

MASTERING YOUR EMOTIONS DURING CANCER

A Hands On Approach
For Cancer Patients And Their Supporters

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Joe: Hey, this Joe Bakhmoutski and welcome to Simplify Cancer Podcast. When you're dealing with cancer, maybe you've just been diagnosed, or maybe you're going through treatment, or maybe it's someone you love and you're trying to get through it together. Whatever the case may be, you're on this crazy rollercoaster of emotions and feelings that are hard to put into words. You're under attack on so many levels, and there is so much at stake that you need to do some work to get it under control, to get it to a point where you want it to be. That's what Jill and I are talking about today, practical ways to take charge of your life as you tackle cancer on every level, through every twist and turn because you need to win, and you want to do it on your terms. Hi Jill, I'm really excited for us to be doing this again.

Jill: Thanks, Joe, I'm pleased to be here.

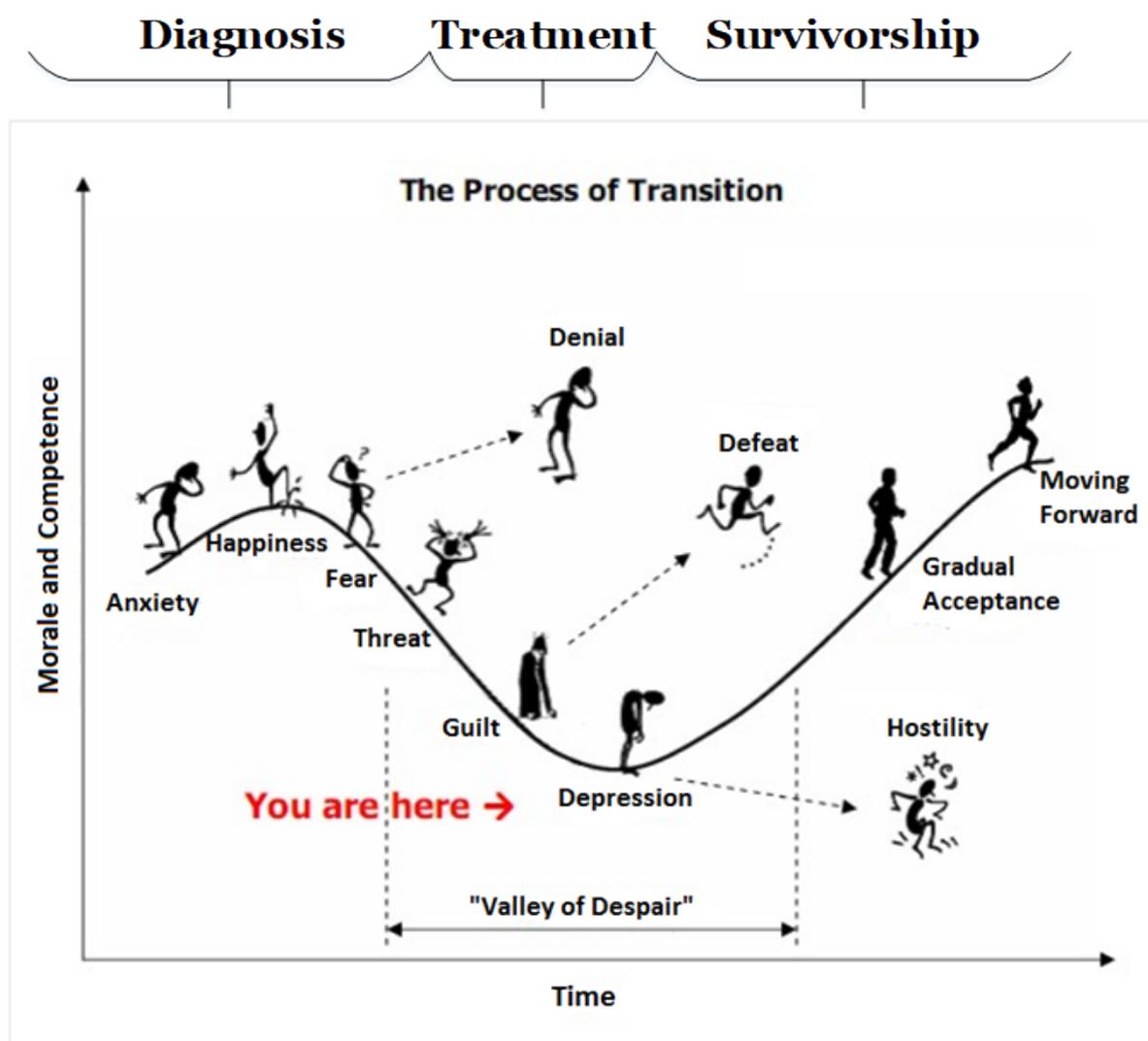
Joe: That's fantastic. Jill, I thought we could talk about a couple of things today and maybe we can start to talk about some of the phases that you go through emotionally, when you transition across the cancer continuum, when you go from your diagnosis and treatment and survivorship. How do you go through these emotions, the whole range of it? How do we deal with them? Should we start looking at our diagram here?

Jill: Yes. A diagram that I quite often refer to is called the Valley of Despair. There's been a lot of research by well-regarded people and it's the process of transition of your emotions starting off. It becomes like a rollercoaster ride, anxiety, happiness, fear, threat, guilt, depression, hostility, gradual acceptance, and then moving forward. More importantly, how does that then relate back your cancer continuum? When you're just prior to your first session and your diagnosis, you've got anxiety, you know something's not quite right, you're worried about the future, so anxiety builds with the fear of the unknown. It's like, what's going to happen to me? How do I deal with this? What if? The way to deal with your anxiety is bring yourself back to the moment, the present time. Don't dwell on what's happened in the past, because that's what we base our experiences on, what's happened in the past.

We know what's happening at the present time and none of us can dictate what's happening in the future. That's where anxiety lives, it's around that future state. The anxiety and the worry that you have, oh my goodness, I'm going to my oncologist, what are they going to tell me? I've just had tests, I know something's wrong, what if? It's going through that stressful time before you actually have your initial diagnosis.

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Then you get to the point where, okay, I've been to the oncologist, I have been diagnosed with cancer, but you know, you've got a definite thing that you can associate with. It's like, yes, I have cancer. In a way, you're sad that you've got cancer, but you're happy that you've got a diagnosis. That fear of the unknown now has a name to it. That's coming through your diagnosis, as well.



Joe: I'll just swiftly jump in there, Jill. I think also the happiness can be associated with maybe an initial treatment, like in my case, I know I had an operation for testicular cancer, to remove a testicle. I was told the cancer is gone. I thought, I'm on top of the world, fantastic, I can move on with my life. Little did I know that three months later, it actually turned out that the cancer had spread and so yes, it was like you said, like a rollercoaster.

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Jill: Yes. That's what the whole process is, it's never just a straight continuum, like you're faced with different experiences along the way. That's where you need to tune into what's actually happening, be aware of how you're feeling. It's okay to say, "I feel..." Putting a name to your feelings helps you deal with them. It's like, I know when Sam was first diagnosed, we knew that with Sam's prostate cancer, he was having trouble going to the toilet, going and urinating. We didn't know whether it was kidneys, we didn't know if it was prostate, we didn't know whether it was obesity.

We didn't know what it was. It was like that anxiety, what happens if I can't wee anymore? It's like... When he went off to the oncologist and had all of his tests and it came back that, yes, you've got prostate cancer. Okay, so now we know what's going on, he went in and had his biopsy, and they identified where it was in the prostate. Then they put a plan together and it was like, okay, we're taking control of this again. That happiness comes in there. Then you move really quickly back from the happiness to the fear. Yes, I do have cancer. I have a plan in place, but what if, what happens when? Quite often, you spin off into, no, this isn't happening to me, this is not real, maybe they've got it wrong. Seeking those opinions of others, having trust in your oncologist, having trust in your family. That's bringing all of that back in.

Joe: Yes, exactly. As you say, you start questioning yourself, you start saying things like what have I done to deserve this? Why is it happening to me? What's going to happen if I die? What about my partner? What about my family? What am I leaving behind? What's my legacy?

Jill: Exactly. What happens to my partner, my child? What have I done to make a difference in this world? What am I leaving behind? What will I be remembered as? A good, honest person that's been kind and loving and caring, or a person that's got cancer, that's been totally consumed by everything. Then you start to have your choices again. Then you start to bargain. It's like, well, if I do this, maybe it'll all go away. I know, and I look back and smile, when same was first diagnosed, it was like, yes, we did seek other tests, other opinions, and then it was like, okay, if Sam drinks pomegranate juice maybe this will go away.

If we eat more meals with cabbage in it, maybe this will go away. You start to do this whole bargaining thing. Looking back, we were so caught up in that, that it was consuming, because we thought, if we do this, maybe everything will be okay, rather than just having the trust and the confidence. Yes, you do have to have your action plan there.

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Joe: It's the guilt, isn't it?

Jill: It is, yes.

Joe: It's the guilt that you did something wrong that cancer might be happening for a reason, whereas, the truth is, it's a lottery, we know, the research tells us that it's completely random, but we feel guilty about not leading the right lifestyle, not making better decisions along the way, not having done enough in terms of what we talked about, legacy, in terms of being present, in terms of your career and whatever, that all of this guilt just suddenly comes up, doesn't it? It just takes over.

Jill: It does. It can be quite consuming. It can take over your life, that whole guilt feeling, that, was it because I was mean to a kid at school when I was at high school? Is it because I haven't spoken and am I now being punished? Is it because my wife and I argue, and this is a way that the greater being is showing me and bringing me back to be a good person. It's going through that whole guilt. If you allow that to take over, you actually feel defeated. That's not good for anybody, mentally or physically. When a person has cancer, feeling defeated means that you're giving the control to the cancer.

That will take over your body, that will define who you are: I am the person with cancer. It's not hiding from it, but it's not being defeated by it. Have that fighting spirit. It does that you a little while. It took Sam a while not to feel defeated. You do become introspective, you do go through depression. I saw Sam change from a happy go lucky person who always had his own opinions, to being a person that just wanted to sit on the couch and do nothing, he wanted to sleep. I recognised that that wasn't normal behaviour for him. Once again, we went off to the doctor and Sam was diagnosed with depression. That took a toll. It was like I'd lost my life partner.

Yes, he now had cancer, but he had disappeared. It was like, that's hard to deal with, from a support person, as a lifelong partner. It was like, I want that person back. You then, as a support person, put in a lot of extra energy to make sure that the person that's being diagnosed is getting the best care and the best treatment available. You're always on that watch. I'm forever vigilant, even now, even Sam's into the survivorship part of the continuum, but I'm forever vigilant, making sure that is he okay? It's quite draining from a carer's point of view, as well.

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Joe: Yes, then we talked about depression and that was probably the really lowest point of this valley of despair. Guilt is there, as well, all of these really negative emotions that bring you down. Jill, one of the things that really helped me, and this probably happened somewhere when I actually started treatment, for example, when I was on my chemotherapy, what really hit home for me was one day, I feel like I accepted cancer, it sounds so ridiculous when I say it. Obviously, it's happening. I think I was in denial.

I think that's why a lot of these conflicting emotions were coming up for me, things like guilt and being threatened and fear, it's because I didn't really acknowledge it, I didn't really deal with it. When I finally realised, yes, it's happening, it's here, it's not part of it. It's almost like another being, that's almost next to me. That's how it helped me to put it aside and say, "Well, yes, cancer is here but it's not inside me, it's here on the side." That kind of helped me a little bit to come out of this really negative space and to come out of it and try to actually deal with it in a proactive way.

Jill: Yes, definitely. It's acknowledging, not letting cancer define who you are, but acknowledging, yes, it's there. Once you actually give it a name, you can then determine what you're going to do with it. By avoiding that whole situation of no, I'm in denial, it's not really happening to me, you're avoiding what the issue really is. Yes, you do have cancer. Then it's like, what are we going to do about? Once you've defined it and acknowledged that it exists, don't let it take over who you are as a person. Yes, it'll take over your life for a little while, while you're going through all of your treatment and stuff like that, but don't let it define who you are. You're still your authentic self. That's what you need to stay true to, rather than being something or somebody that you're not.

Joe: Jill, just talking about looking at all of these stages. We talk about the person that's going through cancer diagnosis, through treatment, and obviously linked to survivorship. In terms of your perspective, as the partner, was this a similar journey, or how was it different for you, because you obviously had to support Sam through it? What was that experience like?

Jill: For me, as a carer, I went through all of those range of emotions, as well. Right from when we knew something was wrong, before the diagnosis, I was worried, what is it. That anxiety. We all have, especially if you've got a lifelong partner, you've got your life plan. Yes, I'm going to get married, have kids, experience things with my partner and live a long and productive life. When something

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happens and goes wrong, I started to think, is my life plan changing? It's like, you have to rethink, not just Sam, who he was and what he was dealing with.

What does that mean to me? Am I going to lose my lifelong partner? Is my life plan going to change? The anxiety there, and that still happens, especially when Sam comes up to his regular check-ups, it's like, is it going to be okay? That anxiety. This rollercoaster ride just doesn't go in one direction. You can go backwards and forwards, depending on what's happening in your life. Then once Sam went to the oncologist and was diagnosed, I was happy that he was doing something about it. Then it comes back it.

Oh my goodness, what are we going to do? That fear of the unknown again and then feeling a threat. Yes, my partner might be taken away from me. I didn't go into depression. The way I deal with it is to define it, have an action plan, then I feel like I'm in control. I had my plan, my plan a was to be with Sam as my lifelong partner. I had to think about what my plan B might be. I then had to consider, what if he's not in my life? Would I survive? Thinking about that. Yes, I did go through denial, no, this is not happening. If we go on a holiday, maybe we'll forget about this. I don't think I ever got to the point of feeling defeated, because I was determined I was going to do everything possible to, one, help Sam get through it, and two, help me get through it. If I ended up being defeated, I wouldn't be able to support Sam. That's a fine line on your emotions. You just have to keep it in check.

You just have to acknowledge that that may occur but keep it in check. Hostility. Yes, I was really angry. I was like, why is this happening to us? We're not bad people. In the world as a whole, there are some bad people out there, why wasn't it them? I was really angry. Why did it happen to us? We've got family, friends, work colleagues, why was this happening to us? It's like, jeez, what are we going to do about it? The way we dealt with that was talking to people, that communication with the people around you, and then we found that they became supporters of both Sam and I. Our friends and family would do regular checks, how are you going?

Are you okay? Is there anything that we can do for you? Having that network helped us along the way, which then took us into gradual acceptance. Sam was diagnosed with prostate cancer quite a while ago. He has had treatment. His last check, which was over a year ago, he was travelling really well. The cancer had shrunk to a minute section and it hadn't spread. It was like, okay, his prognosis was good. His life expectancy was going back up, which then

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gave us hope that there may be a future. Now, Sam's coming up to his check-up again. I've gone back to feeling anxious about it. The anxiety. What happens if something changes.

There's always that fear of the unknown, but I know once he goes in and he gets the results of his tests, we'll then be able to put our action plan back in place and keep moving forward. Always moving forward. Sometimes you get so overwhelmed by: I have cancer, my partner has cancer, that you feel like you're marking time, that you feel like the whole world is stopping around you. By acknowledging that it exists, having plans, having your support network around you, both you and your partner, the carer, you feel like you've got way forward.

Joe: Also, I want to come back to something we touched on earlier, Jill, about looking at yourself and thinking about your future life and how that looks like, because for me, that's definitely changed. I think in a more positive way. If we talk about the other end of the spectrum, where we talk about moving forward, I think that's helped me to deal with these check-ups and the unknown that comes with that, was finding new meaning in things, or having different things, for example, working on this podcast. Writing. All of those things give me an additional meaning and a new direction that really fuels my perspective with something different. Did you have a similar experience?

Jill: Very. Exactly. It's like looking for the positive in everything that we do. Yes, there's a positive and negative. There's that balance. Rather than dwelling on the negative, with everything, enjoy the moment that you're in, enjoy the experiences that you're having. Yes, you're going to have challenges along the way, but change your perspective, like you mentioned, on how you feel about things, how you view situations.

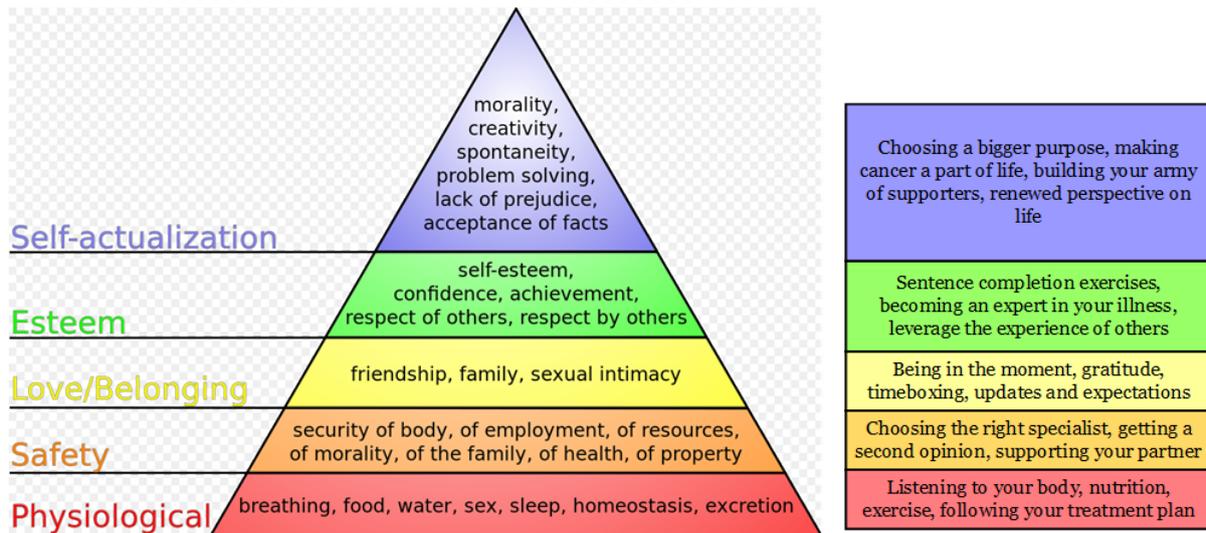
Think about where you want to put your energy. Do you want to put your energy into being sad and angry? Or do you want to put your energy into something that you can actually physically do? Enjoy the people that you're with, because we've all got a lifelong plan, life's finite, take the moments that you're in and make the most of them. If your child smiles, be happy about that. If your wife achieves something, be happy for her. With Sam, I get enjoyment out of little steps forward that I can see him making.

For me, personally, I've gone off and I've done studying. I've achieved. Sam supported me in that. Changing that perspective. Feeling like you're back in

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control of things, rather than saying, "There's nothing I can do about this." That whole perspective, be in the moment. Enjoy what's going on, change your perception of what's happening around you. Have that situational awareness.

Joe: That's fantastic, Jill. I think this is a perfect lead into talking about addressing those needs that you have across the spectrum of Maslow's Hierarchy. Do you want to give us an overview of what that is and then we'll probably dive into each stage and talk about some specific tactics to deal with it?



Jill: Maslow's Hierarchy of needs, and it's formed in the base of a pyramid or a triangle. The base is physiological. The next step up is safety. The next step up is love and belonging. The next step up is esteem. The top of the pyramid is self-actualisation. Going right back down to the bottom physiological, that covers off breathing, food, water, sex, sleep, homeostats, and excretion. When you're at pre-diagnosis stage, you need to listen to your body, what is your body telling you? Something is different in one of these areas. The hierarchy of needs is starting to be threatened at the foundational level. As we all know, if a house doesn't have strong foundations, the house doesn't stand. Look at your nutrition, your exercise, follow-up, get those opinions, get your diagnosis happening, look at what your treatment plan is.

Joe: Also, into that, that one of the things that really affected me, even after the diagnosis was that all of a sudden, every single thing, every little symptom in your mind is now about cancer. Headache, is that a tumour in my brain? All of a sudden, and again, this came back to taking those questions and looking at them objectively. How I would do it in practical terms is the exercise that I call: The outcome map. I literally take out a piece of paper and I draw out whatever

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that symptom is, and I write down that the options are and the likelihood against each. That makes it real for me.

Okay, now I can look at it objectively because it's now out on paper and say, yes, you know, I'm probably completely exaggerating this. If in another case, if I think, well, actually, yes, this could be related to cancer, or it may be something else that needs attention, then I take that, and I make a decision right there. Then to go and see my GP or writing down a list of questions for my next oncologist appointment or asking an oncology nurse. All of those things, monitoring yourself and getting in touch with yourself, allow you to go back to a position where you feel threatened on a most basic level, to actually trying to have an action plan.

Jill: Exactly. In project management, there's a term called: Risk management. It's identifying the risks, all the things that could go wrong. This helps you overcome your anxiety, as well. If you can list down all of the things that you're thinking about that might happen in the future, you can then end up with a mitigation. If this happens, then I can do this. Once again, it's taking control, it's having that plan, having a way forward with all of this. It comes down to the safety, which is the next rung on Maslow's Hierarchy of Needs.

It's around the security of body, of employment, of resources, of morality, of the family, of health and property. Doing that whole risk management, what happens if this happens to my body, what happens if this happens to my job? What happens if we don't have the money to have our house? What happens if I become mean and angry? My morality. What happens to my family? What happens to my health? What happens to the property that I have? It's all about that action plan, choosing the right specialist, getting a second opinion, if necessary. Letting your work know.

Supporting your partner. Letting your friends know that you're going through this, so that your support network becomes a safety shield around you, that you can actually start to deal with some of this, but also be mindful that your carer is going through this, as well, so supporting your partner both ways.

Joe: Yes, absolutely. I think you mentioned having your circle of people in your life, those people who truly care for you and support you. That's definitely one of the things about it, is being transparent about what you're going through, both as the person if you have cancer, or if you're the partner of someone with cancer. It's really important to open up and say, "Yes, this cancer this is driving

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me crazy. Yes, I really have no idea what's going to happen and I'm afraid." Saying, "I need help with this. I need help with getting to the hospital. I need help with doing the groceries. I just want to have a conversation about normal stuff."

Jill: Come and have a cup of coffee with me.

Joe: Sometimes, we talked about this before, that sometimes people are afraid to say the wrong thing or do the wrong thing.

Jill: They don't know how to talk to people with cancer.

Joe: Yes, exactly.

Jill: They don't know what to say, so some people will back away. You might lose friends that you had for a long time, not because you've been a bad person, it's because they don't know how to deal with it. This comes to the next rung on Maslow's Hierarchy of Needs, love and belonging, which is friendship, family, and sexual intimacy. Now, when Sam was diagnosed with cancer, we had adult children. We sat them all down and we discussed all of this. They have been an amazing support.

Sam didn't feel alienated from the family, he felt supported. My kids have helped me come to terms with the rollercoaster of the emotions, because it is. I know that I can speak to them and they'll say, "What do you need? Come and have a cup of coffee with me, mum. Dad, how are you going?" We also spoke to our wider circle of friends. Making them aware of what was going on, letting people know that, yes, you are afraid but you're not going to be defined by it. Sexual intimacy.

A lot of people would sit and say, "I've got cancer, I cannot come close to you." That's not what it's all about. It's about being in the moment with the person, enjoy that special hug, they're still who they were before, it's just that they've got a diagnosis of cancer. Have that gratitude of who that person is. They haven't changed, willingly, they're still your lifelong partner. Time box what's going on, is this going to continue forever? Understanding that then you can deal with it, and provide updates for your family and friends, and help manage expectations, especially from a carer's point of view, managing expectations of what did Sam think I was going to do to support him?

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It's like, well, I can do this, this, and this, but I need help in these aspects of our life. It's calling out for that, and it's having that gratitude of that support network that's around you. You're not in this on your own.

Joe: Exactly. Being in the moment I think is a phrase that gets thrown around a lot these days. I think it's a really tangible and practical thing, it's not thinking about something else when you're talking to your partner, you're actually listening then, you're having a conversation and not thinking, what are we going to have for dinner? If you're with a friend, he's talking to them about what's going on in their life and not thinking about whatever it is that you have going on about the game you're going to watch or something.

Being in the moment really is about, I'm with this person right now, I'm not thinking about doing the groceries later, or watching a movie or what am I going to do tomorrow? It's really being in that moment right now, listening to where they are, saying where you're at. Really, that's what being in the moment is for me. Also, I know there is all this stuff about mindfulness, all this stuff about being mindful of where you are in the moment, one of the things that I've really discovered that was a surprise for me, really, mindfulness is about observing your own internal state.

If, for example, you go through this rollercoaster of emotions that we talked about, going through being anxious or feeling guilty or threatened. What's really helped me is to go, not to push it away and not to say, no, it's not happening, but to say, do you know what? I am scared. Let me just feel how does it feel in my body. I can feel that I'm fidgety, I'm not myself. Letting that sink in, letting that feeling go through has really helped me settle it down, almost on a physiological level, you know?

Jill: That's exactly right. A lot of people aren't in tune with their emotions. A lot of people try to suppress their emotions, acknowledging that it is okay to say, "I'm scared. I'm afraid." Being in the moment with that person, doing that whole mindfulness aspect helps combat anxiety, because that mindfulness and being in the moment, it brings you back to the present, not what will happen in the future. The future we've got no control over yet. The present we have control over. Being in the moment, mindfulness combats anxiety and it also helps you to pick up on things that you may have missed, if you're worrying about doing the groceries later, it helps you look at the person that you're with, to see how they're going? You share extra special moments by doing this, that you might have just skipped over. It's like, that's what creates that strong bond.

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It doesn't have to be with your partner or your loved one, it can be with your kids, it could be with your friends, it could be with your work colleagues. Being in the moment, enjoy what they're doing, participate. Working through it together, which takes you up to the next level in Maslow's Hierarchy of Needs, esteem. This is around self-esteem, confidence, achievement, respect of others, and respect by others. Mindfulness and being in the moment helps you with the confidence to know what you're doing at that particular point in time.

You might not know tomorrow, but you know what you're doing right then, you're getting that sense of achievement that you can do something right now. Your partner or your carer is going to help you do that. They're validating that you're a worthy person, so that your self-esteem will start to improve.

Joe: One of the ways to do that, I've spent a bit of time looking at the work of Nathaniel Brandon, the world's expert on self-esteem, one of his things is about doing sentence completion exercise. Having what he calls a sentence stem, so something like if I get five percent better at being more present in the moment, then you finish up with whatever comes up next for you, you end up with some really surprising results. If I spend five percent more time on doing the things I really care about, then... and you come up with all the answers you need to really feel like you're more in control, that you deserve happiness, that you deserve the life you want to have.

Jill: Exactly. It's empowering, isn't it?

Joe: Yes, absolutely.

Jill: Having that sense of achievement that I deserve this, I can do this, it's like you then show other people that you're not going to be dictated to by the cancer. They give you respect. You're taking control of your own life and your destiny. Once they show you the respect, you've got immense respect for them as individuals. It's that mutual collaboration. Definitely identify that if I do this, that this can happen. Sam and I had to sit and go: If this happens, then we can do that. It comes back to that risk management again and that mitigation, if this happens, then we can do this. It's having that control, the confidence that you will know that in the future, if something crazy does happen, you've got the plan there to deal with it.

Joe: Exactly. That, to me, Jill, is also about becoming an expert on your own illness. If you understand exactly what's going on, every step of the way, what are the possible options? What would happen if this test comes back positive or

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negative? What would happen then? It gives you confidence in that you know what the next steps are, it gives you the capability to ask the right questions of your specialist. It gives you a sense of being in control.

Jill: That's correct. It's like leverage the experience of others. It's very important to understand what cancer is, what cancer can do to you, physically and emotionally, what cancer can do to your support network. Find out as much information as possible, because then that means you're in control of it. Leverage the information that you get from your specialist, your oncologist. They're the one to deal with this day in, day out. This is the first time that you're dealing with it. Leverage their experience.

It's being prepared for the positive and the negative and then that helps you move forward. It's taking you to the top of Maslow's Hierarchy of Needs, the top of the pyramid, your morality, your creativity, problem-solving, your lack of prejudice, acceptance of the facts. If you can do those, you've achieved self-actualisation. You know who you are, where you are, and what you can do about things. Choosing your bigger purpose, don't let cancer define who you are, you're still an individual. You're still your authentic self. You've got to make cancer a part of your life, but not be consumed by it. It's building your army of supporters around you and then you'll have a renewed perspective of life. Look at the little things.

They are the things that make the difference, be in the moment. Look for those positive experiences. Learn and grow from the negative experiences but accept that they're all part of this. Know who you are and how you're going to deal with things. It's very scary. It really is, but once you come to terms with all of that, going through your diagnosis, your treatment, and your survivorship, you're armed with what you'll need as you go through that rollercoaster of emotions. I'm not saying that it's all going to be smooth sailing and it's all going to be in the same positive direction. Sometimes you'll have setbacks, but knowing who you can call on, going through all those hierarchy of needs. Where have you been taken to at that particular point in time? What do you need to do to mitigate that risk?

Joe: That's fantastic, Jill. Thank you so much.

Jill: That's okay, it's been a pleasure, Joe.

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Joe

My name is Joe and for me, cancer was always something that happens to somebody else - until it lands on you.

That's why it's such a shock - everything is up in the air and it's a big mental effort to pull yourself together and get on with life despite cancer.

Losing my testicle, chemo and procedure hammers home what I always knew, but was never forced to confront in a real, tangible way - how fragile and short life is and how I need to make the most of it, on my terms.



Joe Bakhmoutski

Founder of Simplify Cancer

www.simplifycancer.com