. There are cars and ambulances and people and running children and immense moving images. I look forward and above to the buildings beyond. It is unfamiliar. I do not recognize anything: tall buildings, council blocks and lower level houses. Grey concrete. Sky above. I have never seen this before. Where am I? What had happened? I don't know where I am. I am afraid".

"I need to do something... I am lost, so lost... I turn around and walk back into the building. It is a hospital. I know this somehow. I finally see a public telephone booth on the wall. I rush over to use it so that I can call for help. When I pick up the receiver I am instructed for money. I have no money. My pyjamas have no pockets. Don't have any money. I have nothing. I don't know where I am. I can't call for help. I look around and see some chairs. There are people sitting on the chairs but I see a space. I sit down and I wait. I don't know what to do. I wait."

This is the first memory that I have that I know to be true, to be factual after awakening from the coma. There are other memories that are dreams or maybe factual or maybe a combination. But this is the memory that I would flash back to over and over again in the years after awakening from the coma. I had had a

cardiac arrest. I had been resuscitated and had spent near two months in a coma. The last thing I remembered was driving back from Oxford with the final proofs for the Nature paper, delivering them to the publisher and going to bed. Then the next moment I was running through hospital corridors. Lost. Alone. Scared.

When I was in ITU there were lots of tubes hooked up to machines around me, your veins collapse after you have been in ITU for a while and they have to use the veins in your neck to attach the tubes to. At one point during a time I had a delirium I pushed staff away from the bed and I pulled out the tube and the blood squirted out from the artery. I thought a vampire had bitten my neck, this led to many hallucinations and later dreams about vampires.

I was wary of the staff around me. In reality my keepers were registered mental health nurses who had been assigned to me after I had jumped through a window in an effort to get to a bomb to stop it going off and killing everyone. In my delirium they had become my prison keepers, following me everywhere even to have a shower. I thought I was in a prison that I had to escape from. A prison where they hooked me up to machines and experimented on me and made me take pills that I had no idea what they were for.

In the following years, I remember doing a cognitive puzzle, from a 'brain training program', this one was just digging yourself through a maze, it helped me with my directions I just got lost absolutely everywhere and I was hopeless. It just helped me and then I had this flashback with tunnels I guess I did spend time in the MRI scans.

That sounds like a truly confusing period after you woke up, a challenging time for re-integrating your experiences and disentangling the memories from before your heart attack and the experiences you had in hospital.

I realize now how much time it took me to remember things and events and to make sense of the world, of my vivid dreams of the people surrounding me, that they were not all vampires or criminals trying to make me take drugs, but hospital staff, nurses, doctors and allied staff. I had fragmented delusional memories, due to the brain hypoxia and the near 7 weeks I had been unconscious.

I don't feel it's a linear process; my actual experience after having the heart attack was I couldn't remember what had happened and then as I went forward I was trying to almost in my brain reconnect back to memories I couldn't access at the time. So I ended up feeling that my life was really disjointed.

The first time I looked at myself in the mirror, I didn't recognize myself at all. That was I had a bloated face, my hair was grey and stringy and when I combed through it with my hands I held clumps of hair ...I had a scar down one side and a scar down my other side that were red, my teeth were black and rotting in my head. I did not recognize myself at all and I was vastly overweight. That flashback I still have sometimes. I can feel it in my body, I can feel fear, I didn't understand how that person in the mirror was me.

All I could remember for a long time were the events that were highly emotional. Such as looking in the mirror; running through the hospital; being told what the year was – highly emotional as I thought it was the year 2000. I can't remember what I was thinking, I can only remember what I was feeling. And I was feeling afraid, lost, very confused, and very isolated.

These were your experiences in ITU, afterwards when you were discharged the process of healing started, how did that go for you?

I wanted to go home so I said I was not seeing things anymore. And it wasn't that bad, only a little bit at that time and I wasn't really delusional, only a little from time to time, like dipping into a dreamy state and waking up. It was really nice to be home. Thanks to my partner talking to me about Occam's razor: If everyone said that there was not something coming out of the wall and only I could see it, then logically, rationally what was the most probable reality? This helped me to understand when I was delusional and when realistic. I stopped believing the images coming out of the wall.

On the very first day I was set free I really, really wanted to get out and that was nice, my family and my partner came to bring me home and I went home in the car and everything was different; the shapes of the cars were different, the people's heads were different and everybody had this thing to their head called a phone, so strange, the shape of the ambulance had changed; they had gone square they used to be round. Nine years had not caught up with me I was being transported to the future, from the year 2000.

When I saw the psychiatrist he asked me what year it is and I said "2000", and then he said; "No it's not the year 2000, it is the year 2009". They were trying to be rational about things with me. "Why do you think it's the year 2000? How can it be that it is actually the year 2009?" he asked. I started answering and said I had been on a spaceship and I had been travelling at the speed of light so according to Einstein's theory of relativity there is time dilation which means that time would have gone slower for me while I had gone away. That was my rational answer... the psychiatrist didn't buy into that. Then I was asked what were you doing in the year 2000 and I answered I was a post doc in a physics laboratory, making crystals that make things invisible, he didn't believe that either. Why would he? To me that was like: "Had I imagined it? Was I dreaming my life?". What was real, what wasn't, nobody believed me. It made me so unsure of everything, I had the reality checks what was real and what wasn't but then there was also my memory, what was real and what wasn't real in my memory which has followed me ever since, because I *did* have brain hypoxia, I *did* have trauma and I *did* have distress and trying to untangle that has been extremely difficult.

My understanding is that the damage was done in the hippocampus, which has the access to long-term memories so part of the problem was accessing the memories. In the beginning I had difficulty accessing anything, including speaking.

There was a real gap in your memory which combined with your other experiences must have been a bit bewildering. Would you like to share what has been helpful in this period?

I haven't ever been antisocial throughout my life but definitely a bit introverted. I am now much more open and will approach people and talk to people. I spent the time when I had depression at home not connecting with people, being in the house and playing games online. Almost immediately after I left the hospital I found a place where I could do some volunteering and be with people. I just really felt the need to connect and I started in the office of the children's heart federation, helping out in the office.

When I was doing my PhD and later as post doc at Oxford, I was working in laser laboratories, very isolated, in very dark places where there was not much natural sunlight. I did talk with people but there wasn't a huge amount of interaction during the day, I often worked alone.

My life has changed for the better, but I might also be near the end. I am certainly happier! Although I am a bit teary right now, I am much happier and much more content than I had been for most of my life. The point when I realized that... I felt hope! Initially it was all doom and gloom, despair, hopelessness, but inside that there was something that had changed, from before the heart attack. I had been depressed before my heart attack and there was no drive in me to do anything about it, but afterwards there was this drive to do something about my situation. I remember that because when I was looking in the mirror and not recognizing myself, I decided that I was going to lose the weight, I started straight away in the hospital, walking up and down the ward, up and down and up and down with my keeper who sat there and watched me.

You seemed motivated to make changes. You also talked about connecting with people as part of you changing after your post traumatic stress period. Do you want to add anything to this?

When I stopped believing that I wasn't good enough, I started to change. When I truly believed it. My first thoughts were that I was at fault, that I perhaps didn't deserve to live. I mean, I failed. I had been in Oxford, I was at the brink of huge academic success and then I just stopped. That was a huge failure and to me that meant I was not deserving. Afterwards I did not work for nine years, I was dependent on somebody else. I mean I didn't see anything positive in that. When I stopped really believing that I was a failure.... I remember that somebody said to me: "Be kind for yourself Maya" and I asked, "Why? Why should I be kind to myself?" I remember that so clearly, it was very early on in my therapy with regards to the PTSD. When I stopped believing that I was useless, worthless, I was able to grow. That was a limiting belief that put me down and I now have different beliefs therefore now I can grow.

The limiting beliefs you had all your life did not help you and you were able to stop believing they were true. Is there anything in you as a person you think that might have contributed to your remarkable ability to deal with adversity?

I have no answers. I nearly died and came back a different person – even my mother says so. But to me I am the same person who loved to explore the world as a young child and discover how things worked. A person who as a teenager, was in awe of the universe and how life had come to be. A teenager who read Plato, Einstein and Descartes. In my admissions interview for Cambridge University Natural Science degree I talked about how the universe was formed; how different models of the universe held different ideas such as the multiverse, string theory, holographic universe. I was 17 and, although scientifically inclined, not a mathematics expert. But I could imagine the multiverse. I could see it. And I could imagine more than three dimensions. I could imagine the four relatively standard dimensions of Einstein's space and time four-dimensional space. And I could imagine how more dimensions could be rolled up or twisted into other dimensions. My curiosity has been integral in my recovery and hope.

I can now feel the joy and happiness of being alive. Rarely at first but with increasing frequency until each day I wake grateful to be alive and feel joy and wonder at being here on this marvellous planet with all the wonderful diverse beings it supports.

That sounds as if you have woken up in different ways...

People ask me whether I am religious or spiritual. I say yes to the spiritual bit, which I wouldn't have done before in my life, as I would have used the label of atheist, this has changed since the years of the heart attack. I am much more open to different possibilities of the order of the world if there is such a thing, how our universes formed, how we formed, how we construct our lives and what it means to be alive, and consciousness itself. I have much more sense of not feeling I am an 'I' or 'me', that there is a me in this body, but much more important is my connectedness with other people... by engaging with people I get a feeling of not being such a discreet unit and that there is more shared experiences going on between us. And that certainly is a huge change from my research days. I believe that really experienced long term meditators lose much more that sense of a fixed self. I still have a strong sense of self but there is more fluidity, there are more ways for me to feel, to think depending on situations or people. During my stay at a retreat, for example, I start to feel very connected to people, to feel their presence, in that connection there is a sharing, it is not so discreet.

I observed something different after the heart attack. I specifically seem to remember the exams for the Masters in Psychology. I was doing this about three years after the heart attack and it turned out to be a difficult traumatic experience almost because I had difficulty with my memory, we had essay topics in advance so at least I could prepare. I was trying to prepare an essay titled: *"The ethics of the researchers"* and I found myself very distressed about the subject of the essay. It triggered memories of Oxford (when I was a post-doc) and I found myself literally switching between very intently studying writing these essays and changing into someone who was jumping up, dancing around the room wanting to listen to music, wanting to meditate, having deep meaningful conversations with people, eating healthy foods, a really happy, very happy

person and then switching back... and this started to happen on an hourly basis, and also during the nights. I was awake all night, at which point I took myself to the doctor and then the hospital as I was experiencing chest pains as well. I got to see a cardiologist and a psychiatrist: that's when two aspects of myself really seemed to be separate, anxious, despairing, angry, and then there was a bit of me that was going ... "Oh this is interesting, what is going on here?". For me that was the observer which I had found in meditation that awareness that sort of curiosity, very much a sense of feeling, of knowing things rather than a thought that goes on. It's the direct sensory perception, not through the curtain of thoughts, nor the temptation of thoughts. ... but noticing my body and my senses, and sensing outside the body and also in a way sensing thoughts.

This concept of noticing your experience is at the core of practising mindfulness. You told me that you started to practice mindfulness and compassion only months after your discharge home. Which practices of mindfulness have been most helpful for you?

The concept of non-striving for example. Mindfulness as loosening up, unknotting different parts, this is what you do in mindfulness on a physical level. It can create more space in the brain, this literally means something as you get more access to other neuro-networks that are not just involved in that one focus that drives.

And coming back to the present moment. There are times when I can feel fear and anxiety and that is normally triggered by thoughts, if I got chest-pain or the heart is really erratic the thoughts come up that it could stop, that it could burst, and then I can get into that cycle where the thoughts are actually maintaining the emotions. I am sometimes afraid to experience my emotions as I can be afraid of this affecting my heart. If I am tired, if my resources are low, or if I am hurting it makes it more difficult not to get tied in with my thoughts, but even then I am able to step back from it. Because maintaining emotional regulations is very important in heart failure. People die from cardiac arrest through having autonomic nervous system storms. For me maintaining an equanimity is very important and being in the present moment.

How do you think that your illness influences your practice and vice versa?

People who live fully seem less afraid of dying, I met many heart patients who are afraid, really afraid, on the cardiac wards you can feel it, sense it. There is something about the heart that it is the centre of us and when it's failing what that means... you can also feel your heart, the arrhythmia and you can feel the emotions and the stress; the feedback loop is very strong. There is a strong correlation between depression and mortality for people with heart-failure. Current research shows that meditation strongly activates the parasympathetic nervous system; the rest and restore state of the body, or in other words our natural soothing state. The state when we are not doing something or not trying to achieve something, or when we are trying to quiet things when we are under threat. This counts for a lot of us, nowadays we are living very stressful lives. Being able to activate this rest and restore system is very helpful. The body can only heal when it is in its restore system, when the parasympathetic system is

activated. Which is why when we are stressed we often get ill. Sleeping doesn't put you into that system, only a little bit. You actually need to really rest. Meditation and compassion is activating that system very strongly.

Just by being in the present moment we are stepping out of the threat system that is a better place to be. A step further is doing compassion practices. We are actually doing something, we are cultivating positive emotions, compassion, kindness, love, care, soothing and these are activating the parasympathetic nervous system and then we are in a state of rest and restore. So the practices are different and you are training different things while doing them and as a teacher you have to be aware that these practices are different as in the beginning you can get a bit confused. So I found my compassion practices help me, making me feel better also simply resting and the positivity helps me maintaining my mood although it is a combination of everything....

You mention positivity and intentions?

When I mention positive thoughts I do not exactly mean positive thoughts about myself, it is training an inclination in the mind towards kindness and compassion, not just to myself but also to other people, it is not thoughts like 'be happy', or commands like that, it is training intentions, we could call those wishes if we like but really they are intentions to be kind or compassionate and this actually then signals to the brain an intentional focus that the mind is wishing the brain to move towards and it is this which is creating the new neural pathways in the brain which are making the changes, I believe. When I do mindfulness practices or compassion practices I must be aware of the intentions behind what I am doing. I believe that is really where the power comes from. And doing the loving kindness practice with that intention will then start to build up some density in our pathways to make a difference. If you imagine I had nearly 50 years of thinking in a certain way I had to build up a bit of umpf behind my intentions.

When teaching it is important to cultivate the intention to bring our heart into our practice, would you like to say something about that?

I have a deep heartfelt desire to help others. The intention is also bodily, it is a felt wish I want to be aware and present in this moment all the time and I am using the breath for it. Not to be aware of the breath as such, because if you focus solely on the breath it can be a relaxation technique, not a mindfulness practice. When you have an intention, bringing in the attitude of kindness and compassion and non-judgmentalness, this is the core of the mindfulness training. As this is then allowing you to accept things and others as they are, instead of either wishing things away or trying to hang on to them. You have to have the pathways of compassion installed, originally mindfulness and compassion were taught together. I do wonder why Jon Kabat-Zinn left it out as an explicit practice, maybe because it was implicitly taught by the mindfulness teachers.

Ending our conversations with a meditation practice.....

Sitting in a park in London, the warm sun on my skin, an oasis in the middle of a hustling city..... I can feel a warm sensation spreading through my body, up and around and down my body, the muscles are relaxed, the mind is quiet, then I started meditating, I was doing a compassion practice... the experience was pleasant. It is a practice that cultivates positive meanings, positive intentions based on compassion and loving-kindness practices. Now it was very much a practice of where I am, sitting here the people around me the trees the birds, the practice is about setting intentions about setting the mind in a direction to generate positive emotions basically, it's a generative practice. *Clouds in front of the sun, wind picking up* Bit of coolness, my mind is labelling it as missing the warmth, I recognize the tendency to cling on to nice sensations... yesterday it was flooding in London... the weather is very changeable.

Everything changes.

In April 2009 I had a major heart attack and within minutes a cardiac arrest, I was resuscitated after 25 minutes and taken to hospital where I remained in a coma for nearly two months. The lack of oxygen during the arrest resulted in brain hypoxia.

I experienced Post traumatic stress from the ITU and the brain hypoxia. After release from hospital I took part in a cardiac rehab class to learn how to cope with heart disease. This helped me to start exercising and keep the heart healthy and helped me start to engage again with people.

By the end of 2009 I got to the GP who got me into services. I got an 8-week CBT based intervention, which helped me to stop using drinking as a coping strategy, and then I got referred for therapy with regards to my traumatic experiences in the ITU. I had 20 sessions of trauma focused CBT with regards to the cardiac arrest; the focus was on the delusional state I had been in. The nightmares and night terrors that went on for years stopped after the sessions of CBT. I also started the mindfulness classes and started to meditate.

Nine years before my heart attack, I had worked as a postdoc in Oxford physics laboratory to research the fabrication of photonic crystals for the visible spectrum by holographic lithography. After my heart attack I did a Masters in Psychology and started to get involved in Mindfulness & Compassion practice and teaching.

Growing up I was a science fiction fan, and I was a very inquisitive child. My father was a science teacher and we built some interesting things like a telescope to watch the moon, and made crystals. My mother is an artist and was an art-teacher. I think as a child the exposure to so much visual stimuli has helped me to access the visual abilities of my mind. The content of my hallucinations therefore (e.g. about the moon 'Titan', the glaciers, vampires etc.) didn't surprise me.

Further Reading

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