

- Fran: Actually, my chronic pain started after my son was born, and so I needed to find help with care, because I was not allowed to lift him. And so I had to find people to help me with that. So it made adjustments in my marriage and with my child, and with that came a real issue of self-esteem.
- Interviewee 3: Psychologically, it's pretty devastating. You're almost overnight, thrown into a whole different life and you're a different person, you're a new person. I mean, the old you is gone. You can kind of ruminate and look back and try to reach back for that old life and old person in your head and think like, somehow you can magically get it back, but it's gone. You can't, and so yes, it's devastating.
- Host: Life throws enough at you as it is, but how do you cope when you have chronic pain? Often, people with pain find themselves having trouble keeping up with responsibilities they used to handle without a second thought. Small problems begin to seem insurmountable. Stress becomes an exhausting constant, bringing with it, increased pain and a growing feeling of hopelessness. Even if you suddenly had the energy, where would you begin? How can you stop feeling swamped and get yourself back on solid ground?
- In the American Chronic Pain Association's 10 steps from patient to person, steps three and four are learn to set priorities and set realistic goals. These two steps can help you find a starting point and a path back to a more satisfying life.
- Priorities are the prime objectives of your life. They are the things that matter most, the things that take precedence for you.
- Penney Cowan: I think anyone living with pain realizes how hard it is to function in the normal lifestyle. And for so many people with pain, all of the things that we used to just take for granted, you know, cleaning the house, working in the yard, working in the workshop, taking drives, just playing with your children, they were all just part of our everyday life we took for granted.
- But when pain takes over your life, those things fall by the wayside, because it may increase your pain or you're afraid it'll increase your pain and so we let all those things go. And it's really important for us to really sit down and think about, what's the most important thing in my life? Where am I going to start? If I'm going to regain some control of my life, I need a starting point and that's what understanding what your priorities is all about. So you have a reason to get out of bed in the morning and hopefully, by starting this and focusing on your priorities, you might actually put some joy back in your life.
- Interviewee 1: Well, I have a young son. He's three and he's obviously a priority and the priorities aren't that different from where they were before, but you're just more focused on them and some of your long-term thinking drops away. You're not as focused on where are we going to be in 20 years, or what's our 10-year plan? You're just hoping that at the end of this year, you're doing as well as you were at the beginning of it. And a lot of people live that way, but for me it's new. So

it's just paying bills, keeping our head above water and having good days and savoring them and focusing on them.

Host: You can have a number of priorities, but the trick is to select the things that are most important to you, then rank them in order of importance. Once you've done that, you have a place to start and a guide for making decisions about where you want to go.

Penney Cowan: So how do you determine your priorities? A lot of things have been pushed to the side, you haven't done them because of fear of the pain, and you have a bad pain day, but you need to have a starting point. You need to have a reason to get out of bed in the morning.

So what you want to do is to get the 3x5 index cards and carry about 10 of them around with you in a pocket. And every time you think about something that you would like to do or that you have to do, write it down on a card. You don't have to do anything, just write it on the card, put it aside. When you think you have everything written down on those cards, take them out, lay them down on a very large table and just step back and look at all the things that you've identified. Just read each card, look it over and ask yourself, "What can I do today? Where can I start?" And you pick up that card.

And now you have a starting point, you have a place to begin. And you may want to pick up one or two more cards that you're not quite sure about, and then you can take the other cards and you can just put them in different piles. Things that you absolutely have to do, things that you thought about might be important, and then the things that you enjoy, because we can't always focus on things that we just have to do. We need to put some fun back into our lives, because pain takes that away.

Host: Try to think of all the things in your life that need your attention and list them. Be sure to include your interests and things you enjoy doing, as well as your responsibilities. Take your time and don't worry about getting all of these things taken care of right now. You're determining your starting point, not the whole race.

Once you have your list, rank the items in order of importance. Now you have an idea of your priorities. This will help you determine where to start taking action by setting goals for yourself.

Interviewee 1: I am here with my son. My son is laughing, playing with the train set. I bought him that train set. You can go through the day and just realize where you are and what you have. It may not seem like a lot, but it can be enough.

Interviewee 2: It's okay to fail. I mean, in the context where failing is actually learning. As long as you're moving forward, you're probably going in the right way.

Interviewee 3: I'm sitting here and I have a lot of pain, but I'm here, I'm alive, it's a good day. And you have to look at that. It's sort of this ... I do this mantra of, in the morning and at night, and when I lay down, and I just say, "I am at peace." And the first thing when I awake in the morning, "I am at peace." And I just want to end and begin my day with a good thought.

Penney Cowan: Sometimes things happen in life that we have no control over, and even though we have our priorities set and we're determined, this is what we're going to do today, you may have to put that aside. And that's okay. Later on, we're going to talk about our basic rights. One of them is to change your mind. That means to be more flexible, not to be so hard on yourself.

And even though you have your priority identified, sometimes you just have to redirect your attention onto something else, because it's calling for you. And that's why they are on different cards, so we can shift them around. The important thing is you have a starting point. You have a place to begin, you've made a commitment to yourself to begin your journey from patient to person.

Host: In the next part of our video, we look at setting goals for yourself. How to select them, how to plan for them, and how to measure your progress at achieving them. Pain is a powerful adversary. It can drain you of energy, concentration and eventually, your will to get anything done at all if you let it.

Maybe you remember from science class that it takes more energy to start a body moving than to keep it moving. It's the same with goals. Achieving the first one is more difficult than the second or third. Meeting a goal gives you confidence that helps you attain the next one. So to achieve that feeling of momentum, start by determining a small goal you know you can achieve.

Penney Cowan: In our ACPA groups, we always have our members set realistic goals for one month at a time. One woman in the group had diabetic peripheral neuropathy. Her hands and her feet were always numb, but her goal for a month was to bake cookies by herself without any help, because she hasn't been able to do that in a long time.

After the first meeting, she went home. A couple days later, she tried to bake the cookies. Didn't work. She came back to group and they said, why don't we break it down into small manageable steps? So over the next three weeks, what she did was she'd make the dough, she refrigerated it till she got it complete, put it in small bags and baked a few of them at a time and then froze the cookie she'd baked.

At the end of the month, she had accomplished her goal. It was within her power, she had those cookies, she felt like she had just climbed Mount Everest. She felt so good, because she had focused on her abilities. She left those disabilities behind and focused on what she could still do.

Interviewee 3: You just have to constantly set different goals and if you make it, fine. And so sometimes I'm two steps forward and then it's one step back and you can't let that get you down. You just have to keep on and I think that's ... this has been 31 years of chronic pain. It's a long time. And you just have to keep on surviving and being persevering.

Host: With each positive step you take, your confidence will build, but be sure to monitor your body's responses so that you don't do too much and suffer a setback.

Penney Cowan: Chronic pain is interesting because it's never consistent, it's never at the level 10, day in and day out. We actually have good days and we have bad days. On those good days, what we try to do is as much as we possibly can, because we feel so guilty that we haven't been fulfilling our role. And so we start out doing whatever it is that we have to do that we feel we need to do, and we feel an ouch. We feel that first ouch and we totally ignore it. We can tolerate a lot more pain than that. The second ouch comes along. We ignore that one, and the third and a fourth, and we don't stop until our body is screaming.

Two things happen. First of all, we convince ourselves we can never do that activity again. It increased our pain and secondly, the next day is going to be very painful. But just imagine, if after that first ouch you stopped and rested, maybe only worked for a little bit that day, paced. And next day, you might actually have another good day, and to work a little bit more. You might actually have three or four good days. You have to listen to your body, you have to know when to stop, you have to be realistic about your abilities.

Interviewee 3: I used to ride a bike and that I don't do anymore, okay? And I would play tennis and I don't do that either, but I can do things with my grandson that are physical. And these are boys so you know he's climbing everywhere and there's baseball and football, so there are things I can do with him that take the place of that. And actually, you know, are much better.

So that's how I do things. If it's something I physically say I can't do it, I like to then rephrase that with what I can do from it.

Interviewee 2: I would, any time I felt good, I would always try and get my whole list that I had done in one day, and then I would suffer for a day, two days or a week afterwards. And now I just try and whittle off a little bit at a time, and if I don't get something done because I don't feel good, there's always another day.

Interviewee 1: If you are having a good day, don't deprive yourself of good moments and good hours, unless you really enjoy cleaning out the shed. Don't deprive yourself. It's okay to enjoy a good hour and not feel like you have to cram everything that you were supposed to be doing into that time.

- Host: Give yourself permission to be less than perfect. Mistakes are natural, especially if you have been inactive for a while. The important thing is to keep trying and keep making progress by achieving realistic goals that you can build on.
- At first, you may not even believe you are making progress, but over time as you look back over the goals you have met, you will see how the small steps you took became significant when you added them up.
- Penney Cowan: Not that you've accomplished your goal, give yourself credit, take time to celebrate that achievement, and then think about other things that you want to accomplish and how you might be able to do that by breaking them down into small manageable steps and staying within your ability to make it happen. You focused on your abilities, not your disabilities and over a long period of time, you can move forward in regaining control of your life.
- Interviewee 2: I was able to make a trip to Italy and I was very proud that I could make it through, because I had a lot of doubts. It was something that my wife and I only dreamed about and basically, to have been able to do it was absolutely gratifying and it was a trip of a lifetime.
- Interviewee 1: I've just started exercising again and have been able to do that. I was not able to really handle that before. So I can't say that there's a huge number of things that we're not doing now that we would have before. It's just that I have to ... my internal life and how I participate in them is different. You just have to learn to discipline yourself to enjoy, okay, we're going here for fireworks. It used to be kind of no big deal, but now, okay, just handle the pain, realize that you're at this firework display with your son and be happy that you're there.
- Interviewee 3: Occasionally, at the end of something, you go, "Yes." You get that rush, that feeling that you've done something that ... "Wow, I really did do that. I did 15 jumping jacks, that was a great, Fran." And I think it's also important that when you do something like that, you really say, "Yeah, that was great," so that you get that feeling. You give yourself that good feeling.
- Host: As your knowledge and emotional strength increase, you will focus more and more on what you can do, instead of what you can't do. Eventually, despite chronic pain, you will find yourself acting on your priorities by taking on the projects that seemed so impossible when you first began. That is when you'll know you have achieved something special. You are no longer allowing your pain to define you. You will have moved from identifying yourself as a powerless patient to seeing yourself as a person with abilities and value.