



**Mood Disorders** Society of Canada  
Société pour **les troubles de l'humeur** du Canada

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What  
better  
feels like

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**Answers from people  
who have  
experienced depression**

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With special thanks to interviewees:

**Anne**

**Chris**

**David**

**Deanna**

**Heather**

**John L**

**John S**

**Lori**

**Lucy**

**Nancy**

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## Introduction

Just like it is important to recognize the signs and symptoms of depression so people will seek treatment, it is also important to recognize the signs of recovery – what *better* feels like.



Hopelessness is a central symptom of depression and when in the midst of an episode, it is hard for people to believe that one day the darkness will lift and they will get better.

What *better* feels like uses the words of people who have “been there” – experienced depression and come out the other side. They answer questions like what is depression like? What are the signs of getting better? What helped and what didn’t? And what does *better* feel like?

## The interviewees

Ten people from across the country agreed to be interviewed about their depression and their journey to *better*. All had experienced at least one major depressive episode with many having recurring bouts. While each voice is unique, their experiences had striking similarities. The report that follows is their collective story.

## The questionnaire

Each interviewee received the questions in advance so they could reflect upon what their answers would be. Interviewees often remarked that they found the questions to be challenging. People said that they had to really think about their answers. All felt that they had been made to think – in a good way. And all were pleased to be able to contribute. Refer to the **Appendix** for the questionnaire.



## The answers

While the research focused on the answer to the question, what *better* feels like, the questionnaire covered a number of topics – as did the interviewees who did not feel at all constrained by the format and talked about their experiences in whatever ways they wished. The report, therefore, is organized around the themes that emerged from their answers, some of which follow the questions asked and some of which do not.

## This document

This “Answers” document stays true to the voices of the interviewees. It is comprised of what they said, exactly, rather than weaving a narrative out of a summary of the points they wanted readers to understand. This way, their personalities, their passions and their sage advice is in their own words.



## Introducing the interviewees



The following quotes did not fit easily into the themes that arose from the research but they are valuable because these snippets tell you a little bit about who each interviewee is – as a person – and a lot about what they believe in.

**Anne:** “A really important thing for me has been involvement with the activity centre funded by our province. The slogan of our centre is “we’re better when we’re together” and that is really true. When you are depressed it is easy to feel like you are all alone and the whole world is against you. When you get mental health services you feel like you are being judged or rejected by others for a while. Activity centres give you a place to go, a routine to follow if you want it, and people who are welcoming to you every time you show up. Activity centres also help people find things they are interested in like new hobbies. That provides a lot of satisfaction in times when things feel pretty hopeless.”

**Chris:** “I have been hesitant to engage with professional caregivers. I am not helpless. I have most always been employed. I’m not poor so I don’t look like the stereotype of mental illness. And there is part of me that says, “Come on. Why are you struggling? This is just selfish.” So it has been a challenge to be honest with my psychiatrist. I keep asking myself, can I be real and honest? Can I

be vulnerable? How do I stop feeling guilty for the imperfections? So, the relationship has to be safe. And I don’t want the heavy label of ‘mental illness.’ I asked my psychiatrist if she thought I was mentally ill, and she said that she thought that I struggle with depression. I liked that. She was saying, you’re a person who struggles with illness. You’re not the illness itself.”

**David:** “I would like to say to people who are having my experience that the way you are feeling is not reality. Depression fools you into thinking things are a whole lot worse than they are. It tricks you. When you think you should be going out, it says stay home – sleep, or drink or veg in front of the TV. There is a very good chance that you should be going out just like you thought and not listening to ‘depression.’ There is hope. There is care. There is therapy and support. And there is medication that can help.”



**Deanna:** “The waiting lists for mental health care in this province are atrocious. You can get people back to productivity if they get help quickly. My husband is an introverted person and if there was a dispute over some service or other, I was always the one to deal with it. With this situation, he really came out of his shell. He’d tell people, ‘I can get her help right away at a hospital for \$2000.00 per day’ and ‘you can’t find a psychiatrist in the community for \$100 a week?’ We live in Toronto. I was in the perfect spot – if ever there was one – and I couldn’t get care. It made me even more depressed, but it made him really angry, so much so that that is the only time I have heard him yell at someone on the phone. After I left Mount Sinai, and when I was able, I went back to the administrator and told her about the great care I had received as an inpatient but I told her, ‘You suck at sending people out into the community and that is not acceptable.’”

**Heather:** “My number one ingredient is quality counselling support. The key word here is quality. Counsellors can have very different approaches and that needs to be tailored to what I need. Secondly, peer support is essential. There is no substitute for connecting with people with lived experience. Thirdly, for me is the extensive use of self-help resources especially books, magazines, and websites. I am a voracious reader. Reading or even re-reading facts and

information about depression allows me to comprehend something that I might have missed the first time I read it. This information helps me more fully understand my own experiences. Fourthly, it is crucial to build myself physically. Regular exercise is very important. Additionally, regular quality sleep is a very significant ingredient to my recovery. Meditation and mindfulness are highly helpful in my personal recovery. I feel so much better with regular social interaction and avoiding isolation.”

**John L:** “I was one of the founding members of the Moncton Hard of Hearing Group. Four people worked together to establish it and I was one. I was born with moderate hearing loss and I didn’t have decent hearing aids until my mid-thirties. There was tremendous support through that organization and the accomplishment of starting it was important to me. One year, we organized a conference (with my wife and others). The Governor General opened it and there were all kinds of other very positive things. It was an important achievement for me.”

**John S:** “People have control over their own destiny. Others may tell us what’s right and what’s wrong with our care but, if we don’t speak up, we will get what we deserve. You have got to be a partner in your own recovery or the doctors are left to do what they think is best. They don’t have time. They have a few



minutes to hear you, make a diagnosis and get you out the door. It's not their fault that what they have on their mind the last drug they heard about from a pharmaceutical rep that had dropped by. They are, for the most part, genuinely concerned – but they have so little time.”

**Lori:** “I have lots of grievances about the hospital. The hospital environment needs to change – with input from those people who have to endure it. There are lots of good intentions, lots of science behind what people are trying to do but the indignities – the compromise in people's pride. I work in mental health so I know the motivation behind what they're trying to do but much of it is not helpful. To be treated like cattle. To be constantly monitored – I've never been in prison but I think there must be similarities. It's been 19 years for me with this illness and I have been in hospital nine times from three weeks to six months. Through this whole time, there has been no sign of change in the approaches they take. This is very discouraging. I come out and I'm all on fire to write letters but I end up not doing it.”

**Lucy:** “It is important to keep your physician involved. I have a very good family physician and can ask my questions. He did once say that some of my symptoms may be an age related thing and I told him this is NOT age. I don't have high blood pressure. I'm not overweight. I exercise so what I'm feeling is not age. Don't lump what I'm feeling in with the symptoms of aging! He knows what I'm like. We have a good relationship.”

**Nancy:** “I fully engaged in all the support and advice that was provided. I had to. I had no option. I knew I would die if I didn't. I watched the people who attended rehab with me, you could see some people were really engaged and others weren't. I made some very good friends in the program, one of them fully participated, and she is doing really well in life. Another barely showed up or participated in the program and she continues to live in torment. I've seen that there can be poor connections between patients and caregivers. Our ability to get along with others is important at any time in our life, but when you are in such a poor frame of mind, it is not the time to take a stand; it's the time to take the hand that is being held out to help you. “





## Themes



### 1. What depression is like

In order to tell the story completely, it was necessary to start at the beginning. What is depression *really* like? Here's what people had to say.

#### *Too much sleep, too little sleep*

**Heather:** *"I remember a profound and extreme physical and mental craving for sleep. It was completely compelling."*

**John S:** *"The first thing is my sleep started to go. I would wake up early in the morning. I wouldn't feel rested even if I had slept."*

**Nancy:** *"I wasn't eating, I wasn't sleeping. I was in severe mental anguish."*

#### *The pain of waking up in the morning*

**Anne:** *"I was waking up in the morning and thinking, 'Oh no. I can't believe I have to go through another day.'"*

**Lori:** *"Waking up with this heavy, disappointed feeling."*

#### *Loss of interest in food*

**John S:** *"I just couldn't eat without feeling sick. So I would avoid eating during the day and, at night, I'd be famished and then eat way too much – which interfered even further with my sleep."*

**Nancy:** *"I lost 30 to 40 pounds in one month."*



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**Sadness, misery, heaviness**

**Lori:** *"I slip into apathy and nothing seems to matter. I could win a trip to Florida and all I would think about is how much work it will be to get ready to go."*

**Chris:** *"For me, the experience of depression is like being under water. I try to get to the surface but there is an ocean of darkness in which I'm struggling. The episodes which I hate the most are those where I feel like I am suffocating."*

**Lucy:** *"I felt I had this personal dark cloud hanging over my head and just about anything would start the water works."*

**Overpowering negative thoughts**

**Anne:** *"The thoughts of self-harm... that tape about harming myself running in my head."*

**Deanna:** *"I was lost in my head."*

**Heather:** *"I was barely aware of what was going on around me."*

**Loss of attention and focus**

**Heather:** *"I could not retain the content of what was being discussed. It just went into a black hole."*

**Nancy:** *"I couldn't concentrate at work."*

**Lori:** *"I wish I didn't have such a sketchy recall of the times I've been ill. I delved into my journals and I tried desperately to see if I could find times when I was other than indifferent to my situation."*



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**Feelings of failure and self-blame**

**John S:** *“I really judge myself harshly when I am ill. I blame myself.”*

**Heather:** *“When I was in the deepest part of my depression, I would feel intensely guilty about how disabled I felt and how it was affecting the people around me.”*

**Nancy:** *“I felt I was weak and that I was a failure as a person. I didn’t think I was ill. When you’re in a clinical depression, you are full of feelings of self-loathing and personal failure. You don’t recognize that what you’re going through is an illness.”*

**John L:** *“I didn’t feel I was deserving of intimacy. I couldn’t stand that someone would care for me.”*

**Chris:** *“Part of me says, ‘Come on. Why are you struggling? This is just selfish.’”*

**Heather:** *“I need someone to say, ‘Give yourself a break. This is a disease that you don’t have control over.’ I need an external form of permission to support me at these times.”*

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**The need to be away from people**

**John S:** *“When I’m ill, I cut everybody out. I don’t want to go anywhere or do anything.”*



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**Nancy:** *“I was severely isolating, not answering the phone, or the door. It was summer, and I love summer and what I was doing was not like me at all. I started to put cardboard over my windows at home to block out any light from getting in my room. I mean I could barely move but I was going downstairs to search out cardboard boxes and duct tape so I could block what little light was left in my life.”*

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### **No way out**

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**Chris:** *“When I’m really bad, I’m not sure I’m going to make it to the next minute, let alone the next day. Throw in some panic attacks and it’s frighteningly debilitating. I feel like I’m losing my mind yet I feel I have to hold it together for work and for my family and friends.”*

**Heather:** *“I had overwhelming feelings of hopelessness – the feeling that this is not ever going away.”*

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### **The role of early wounds**

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**John L:** *“You see, I was alone a lot as a kid because I was hard of hearing. I always felt I had to prove myself. I had low self-esteem. I lost my father at an early age and I struggled with feeling worthy. These sorts of feelings render one vulnerable to depression.”*

**Chris:** *“I have a strong belief that some people are born with wounded spirits and that they have to live with that wounded spirit. They tend to see the dark rather than the light. Some people have grown up in unloving and hurtful homes. I think these early wounds fuel depression, so it’s not just biochemical. There are life pressures and then the brain chemistry goes haywire – but it’s not only chemical.”*

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### ***I thought feeling bad was just normal***

**David:** *“I was depressed for so long, I thought it was just normal. I never understood the difference between depression as an emotion and depression as an illness. People say, ‘I’m feeling depressed,’ and they mean they are sad and it will go away. But depression, the illness, is a chemical imbalance in the brain that colours everything. The sadness and the hopelessness do not lift all by themselves. When my psychiatrist finally convinced me to take medication and I actually tried it, I began to feel better. I realized that it wasn’t normal to feel sadness and hopelessness all the time. It had been such a part of my life. It made me realize that there is a different way of being and I had been missing it for all these years.”*

**Anne:** *“I had constant thoughts of suicide. They seemed so normal to me.”*

## **2. There is something really wrong here**

Interviewees described how they finally realized they were in deep trouble.

**Deanna:** *“My body did it for me. I completely imploded. I went catatonic as my body shut down. I had ignored every conceivable sign. I think I had problems as early as eight years of age and now I was 33. My coping mechanisms simply broke down. My body and my mind couldn’t do it anymore. I was taken to hospital in an ambulance because I just couldn’t move.”*

**Anne:** *“I finally got help when it occurred to me that not everyone and everything in the world could be negative. It dawned on me that it might be my problem and not theirs. When I just couldn’t move – really couldn’t move, I went to the hospital.”*



**Nancy:** *“A wonderful friend came to see me at my parents. She had knowledge of mental illness as there was history in her immediate family. The moment she saw me, she said, ‘Oh my God, you are so sick.’ She just grabbed me, and hugged me and we cried together. It was the validation I needed. There was relief. She recognized I was ill. I wasn’t failing as a person. She didn’t ask me things like, ‘What’s going on at work?’ ‘Is there something in your marriage?’ She just said. ‘You’re so sick.’ She also told me that if I didn’t go to the hospital myself, she would take me the next day. The next morning I went to the local hospital ER.*”

**Lucy:** *“It wasn’t me that realized I had problems. It was my employer. It was so embarrassing to have my boss come to me and say, ‘You know, I’m going to have to write you up. Your performance is so poor. Yet I know what you can do. Clearly you’re not letting me help you.’ While I was embarrassed, that just opened our relationship right up. We’re still in contact because of her reaching out.”*

**John L:** *“Sometimes I drank a litre and a half of wine a day. I was in a lot of pain – faced with a lot of demons and on my own. I remember going to counselling but I wasn’t taking responsibility. I knew what was going on but I wasn’t prepared to face it. There was a caring family doctor that I saw one day and she asked me, ‘Are you drinking?’ and I told her I was. That was a moment of truth for me. My father was an alcoholic and I was scared to death of becoming one too.”*



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### 3. A little window opens

Interviewees talked about the small signs that the depression might – just might – be lifting.

#### *Waking up and not feeling horrible*

**Lori:** *“When I wake up in the morning and don’t have that heavy, disappointed feeling that I have to face another day, which is a sign that things are getting better.”*

**Lucy:** *“It’s enjoying the start of a new day.”*

#### *Noticing things*

**Deanna:** *“There were two distinct moments in the same week. I was walking home from the bus stop at about 5:30. It was either April or May – the time of year when there can be nice days – or not so nice days. I turned the corner to go down our street, we live on a hill, and I noticed the sunshine and the leaves coming out – and just the feel of the air. It was a crystal clear moment. It was an ‘Oh’ kind of surprise, mostly because I actually noticed my surroundings and was instantly glad to be alive. The second moment was when I was on the subway. The subway was a big issue for me because it triggered suicidal thoughts in me and I had to work so hard to keep myself sane. I noticed this man beside me with this really fascinating tattoo on his arm. I finally leaned over to him and said, ‘Cool ink!’ I realized that I was actually paying attention to what was around me instead of just trying to get to the end of my ride with my head on straight.”*



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**Looking forward to things**

**David:** *“I wanted to do things – things that used to be an ordeal – but now I was looking forward to them. It was no longer OK to spend my time sleeping and in front of the TV. I wanted to get out and do things.”*

**The thoughts begin to lose power**

**Heather:** *“I might notice that, for brief periods, I was thinking about something other than my depression symptoms and my negative thoughts. It was a signal to me. I felt less guilty about not feeling well. If someone was saying to me, ‘You’re not OK’, I was now able to hear them and give myself permission to be not OK.”*

**Anne:** *“That tape about harming myself stopped running in my head.*

**Deanna:** *“I noticed I was ‘out of my head’.”*

**Chris:** *“My thinking is clearer – more objective and accurate. I feel hopeful. It’s like coming through a tunnel into the light.”*

**More get up and go**

**Lucy:** *“I wasn’t always asking myself how am I going to get through this day?”*

**John S:** *“The sign for me is when I start working on my own wellness – start working hard. I go to the gym. I eat properly.”*

**David:** *“The first sign I’m improving is that I have more energy.”*





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**Others see improvement**

**Chris:** “I see that the people around me are feeling better. They are not as worried about me.”

**Heather:** “The frequent reinforcement my counsellor gives me when she sees small signs of improvement that I can’t see myself. She reiterates that there will be more improvements. My ‘logical’ brain accepts what she says to be true even if my ‘depressed’ brain does not feel it.”

**Lori:** “Many people I’ve talked to who’ve had my experience find it difficult to recall what helped them turn the corner. Thank goodness for my journals. What I saw improving was my handwriting – so retrospectively, I could see that something was happening.”

**I’m going to get through this**

**Chris:** “I keep holding on to the knowledge that I’ve been here before and I’ve gotten through it. I hold on to the hope that I will see the light again. If you lose hope, you lose everything. You have to have hope. Some have said that other people can’t give you hope. You have to find it within.”

**Nancy:** “Each evening my parents would take me out for a long walk. They kind of walked me like you’d walk a dog! The same route – the same time. We would walk for about 45 minutes and I was very aware of feeling good for a period of time. The sunshine, the exercise and being outside were clearly good for me. The good feeling lasted for about half an hour but it was long enough. Every day I could see I was getting a little bit better so soon, I might be well. I began to think I’m going to get through this. I don’t feel so desolate. The world is not ending – well, not right now, anyway.”



***Tough realizations***

**Deanna:** *The toughest session I had with my cognitive behavioural therapist was when I realized I had been connecting a lack of control in my life with death – that if I didn't have control, I was going to die. Realizing that hurt like hell but I had finally put the finger on the right button. I started going uphill after that."*

**John L:** *"I was having thoughts of suicide one night. I called some friends and borrowed my mother's car and went to see them and spent the night at their place. I said to myself, 'Enough of this.' That got me over the hump."*

***The benefit of helping others***

**John S:** *"I began to volunteer for Meals on Wheels. I was doing something for someone else and that stopped me from feeling so guilty and ashamed of my illness. I was thinking of someone other than myself."*

**Heather:** *"I have discovered that giving peer support – as well as receiving peer support – is crucial to my wellness. Advocacy and activism is part of that. It is one thing to apply what I have learned about mental health to me, but it is important to play a part in someone else's recovery as they get to 'better.' It is the icing on the cake!"*



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***The role of medication***

**David:** *“When my psychiatrist finally convinced me to take medication and I actually tried it, I began to feel better.”*

**Lori:** *“The comments in my journal were very much about the medications I was taking. I rely so much on the signs that they are taking effect. I had lots of faith in that. Were they changed? Was that working? I expect a lot of it was psychological. I was so hoping that they would work that they eventually did. It’s a little like putting a band-aid on a cut. It doesn’t cure it but it feels better. So I would think, it’s just a matter of time and they will kick in – hopefully.”*

**Nancy:** *“As I got better, and a few times over the years, I have said to my psychiatrist, ‘Perhaps I can come off my medication now.’ And he consistently says, ‘Let’s both go back to the day we met and remember what that was like. You need this medication to stay well and I don’t see you coming off your medication.’ It took me a few years to come to terms with that – but I am there now. I compare my medication to insulin, I need it to stay well and if I was diabetic, I would not be so foolish as to not take a medication that helps keep me well. I’ve also seen family members and friends go off their medication and come crashing down. I’m not prepared to experience that. It’s so important to follow your specialist’s advice.”*



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## 4. What was helpful

### *Eat right, exercise and get your sleep*

Every interviewee stressed the importance of proper diet, lots of exercise and making sure that they were getting a good night's sleep.

**John S:** *“Well, that old thing about your mother being right. Eat three meals a day. Get eight hours of sleep a night. Exercise. Take care of yourself.”*

### *Someone who was there for me*

**Lucy:** *“It was definitely having someone to talk to. That started me on my journey. From there I had to take my own steps. The talking validated how I was feeling but then we had to develop a treatment plan and map out the steps to change.”*

**John S:** *“I have a friend who was there for me when I was sick. He didn't live nearby so he'd call me. He just kept phoning. I know it seems like a little thing but it meant so much to me. It made me feel I wasn't forgotten.”*

**John L:** *“There was a second cousin of mine that was very supportive. We'd sit at her place, sipping some wine and just talk.”*

### *Peer support*

**John S:** *“Peer support is key. Having other people to talk to who knew what I was going through helped me understand I wasn't alone. It's people helping each other and not working in isolation. I went to Emotions Anonymous and the fellowship was fantastic. I'm not a die-hard 12-stepper but that group was helpful.”*



**Heather:** “Peer support is very important to me. Peers, friends and family can coerce me into having contact and can encourage me to do good things for myself, like exercise. When these things happen, I begin to allow myself to have some hope and hope triggers more contact and motivation to attempt to do more good things for myself. If I didn’t have friends supporting me, I would feel I was climbing and never-ending hill and give up.”

### **Friends and family**

**Deanna:** “I have great friends and family. They were all shocked – how could this happen to me? But they went out of their way to connect. An associate of mine at work brought me a box of books. Another colleague drove in from London and brought me lasagna and took me for a walk. Another came over and just sat with me; he had gone through several bouts of depression and he came just to be there. My husband gave me a tee shirt with the Superman symbol on it and told me I didn’t need to be a Super Mom. My boss took me out for coffee and just listened. My Mom came from Alberta and looked after our daughter. People sent me flowers. Even an old boyfriend reached out. I see too many employees at my workplace who don’t have that.”

**Nancy:** “My parents were amazing. They were very supportive. They didn’t know what to do but they knew I needed help. My husband was working crazy shifts and they knew I needed people around me so they asked us to move in with them. My Dad thought the answer was to keep busy so he had me cutting the grass. I was sobbing away – but I cut the grass.”

**Lori:** “I am blessed with a great support system and I can tell them how I’m feeling. I can unload on someone and rely on them to see that I’m not doing well when I can’t see it myself – that’s helpful.”



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**Anne:** *“The support of my partner and my family have been extremely important and helpful.”*

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### **Yoga and meditation**

**Anne:** *“Also, mindfulness meditation and yoga – they were helpful. You can get tapes for this and do it alone or sometimes you can find a group. It’s just a chance to calm the mind down and focus on what’s important. Yoga is really just medication in motion. I’ve also found a really engaging hobby. They say that when someone is engaged in a hobby they really love, their brain wave patterns resemble someone who is meditating. I can see that. I know I feel so much better if I’ve been working on a craft project for a while and have just been able to forget everything else going on in my life. It’s easier to deal with other things when I’ve had that kind of a satisfying break.”*

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### **A caring professional**

**Chris:** *“There are three things; time, talk and tunnel. I know it is going to take time and I have to acknowledge that. So, what do I do with that time is the second thing; talk. I see a psychiatrist and I have a Christian spiritual mentor who also helps. I feel there has been some sort of build up inside of me and talking provides a sort of ‘sigh’ of release. So talking it through with someone I trust and feel safe with is helpful. Then the third thing is the tunnel and by that I mean knowing that I’ve been in this tunnel before and I will get through.”*

**Nancy:** *“When I went to the ER, they triaged me quickly and got me to a quiet room. The on-call psychiatrist came to meet with me. He assessed me and said that he thought I’d be a couple of days in the hospital. He also said, ‘I will see you every day and we will find a way to turn a corner on this.’ I believed him with all my heart.”*

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## Stories

**Chris:** *“I like reading stories about people’s recovery and what inspired them. I especially appreciate stories of Christian people who have experienced states of despair and who, through faith and prayer, have recovered.”*

## 5. What was not helpful

### *Unsolicited advice*

One thing interviewees all agreed upon was that unsolicited advice from well-meaning – and some not so well-meaning people – was NOT helpful.

- Take a bubble bath.
- I wish you’d think more positively.
- Pull up your socks.
- Read a good book.
- Have a pedicure.
- Just lighten up.
- Calm down.
- Pull yourself together.
- You’re just stressed.
- Go have some fun.

**Nancy:** *“When people say these things, it’s clear they don’t recognize the seriousness of the illness.”*



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**Ignoring it**

**Deanna:** “After five years of therapy, it’s clear that I had many episodes before this one but I’d managed to get through them. I had ignored the anxiety, the stomach upsets, the excessive sleeping. I just kept saying, ‘I’m fine. I’m fine.’ I didn’t think it could happen to me. I’m a total overachiever and I hold ridiculous standards for myself. I never gave myself credit for what I’d achieved. I would always focus on what I didn’t get done or how much better things could have been done. I also have a stubborn streak and I just hang in there and work things through and continue to raise the bar for myself so that I never actually got to the bar in my head. I did this on way too many things as it turned out. I was being willfully blind about my own actions.”

**Lucy:** “What is really unhelpful is ignoring that you’ve got a problem. I didn’t realize how bad it was – or I did realize in some way but refused to admit it – I’m not sure which.”

**John L:** “I was not helpful to myself by not seeking help earlier.”

**Heather:** “My own denial, especially during my first major episode was very detrimental. Once I could acknowledge my depression and accept it, then the barriers I had to face were external.”

**David:** “I didn’t even know what was wrong – or even that something was wrong.”





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**Professionals who lecture, don't take you seriously or who talk down to you**

**John S:** *"Doctors who insist they know it all. They say, 'You're the patient and I'm the doctor. You will do as I say.'"*

**Anne:** *"It's not helpful when you walk into the hospital and the staff don't take you seriously. I had such physical pain and I was viewed as a hypochondriac. There is more education now about the association between physical pain and depression but at the time, the professionals would diminish these symptoms and that was extremely unhelpful."*

**Lori:** *"In the hospital, we'd get up in the morning – they're telling us breakfast is in 10 minutes so we scramble to the community room. The occupational therapist reads the newspaper out loud to us all. I know the point is to keep us up to date on current events. At those times, I am very vulnerable. The assumption is that we can't even read. Then there is the schedule with the coloured tabs – because we can't figure it out for ourselves. And then there is that voice – like she's talking to children. Every one of us there is thinking, 'Well, she is not doing this for me.' I'm not that ill. I'm not as sick as the rest of them. This cannot be for my benefit.' This creation of dependency breeds negativity. You're eventually going to believe – this is for me after all."*

**Self-medicating with alcohol**

**Anne:** *"Long ago, I didn't know the term "self-medication" but I do now. I can tell you for a fact that alcohol is not helpful – not helpful at all. It just makes things worse."*

**John L:** *"Drinking a bottle of wine a day will tell you're not getting better."*



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**People doing everything for you**

**Lori:** “When I’m ill, my mind set is different. I’m low. I can’t even get dressed. So the staff help me dress – they won’t just leave me to struggle with it. This tells me so clearly that I’m not capable. Overtime, it affects my thinking. The last time I was sure the staff were meeting with my mother to discuss a placement in a nursing home for me. This turned out not to be the case but I felt so debilitated, I was convinced I would never recover. When I get home, my mother and my sister make it clear that I need to do things for myself. Within weeks, I’ve improved. I clear the snow off the car myself. If they told me, ‘I’ll do it for you,’ it would be hard to resist but they don’t. I have to do things for myself.”

**Mis-diagnosis**

**Deanna:** “When I went to emergency at Mount Sinai, we arrived at about 7:30 p.m. But we waited until 3 AM in the morning to be seen and to try and find a nurse who could escort me to the Centre for Addiction and Mental Health. They couldn’t find anyone to escort me, so my husband eventually asked if he could take me home because he had to pick up my daughter who was with a neighbour. They let us go with a prescription for Ativan and a promise from him that he would take me directly to the CAMH the next morning. The next day, we went directly to the CAMH and the psychiatrist there diagnosed me with dysthymia and gave me some strong sleeping pills. I was almost catatonic and she diagnosed me with a mild mood fluctuation! She was so off the mark. After sleeping about 19 hours every day for a week and my husband helping me do everything from taking a bath to brushing my teeth, he took me back to CAMH and I saw a social worker this time and she said, ‘What the hell?’ She ran around and dragged another psychiatrist in to see me. He admitted me immediately. I was there for three days, then transferred to Mount Sinai.”



***Friends that just don't want to hear***

**Heather:** *“While waiting for access to counseling services, I was given the suggestion to develop a ‘circle of care’ – friends and family members that I could ask to take turns helping me function so that no one person had to bear the full load of support. I believe that to be good in theory. However, I did approach people and watched them back away. That was difficult to experience, especially in my depressed state of mind. It was tough enough to ask for help but feeling that I could not be open about my struggles was not helpful at all.”*

***The disconnect between hospital and community care***

**Deanna:** *“The connection between in-patient acute care and community care is zilch.”*

***Unsupportive employers***

**Heather:** *“Unfortunately, there have been times when my employers have not been helpful. I suspect that not having specific processes and policies in place at a corporate level to help employees with mental health contributes to that. It has been a large obstacle to my recovery when circumstances at work have added to the stigma surrounding mental illness. When I consider how much time a person spends at work, this type of support needs to be there.”*



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## 6. The ins and outs of working with professional caregivers

### *Not trying to fix – me*

**Chris:** “I need to be with people who see me as a person and not an “illness.” It’s nice to have people who are not always trying to fix me – me as a person. But there are kinds of fixes, you know. Good ones like proper eating and taking my medication. And there are bad fixes like drinking to turn off the brain pain.”

### *There must be trust*

**John S:** “I have seen a whole series of psychiatrists over the years. The essential ingredient is trust. There have been a few that I didn’t trust but I have trusted the majority. I want them to listen to me. Respect that I am an intelligent human being. That they don’t get offended if I ask questions. My present doctor is excellent. If he gives me a new drug, he knows I’ll go to the internet and research it and he’s not intimidated by that. He knows I need to know what I’m taking and I need to ask questions. Less successful relationships have been with doctors who have felt insulted when I asked questions.”

### *Think of it like you are taking a course*

**Anne:** “Listen to the professional, ask for resources but you have to do the homework. There is no point in just sitting there for a half hour a week – or month – and thinking that this is all that’s needed to make you better. You have to do the work. And show-up. Depression is insidious. It can convince you, and others for that matter that you are okay and you don’t have to go to therapy. That you don’t need to go to the appointment. Don’t believe it. Go anyway and talk to your therapist about how you felt like you didn’t need to go and why. Honest communication with a therapist is so important.”



**Nancy:** *"I set up the binders. I took notes. I did homework. It was like being in school again. I had to re-build myself from such a broken place. It was so hard."*

### **Staying in contact with your professionals**

**Deanna:** *"Frequency of contact with my professionals is absolutely necessary. I see my psychiatrist once a week and also my cognitive behavioural therapist. Without this frequency, I could slide very easily. Mind you, any more contact than that and it's too much. It is so painful to work through things but knowing that I will see them the next week is critical. I'm a verbal extrovert and talking through things is important to me."*

### **Follow the advice**

**Nancy:** *"I had an excellent psychiatrist. He just made the right calls, and I followed his advice – as scary as it was. Walking into that psychiatric ward was one of the scariest moments of my life, but I believed in him to help me get well. I will admit that I didn't like everything my psychiatrist said. We had some interesting discussions. But, at the end of the day, he saved my life."*

**Anne:** *"People have to get over the idea that the self-care exercises – you know, doing satisfaction scales or doing a cost/benefit analysis of your activities – those sorts of things are hokey. It sounds hokey and it can feel hokey – keeping a notebook about the good things that have happened in your day. But it works. So people have to stop worrying about what other people think. Get over it – and just do it."*



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### ***Cognitive behavioural therapy (CBT)***

Many interviewees credited CBT with helping in their recovery and maintaining their wellness.

**Nancy:** *“It was cognitive behavioural therapy that was so helpful. I was fully engaged in that program.”*

**Anne:** *“I’ve been on this road for 12 to 15 years. One thing that made a huge difference is cognitive behavioural therapy. It changed my thinking. I go back to the exercises from time to time – not a therapist but the workbooks and take a look at how my thought patterns may not be working for me.”*

**Deanna:** *“I find ‘thought records’ are also important. How I’m feeling physically and what I’m feeling – being really clear about what I’m feeling – naming it. I have to know that I’m angry or that I’m grieving – not that I’m just “upset.” I need to focus on what anger feels like before I am able to understand what I’m angry about. I try to do this with my daughter now – get her to name the emotions she is feeling so she’ll have the vocabulary when she grows up and may be able to avoid what happened to me by recognizing signs earlier and being able to identify the emotions that go with them.”*

### ***It’s a partnership***

**John S:** *“People with mental illness all too often think they are lucky to get what they get and they put up with a lot of crap. They can feel they are not entitled to anything better but this is not true. You shouldn’t be afraid to express the things you want to. I want to be an empowered partner in my own wellness.”*



**Lori:** *“I have worked with the same psychiatrist for 15 years and we have a great working relationship. We know each other well. I work with him on goal setting which can be overwhelming as well as monotonous – at the time – but he knows me well so I get through. I see him from every 3 weeks to every 6 months, depending on my health.”*

**Lucy:** *“Open communication with my doctor was very important. I’ve had to go back when I had issues with the medication and we had to work through what was going on. I also suffer from seasonal affective disorder and the fall is very difficult for me. I have to keep the doctor in the loop at that time. We just talked things through and the light therapy during the winter months has helped. So, it is important to keep your physician involved.”*

## 7. Medication, yes but...

**Chris:** *“Medications help reduce the symptoms. But I am challenged with side effects. Unfortunately, I never found the ‘right’ anti-depressant for me. I know others have had the experience where the light just went on with medication and everything was sweet from then on but that hasn’t happened for me.”*

**Lucy:** *“The medication was helpful. It didn’t feel great, mind you, but I needed something. It made me feel like a 40 watt bulb in a 100 watt socket. I was numbed emotionally and sexually. You have to have emotion or it’s not really a life. So medication is not a cure by itself, but it helped. I also found that keeping a journal was important so I could look back at my progress.”*



**Heather:** *“I have had six major depressive episodes and, each time, it was a different medication that worked for me. It has been a long journey of trial and error when it comes to medication. It seemed like an unbearably long time as I tried one and waited to see if there was any improvement. During my last depression, my doctor tried a supplementary medication in addition to my regular one and within two to three weeks, I began to see dramatic improvement.”*

**Nancy:** *“I was committed to my prescribed medication but I had to have patience to get through the side effects.”*

**Anne:** *“The antidepressants made me gain weight. Being heavier made me more depressed. Then I would eat to feel better. I had to make the conscious decision that it was better to be bigger and not so depressed. Another side effect of antidepressants is that they make me sleepy on one hand, but prevent me from having a normal sleep cycle on the other. This was not something I realized or that any doctor ever discussed with me. I only found out after it changed when I got off the antidepressants at one point. If I’d been better informed of these side effects or if the doctors had monitored them, then maybe something could have been adjusted. I think I ended up sicker from the meds than from the depression before weaning off the drugs became part of my recovery. Talking to the doctor about these things is so important.”*





## 8. What *better* feels like

Many people reported that they found this question difficult to answer and, as Heather said, “There is really no one word that adequately describes it.” However, readers will see that there are commonalities in the words interviewees chose. So, here are the carefully considered descriptions of what *better* feels like.

**Anne:** *“Better means just lighter. The feelings of heaviness go away and I feel lighter, clearer and I have more energy. There is a certain satisfaction of being in the routine of being better. Being able to get up in the morning, thinking about having a good meal, exercising so many times a week – those things. When I’m unwell, I lose all that.”*

**Chris:** *“I don’t see myself as recovered, but in a process of recovery. But I understand ‘better.’ It’s not worrying about the depression and how it affects your loved ones. Not feeling ‘it.’ Not talking about ‘it.’ Not analyzing ‘it.’ Not thinking about ‘it’ all the time. Better is when ‘it’ is on the shelf. When I feel good mentally and physically, when I see the light of day rather than the dark of night that is what better is like. When I can count my blessings. When I can live in the present – in the moment. Depression is living in the moment but in a bad way. It’s a dead moment. But when I’m better I live in a brighter, lighter moment. When I wake up rested, that is good. I literally feel something in my brain when depressed and when I’m better, the fog lifts. And I don’t feel like crying anymore. There are lots of ways of crying – some ways have no tears.”*

**David:** *“Being excited about life, looking forward to the next thing. I want to do things, spend time with people. Life has become easy. It’s no longer an ordeal. It flows smoothly. I also have energy and stamina. If I have a set-back, I can take it in stride and not feel that I’m falling into a deep dark pit. Better is also physical. My body feels good. I want to exercise instead of feeling like I have to force myself. I see the humour in things and that happens automatically without me having to search for it – it just comes to me. And I feel grateful just to be alive.”*



**Deanna:** Deanna had created a list in answer to the “what does better feel like” question:

- “Being able to live in the moment.
- Looking forward to the future.
- Being inspired by small things.
- Not having to take so much of my anxiety medication! When the prescription lasts longer, I know I’m better.
- Being able to accept someone saying ‘thank you’ or ‘you’ve done a good job.’
- Looking into my daughter’s eyes – really seeing her. Before she was just someone I had to take care of.
- Looking at life as something to live instead of waded through dragging my disability with me.
- Focusing on what I can do instead of what I can’t do.
- Giving back is important too. I made it through and other people can too. I promised myself that when I was better, I would give back, advocate, tell my story, whatever helps. And since I am doing this, I must be better!”

**Heather:** “It is a wonderful feeling. It doesn’t even have to be ‘complete’ recovery to feel wonderful. It can simply be the feeling of improvement from the day before. It’s the feeling that tomorrow will be even better. It is momentum. It is motivating and calming at the same time. It is so hard to describe in words. Mentally, physically, and emotionally, I feel peaceful. When I have a sense of accomplishment involving my recovery, that is a large part of what better feels like. No one made me better. I participated fully in the process – I was involved and I moved through it ... I was part of it. Also, when I feel a return of creativity and I am interested in creativity again I know I am better.”



**John L:** *“Having a sense of worth and value. I have a good sense of that now. Also a sense of contentment. There was a saying at the entrance of a rock garden in Japan that translated as, ‘I seek only to be content.’ Contentment is deeper than just moments of enjoyment or happiness. I am also doing the best work of my career and feel I am making a valuable contribution to the people I work with. And I have a sense of closeness with my wife. I am not the world’s greatest at intimate relationships. I try, but it’s hard.”*

**John S:** *“Just wanting to get up in the morning and do something during the day. That I feel I have the self-confidence to achieve something. I am looking forward to doing things. I don’t have a lot of fun. I am constantly observing myself. So when I think, this is going to be fun – like spending time with my grandchildren, that’s a big thing. Having a laugh, a really good laugh where you just let go. That’s a good day.”*

**Lori:** *“This is a very difficult question for me. I have to look at it retrospectively because, at the time – when I’m right in the throws – it’s not easy to recognize ‘better.’ I suppose it depends on what you’ve been through to define it. For me, I start to recognize myself. The components of myself, my mind, my body, seem to come back together. I am better – but not recovered. I imagine it’s the same if you’ve had surgery for example. After a while, you start feeling like yourself again, and people respond to you as yourself. You recognize your old self – my heart is beating and my thoughts are back.”*



**Lucy:** “Just getting up in the morning and feeling happy – taking pleasure in starting a new day. I’m not worrying about how I’ll get through. The sun. Seeing a flower – the smell of freshly mown grass – it’s the little things. Hearing the wind in the trees. These little things – and stopping to appreciate them. Just enjoying life and being grateful for the little pleasures. I enjoy a kiss from my granddaughter. I look forward to doing things. Before, the phone would ring and I’d run away and lock myself in the bedroom.”

**Nancy:** “Better is taking pleasure in every moment of simple, everyday life. I am grateful to be able to work. I enjoy wanting to see family and friends. I am interested in life, in being part of life, enjoying hobbies and having interests and goals. I appreciate living – and I am mindful of being in good mental health.”

## 9. A final thought...

A couple of the interviewees mentioned their awareness of the benefits they’ve had in their journey to ‘better’— benefits that many, many people do not have. It’s worth remembering.

**Deanna:** “I have all the privileges in the world. I am white, I speak English, I’m well educated. I have a house, money in the bank, a strong marriage, a supportive family and a great employer. Despite all this, I couldn’t get timely access to care. I can’t imagine what happens to people who don’t have the advantages I do. In fact, it outright scares me.”

**Chris:** “I just cannot imagine what it is like to have no job, no decent housing – perhaps living in a group home with everyone telling you what to do – and dealing with a mental illness.”





## In conclusion

Mood Disorders Society of Canada would like to thank the people who agreed to be interviewed for this project. This sharing of collective wisdom constitutes a unique contribution towards the health and well-being of Canadians who struggle with depression. There is no substitute for hearing from people who have “been there” and who have emerged stronger and wiser as a result.



Please see “What *Better* Feels Like: Maintaining Wellness Guide that MDSC has created, also based on the experience of the people who participated in this project. The Guide is available for download at [www.mooddisorderscanada.ca/page/what-better-feels-like](http://www.mooddisorderscanada.ca/page/what-better-feels-like).

## Appendix: Questionnaire

1. Can you recall the first sign (s) you noticed that made you think that your depression might be lifting? Can you describe those signs?
2. How did you know you weren't getting better and what did you do?
3. What do you think was the trigger (s) that allowed you to turn the corner?
4. What do you see as the “ingredients” that led to your getting better? What was helpful?
5. If not covered in the question above, can you tell me specifically how you worked with your professional caregivers?
6. What was not helpful?
7. Define what *better* feels like – for you.
8. Tell me what you do to maintain your wellness?





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