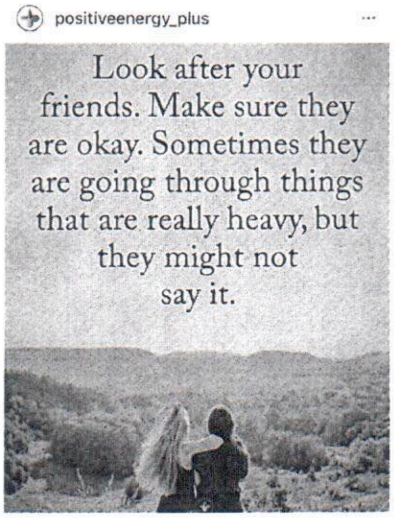


Look after your friends. Make sure they are okay. Sometimes they are going through things that are really heavy, but they might not say it.

# You Can't Do It Alone

When I first found out we had mites, I was not able to be around people. I didn't want to be around family or friends for fear of contaminating them. I didn't want to leave my house, which was a mistake because I hadn't yet found out how infested it was. I know part of the reason I didn't want to go anywhere was I was sad and depressed. But I was also exhausted. With all the cleaning, washing sheets, bagging clothes and then the heavy stuff, tearing out carpets and throwing away furniture, there was no time for anything else.

And, of course, sleep deprivation is a real problem. Mites are more active at night. Between the itching, the crawling feeling and the worrying, getting more than a few hours of sleep at night was almost impossible. A quote from birdmites.org says: "The lack of sleep is one of the most devastating aspects of a mite infestation. Social isolation is a real concern for the person with a mite infestation. Since this problem is not common, others may not understand what you are dealing with. Those who have never gone through this, or even heard of it, have no idea how seriously it affects a person's life. It makes it all but impossible to tell friends and coworkers what you are going through. This lack of a support system can make the depression worse. And a person does not want to feel like they are somehow contaminating others, and so may limit their social contacts. It is not well understood how these parasites choose a host. Some people in close contact may be bothered by them, and others may not be. When it seems like there are no answers for this affliction, a person can become depressed and suicidal. Discouragement and depression can lead to suicidal thoughts, when it seems like the only way out from this living hell. It is hard to go through something this difficult for a long period of time without losing hope. There are some who have attempted suicide due to a long-standing parasite infestation. An anti-depressant may be needed for a period of time if the person and their doctor feels it may help. And having the support of someone who cares is important."

There were a few times during our mite battle that I thought I should get some type of professional help, see a therapist; but then I thought about having to tell her I had mites and could possibly be contaminating her chair. I couldn't make the call.

I learned early on in this fight that no one wants to talk about mites. I remember when I was taking samples of what I thought could be mites to a local entomologist office in town. The receptionist at the office was friendly and always tried to be supportive and we would actually talk about the problem I was having. She told me that her granddaughter was allergic to dust mites and they had not had any success in finding someone to help her so she totally understood when I said I was part of the 10% that no one cared about. She said her granddaughter was also part of the 10%. She told me that people really do need to start talking about the problem whether it be scabies, mites of some other type of parasite. In her job, she saw that all of these problems were becoming more common than anyone knows. And from what I saw on the support sites, I believe that is true. It is a problem all over the world. And in our country, the medical profession just pretends it isn't happening. The CDC doesn't even acknowledge that Morgellons is a disease; yet there are so many people suffering with Morgellons. It is so similar to the vaccine issue. Thousands of parents know their children were injured by a vaccine, yet the CDC and FDA will not acknowledge it. When you are a small percentage of people who are suffering, our medical system has a way of just acting like you don't exist.

So the month of June was like a blur and July didn't seem to be getting any better. I had always been a very active person. I like to play tennis, bike, kayak and I had no time or energy to do anything but fight the mites. I've played in a women's tennis league for thirty years and some of the women I normally play with were starting to wonder what was going on with me since I hadn't been at tennis for weeks. At my age, it's not unusual to hear about a friend dealing with serious health issues. A couple of my tennis friends were actually going through cancer treatments the same time I was going through the mitemare. I kept thinking about the comment I read in the support group. The woman who said she almost wished it was cancer instead of mites that she was dealing with because at least she'd have a real diagnosis that people believed and there would be doctors to help her, people to rally around her and cheer her on. I know it seems like such a strange comment, but I could totally understand what she was saying. When you have mites you are isolated and feel alone. You also feel like no one wants to talk about it. And from what I was reading in the support groups, if you didn't get help and find a way to get rid of the mites, you could get more serious diseases; so you are afraid that you might end up losing this battle, and then get Lyme disease or Morgellons or even cancer down the road.

So I let a couple close friends know a little about what was going on and even though I never tried to hide what we were dealing with; I still felt no one would really understand unless they had gone through it and knew just how all encompassing it was. Even the friends that I told didn't really know what to say. But it helped that they just kept in touch. My friend, Susan, from tennis texted me often just to say she was thinking about me and that she knew I was strong and would get through whatever I was dealing with and she said she was praying for me and to know I wasn't alone. In fact, as I went back and read our texts while writing this book, I thought I would share them because this is a good description of what was going on.

When I quit going to tennis she sent this:

"Are you ok? I'm worried about you."

"I'm going through a bad thing right now. It's a health thing that is affecting my whole family and I'm really almost losing it. I can't play tennis for awhile, no energy, not sleeping."

A week later she sent:

"Are you ok, did you find out anything?"

"Hard to talk about. Right now any energy I have I'm using to get through this. If it was just me, I wouldn't care but it's the whole family, all the babies. It's all I can focus on, helping everyone get through this, also taking some strong drugs."

A week later she sent:
"How are you doing today?"

"It's a day to day thing. You know I have been through some bad things in my life like having a gun at my head and taken hostage and if I hadn't stayed calm, I would have been killed; watching my dad have an aneurism in front of me and never coming back. I've dealt with pain and this heart problem; but this has hit me really hard because it's not just affecting me but my whole family. I'm hoping the doctors are right about the drugs (permethrin and ivermectin) making this go away but I have my doubts because I've read what people are going through. Every day I try to help the kids with it too, and no it isn't going to kill any of us; but it can make everything change and has such a snowball effect. Right now, I can't garden, hug my grandchildren or kids, feel comfortable being with people, or do any physical activity because I have no energy and I am in pain. It's mentally and physically exhausting. But I will get through this as long as my family is ok."

Her reply: "What the hell do you have and maybe you should stop reading about things. It's good you are so smart that you diagnosed this but stop reading about it. I think sometimes knowing too much isn't a good thing and keep believing that you will be all right. Positive thoughts are good. Miss you."

"I miss you too. I miss my life. This is all encompassing and time consuming. But I did the second treatment the doctors prescribed and I found some essential oils that are helping. I called all my homeopathic and naturopathic doctors so got a little advice from them. I am taking high doses of Vit C and Vit D which seem to be helping with energy. But I still have itching so working hard to make sure the environment is ok. Thank God the treatments seemed to work for the kids and that was my biggest fear. This is just too awful to really talk about. I wouldn't wish this on my worst enemy. Well actually, there is one guy I'd give a big hug."

A week later she sent: “Hey I hope you are feeling a little better tonight whatever you are going through. I know it sucks but hopefully it’s going to get better soon. I’m thinking about you so you aren’t alone.”

A week later she texted:
“What did the doctors say?”

“The entomologist is supposed to call tomorrow. But Carly just texted me and she got some bites riding in my car because I didn’t know my car was infested because the doctors just tell you to wash your sheets like that could ever stop this. When I called the dermatologist’s office back to tell them the permethrin didn’t work, they just sent me some paper talking about how gerbils can give people mites and that I have to take care of the environment. WTF??? I don’t have gerbils and I have about a thousand papers in front of me that I have printed online with more information than that. Thanks for the help. What do they think throwing away all of your carpeting and furniture is? I’m trying to fix the environment even though I can’t find one single exterminating company to help me. I think I’m living in the Twilight Zone. The only help I’m getting is from the support groups online. How can doctors not have a clue how to help? My biggest fear was that the kids would get this and now it happened from riding in my car! I have to help Carly now so it doesn’t get in her house. I fucking can’t take this because it is such a fucked up thing. How can all of this happen from one dead bird in a mailbox. And why doesn’t anyone warn people this can happen? And I just found out that a young girl in one of the support groups may have killed herself and I totally understand. When you lay in bed at night and feel like you are getting eaten alive, it can make you not want to be alive.”

Her reply:
“OMG, I’m so sorry this is happening now. Did that medicine work for Carly the first time?”

“Yes, she took it when this all began and it worked, but I guess she was exposed in my car because now she has bites. So now she has to stop it by doing everything I am doing in the house and she did do the cream again so maybe that will stop it again. But if it doesn’t, I have to find something that will help her. I’ve done permethrin twice, sulphur treatments three times, which did kill them but then they are in the house so they came back. I’ve done Eurax treatments which helped but if I can’t find chemicals to help kill them in this house, then I am walking away from my house. People just leave their homes and everything in it. How can that be happening? And because most people, 90% are helped, I guess no one cares about the 10% that can’t find help. So I’ll just keep trying everything people say helps because no doctor is saying to try anything.”

She replied: “Holy shit! What can you do about your car? WTF?”

“I read you can buy some type of menthol crystals so I’m trying to find those and Dave bought some bug bombs and going to try that. You have to kill the mites but also get rid of any eggs or they come back. I can't sleep now because I lay there worrying about Carly. I have to give her something now for the bites she has. And I am still trying to find a doctor who knows something.

Susan: "Just believe everything will be all right and keep busy, maybe you will be the one to figure this all out."

"That's what my friend in the support group told me. She said I will feel good about helping Carly and it will take my mind off my agony and I can use everything I've learned to help her."

A couple weeks later I texted Susan that I couldn't be at tennis: "I wish I could play this week. Last week I felt so good. I thought we were almost at the end of this. Carly is better and I had no new bites. Then they came back. I am bit all over. They are attacking my joints and I have swollen heels; and I wouldn't be able to play now because it hurts to run. I can't believe this is happening now, but I am trying to stay positive. Looking for some kind of doctor to help with this pain and swelling. Not sure if it is from all the chemicals we've tried in the house or the mites. All the carpet will be out tomorrow. Nothing much left in the house where they can be hiding but I just found out they can be on the ceilings and we haven't been focusing on the ceilings. So now we will try spraying the ceilings too."

Her reply: "I love you."

My next text a few weeks later was: "Good news! I might have found someone to help me. She knows why they are attacking my joints and why my feet are swollen and she told me what to do for that. She had mites and got rid of them and is going to help me. She worked with a doctor in Thailand.

Susan: "Wow, that's awesome!!! I'm so relieved for you!!!"

A week later I texted: "Thank God I found Janet. Every doctor I talked to had nothing to help me. But I will do whatever Janet says because she got rid of mites and I have to believe that we will get rid of them too. And if this does help me, then I will help everyone on the support sites. At least I have some hope now. I will get over this and be healthier than before."

A week or two later I texted: "I think we are beating these devils. We just spray everything every day and I spray my car every day. I only have a couple bites which means they are still here somewhere but dying off. All the supplements I am taking and drinks I am drinking give me lots of energy and I feel healthy."

Wow, just reading those texts takes me back to how bad it really was and makes me so thankful that I found Janet. I will tell you more about finding Janet later in the book. But I know finding her was what turned it around for me. So even though I only had a couple people other than my family and the support groups that I could really talk to about it, just knowing they were thinking about me and praying for me really helped. Always look after your friends, you never know what they are going through.

Another reason I had a hard time talking about what I was going through was because any time I started talking about it with someone, they started itching. The power of suggestion is real and, in fact; one friend did have some type of parasite in her house, but because she knew what I was dealing with, she panicked and thought she would end up going through the same thing I had been going through all summer. So I learned that it was probably better not to talk about it much.

Then there were a couple times over the summer that it ended up being a good thing that I did talk about it because two people I knew had been itching; and I told them the symptoms of bird mites, they ended up getting checked and they did, indeed, have some type of mite and were treated for it before it got too bad and before their houses were infested. The sooner a person gets treated, the less chance they have of becoming part of the 10% that has such a hard time getting rid of the mites. I really believe if more people talked about mites or scabies it would prevent other people from suffering the way so many on the support sites suffer.

When I think back to how hard it was trying to find a doctor to help me, I wasn't surprised that allopathic doctors know so little about mites. They learn what they are taught in medical school; and I am betting there wasn't a lot being taught about bird mites. But I do think a lot of people are surprised when they see how doctors are not helpful with this. One post in one of the support groups asked this question:

"I'm curious why we are are trying so many home remedies instead of insisting that our doctors take this seriously. Has no one found a doctor that believes them and is trying to help?".

There weren't many answers and the answers that were posted were not very positive:
"

"I've gone through 3-4, been told those are just bug bites or psoriasis which I've never had. Doctors have no way to fix this problem."

And another person said: "Somebody has to be out there if there are studies that have been done on this. But I get it that most doctors are totally ignorant. I'm going to contact a few in Europe."

Another person said, "I have been to 15 doctors in 4 months and no doc has a clue. They have not been trained. Some say delusional and some say eczema or psoriasis, but this is real and has really rocked my world. I think all the chemicals we use to rid our bodies might be killing us."

And another wrote, "I'm hotel hopping currently and have literally a ziplock bag worth of possessions so I don't have an environment now. I plan to not have one until I find a doctor who takes me seriously. I will keep everyone updated."

So it was clear that most of the posts on the support groups confirmed that people had gotten very little help from the medical field. There were many horror stories about going to the ER and being put on psych drugs because no one believed them when people said they were infested with mites. Jane Ishka in the book The Year of the Mite, which is the first book I read about mites and a really wonderful, informative book, talks about what can happen to our immune system when we become infested with mites: "At the beginning of the mite infestation, when I had been bitten very few times, the bites left big red marks. By the height of the infestation, I was bitten three times a minute and had no marks at all. I figured something was happening to my immune system. I learned that many species of parasites-not just mites- suppress their hosts' immune response. This is a developing line of inquiry in the science of parasitology. There is something in bird mite saliva that lowers the host's immune response to the parasite. Something that stops white blood cells from attacking the mite from inside it's gut, and after enough bites, stops the host from developing welts when bitten. That is part of what makes mites such an efficient parasite. And part of what makes it tough to demonstrate you have parasitic mites."

So what this means is that you may still be getting bit but now you may not be showing any marks so the nightmare goes to another level. Now people may just think you are crazy; and since there are times when you think you may be going crazy, it is Twilight Zone time. This is when you really have to work at keeping it together. You KNOW what is happening to you so don't let anyone tell you that you are imagining all of this or that you are losing your mind. Find someone in the support groups that you can talk to in your worst moments. Susan from the support group was that person for me. She had been dealing with mites for a year so she knew it was real and knew how hard it is to get people to believe and to help.

One thing I know is true is if you are going to succeed at beating these things, you must have the support of your family. No, they don't want to talk about it all the time; and you should be perceptive enough to know when you can talk about it and when they might be dealing with their own problems and just can't handle one more mite story. So just don't talk about it then, but don't try to act like everything is better when it isn't. My husband has been listening to me talk about vaccines for years. So I've gotten pretty good at knowing when I can rant a little and when he just isn't in the mood to listen. So it was the same with the mites. He has been there for me mand has helped me every step of the way. He let me cry at the beginning of this without telling me not to. He listened when I read posts about what people were trying; and he let me buy everything I thought we needed to heal ourselves and our environment. I'm lucky he is a reader and we share the same books on our Kindles because he read Mites No More and saw how serious this was. But there were times over the summer when he just couldn't keep talking about it. And I knew at those times to call Susan or my sister, who was also always there for me, and cry to them or rant or do whatever I had to do to get through that day.

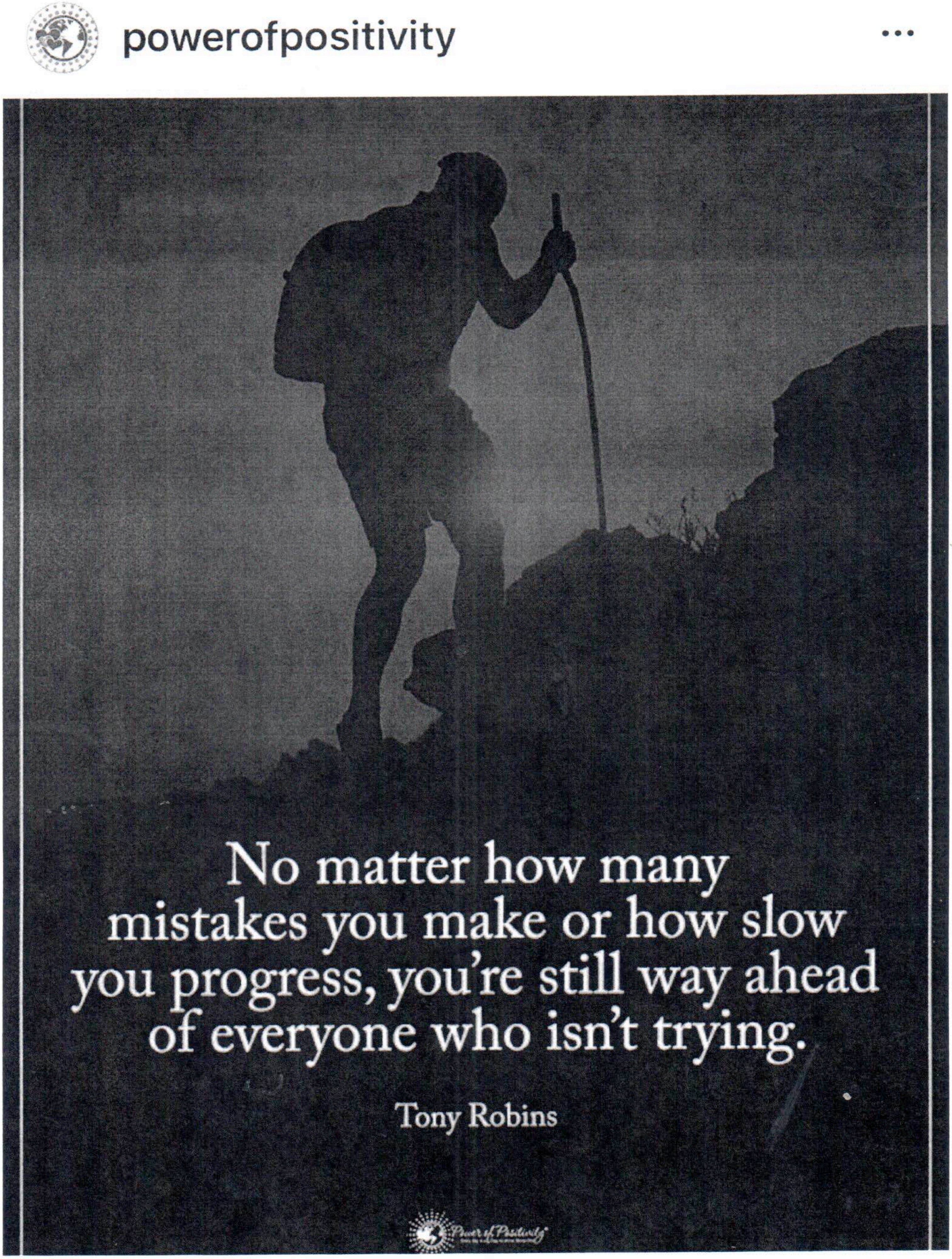
My point is you will need a support team, but don't expect them to be there every minute of every day. It's just not possible. I knew this was my nightmare and everyone else was just a supporting player in this story. So again, this is when the support groups are so helpful. You can always talk to them, compare notes, and keep telling each other to not give up, keep fighting.

I wish I could say my religious beliefs were so strong they got me through this. I believe in God, but somehow I just didn't think my mite problem was high on his list of things to take care of. I didn't think it warranted a miracle. But that's my problem, if you believe in miracles, then just keep praying for one. I did pray because I think sometimes just the act of praying, to whoever you pray to, calms your mind and can give you some comfort. I did tell God I knew he was busy, but could he just send me an angel or some kind of sign as to what I could do to get better. My dad had been gone for eighteen years, but I still miss him every day. I miss his gentle spirit and quiet guidance; and I cried many times during these six months for him. I knew he would listen to me for as long as I had to talk and knew that even if he couldn't tell me what to do to win this battle, he would fight with me in whatever way he could. There were times when I felt his presence in the early morning hours after a sleepless night. I would feel him telling me not to be afraid, to fight and do whatever I had to do to win this, so I did.

If you are all alone in this mite fight, I hope you find someone in the support groups to take you under their wing and help you. Don't be afraid to ask for help. Ultimately, we are all alone in the middle of a sleepless night with our fears and worries. Dig deep inside of yourself and find your inner warrior. In your worst moments, know that you are the one that will have to help yourself. Believe in yourself!

Sometimes the only answer
people are looking for
when they ask for help is
that they won't have to
face the problem alone.

Mark Amend, www.livelifehappy.com



powerofpositivity

No matter how many mistakes you make or how slow you progress, you're still way ahead of everyone who isn't trying.

Tony Robins