

Colin and Georgina **Emotional and psychological support**

Colin

Emotionally, this is the one thing that you have some control over. There are no cures, there are no treatments for Kennedy's. The only thing is exercise, eat properly and your head. And your head is the most difficult thing to try. Even if you haven't got Kennedys, it's really, really difficult. So too much time to think. So I've thought of strategies for how to compensate for it.

First thing is don't think of the future. So if you think of that, where you going to go? Down. So you don't, You pick sunny days, cheerful. You get out as much as you possibly can. Exercise is a great way of doing it.

We go swimming three times a week, 40 minutes. That's as much as my body can take. I come out, it's the only exercise you come out cleaner than you went in, which is a good sign. It gets me stretching, it makes me feel positive.

I won't go onto the Kennedy's website, I won't look at what other people are suffering because that would be huge anxiety. I just live my life and if Georgina thinks something is useful for me to know, she tells me. But when we, we've been to several Kennedy's get togethers and I've come away from them utterly depressed, I don't want to know because it's so bespoke.

When someone comes along and says I've got it, you go just calm down. You might, you might vaguely know you've got it, or you could be in the wheelchair. My one cousin stopped worked at 28 and was in a wheelchair by 30.

I have a mantra, go on, laugh. A Welshman with a mantra. Get well is red. Top of that. Stay well it's green. Your chakra colours red and blue, blue sky, blue ocean, blue. So when I'm doing my mantra, I'm looking at my leaded lights which have all the colours which are all joined together and I focus on that and I feel that the only way I'm keeping myself together is me. Is my will.

Don't get the impression that I stay at this level. I have been so deeply depressed and what stops me from doing anything really stupid is this.

Georgina

I think it's very difficult. That afternoon we went to last week, as I said, no, there was, it was in the garden, there was music being played. I thoroughly enjoyed it. I had a great time. But Colin, yes, it was difficult and he couldn't hear so he came home early.

But you went into a deep fug that evening. You were depths of depression and that does have an impact on me as well. You know, I could have gone there on my own, but that's not the right thing to do either. So it's not always easy.

Colin

In winter, my muscles seize up. I actually on a cold day can't speak. My facial muscles stop working. So that's why we go away. When it comes to depression time. I have been offered antidepressants, I've refused them because you just go along level, you don't go down, but you don't go up.

Georgina

You don't experience the highs or the lows. I mean, today it's glorious despite what the weather is forecasting is absolutely fantastic and it's this that lifts your spirits. Looking out there, seeing the blue skies. I have to be understanding, I have to think, no, it's not, I haven't done anything wrong, but it's not what I've done. It's just a situation.

Colin

Well, here's the joke. I did three years of night in school on counselling, how to be a counsellor. I've done all the bits that a counsellor would do with me. There isn't anything anybody could explain to me or I could get off my chest.

Georgina

I don't. I don't totally agree with that. I think you would benefit from some kind of situation where you were talking to people where you could actually share ideas and things. I think you possibly would benefit from that.

Colin

If I can sort out something on the computer, I can fix something in the house. If I can actually be of use rather than a hindrance, that's enormous. I do all the books, the financial side of it. I do all the brain power type things.

Georgina

And we can both, we discuss things and we both approach problem solving from different ways and that brings up a discussion as well. So I think that keeps you going, keeps us both going, doesn't it? It's important.

Colin

I need stimulus, but today is the only day that counts. Yesterday's gone. Tomorrow when it gets here. As long as I can get off the toilet today, dress myself today, eat today. Yeah. Live for today. Plan for tomorrow but live for today.