

1

00:00:00,210 --> 00:00:05,530

Good afternoon, everybody. Well, I applaud a) the fact that you're here and b) you're still awake.

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00:00:05,540 --> 00:00:09,150

I wouldn't normally be at this time because it's normally my sleepy time.

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00:00:09,540 --> 00:00:14,760

I am not a PhD, I am not a doctor. I'm just a simple little old patient.

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00:00:14,970 --> 00:00:23,040

What I'd like to do is to take you back to a year or two to 2009, because 2009 was a significant year for me.

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00:00:23,430 --> 00:00:26,780

And I'd like to tell you a little bit about what's happened since then.

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00:00:26,940 --> 00:00:33,570

Those of you who are patients will probably be going, yeah, I agree with some of that and I totally disagree with others, which is just fine.

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00:00:34,110 --> 00:00:37,110

My wife snores like a warthog.

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00:00:37,920 --> 00:00:41,340

My wife snores like a warthog. You can't say things like that.

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00:00:41,340 --> 00:00:45,330

And I've no idea whether warthogs actually snore. So do I.

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00:00:45,990 --> 00:00:50,100

But the downside with that is that for a short period after

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00:00:50,100 --> 00:00:54,990

I was involved in a road accident and I had kicking syndrome or whatever it's called in posh medical terms.

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00:00:55,200 --> 00:00:58,769

We decided we wouldn't sleep together and that was the, that's

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00:00:58,770 --> 00:01:03,270

really bad news in terms of my health, not only because of the obvious,

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00:01:03,270 --> 00:01:09,750

but when I started getting night sweats in huge quantities, I was the only person who knew about it.

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00:01:10,230 --> 00:01:19,110

So it didn't disturb her sleep, and so being a male, of course, I ignored that because, I mean, I did believe in man-opause or men-opause.

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00:01:19,350 --> 00:01:22,950

And I know when she was pregnant, I was the one that always suffered, not her.

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00:01:23,190 --> 00:01:28,349

So I knew about all that stuff. So I ignored it for a while.

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00:01:28,350 --> 00:01:36,600

Then we were out on an October morning in, not far from here, actually, beautiful autumnal morning.

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00:01:36,600 --> 00:01:42,560

We were walking. We walked a few miles. My wife was getting further and further ahead of me, which was a bit of a surprise.

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00:01:42,570 --> 00:01:45,600

She is much younger and fitter than I am, but generally I can keep up.

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00:01:45,990 --> 00:01:52,830

But that day I just could not keep up at all. I thought hang on, there's something a bit more serious here going on,

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00:01:52,830 --> 00:01:58,110

so I decided I would do a very un-man thing and go to the GP because I hadn't done doctors for years.

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00:01:58,350 --> 00:02:01,919

Couldn't be bothered, couldn't find time. Find lots of excuses.

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00:02:01,920 --> 00:02:09,030

All the male stuff that none of the men in here will know about. But I decide to go to the GP and it was the GP I hadn't seen before.

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00:02:09,180 --> 00:02:16,140

Now I actually am of the theory that it's a good idea to see a different GP occasionally, because sometimes they may have completely different ideas,

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00:02:16,180 --> 00:02:22,979

and they haven't read all your case notes, well they might not have even read anything, but you're regular GP might not have done, but it might have done. Anyway,

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00:02:22,980 --> 00:02:29,820

the GP said I was absolutely fine, basically "bugger off". So I disappeared and I was still having some of the same issues.

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00:02:30,060 --> 00:02:40,260

So I happened to be able to see my regular GP and he took about 30 seconds or so said "I think it might be follicular lymphoma".

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00:02:40,440 --> 00:02:45,000

Never heard of it. Didn't even know it was cancer because, you know, I know nothing.

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00:02:45,390 --> 00:02:51,240

And so as a consequence of that and I need to get the date exactly right, because it's important,

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00:02:51,600 --> 00:03:00,360

the 23rd of December 2009, so a little bit close to Christmas, I went to something called a node biopsy.

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00:03:00,360 --> 00:03:07,410

You see, I have to read the medical terms because I don't know very much. Anyway, I remember having this node biopsy and this guy in the hospital said "do you want to have a look?"

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00:03:08,050 --> 00:03:17,340

I thought you've got to be bloody joking, that's the last thing I want to do. Anyway, I'm just laid out on the bed thinking "I'm going away to the Lake District", like the guy

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00:03:17,340 --> 00:03:22,200

this morning, I'm going away to the Lake District in about 24 hours and it's starting to snow outside.

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00:03:22,800 --> 00:03:26,820

Well, we still went to the Lake District. It snowed outside. In fact, it snowed a hell of a lot.

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00:03:27,180 --> 00:03:31,440

And I felt really bad on 23rd, 24th.

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00:03:31,680 --> 00:03:38,999

And I'd have to say my cancer journey, that was probably the absolute low because on the 25th it was a bright,

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00:03:39,000 --> 00:03:44,219

crisp morning and everybody in the family, and the whole family were up in this house we'd rented,

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00:03:44,220 --> 00:03:52,920

went out and had a glorious Christmas walk and came back afterwards and told me about the pretty robins and the beautiful snow on the ground,

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00:03:53,160 --> 00:03:59,460

and I was feeling really bad. One of the things I did, I got a bit of paper and I wrote down, even my wife doesn't know this,

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00:03:59,550 --> 00:04:02,730

So don't tell her those of you who know her, because there are people in here who know her.

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00:04:03,630 --> 00:04:12,250

I got a piece of paper and I wrote down all the important people in my life and I wanted them to pass on some message to them in case the worst happened.

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00:04:12,260 --> 00:04:15,990

I've still got that piece of paper, it's hidden amongst my papers.

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00:04:16,000 --> 00:04:21,959

You know, one day maybe my wife will find it. Maybe, you know, she'll pop her clogs before I do.

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00:04:21,960 --> 00:04:26,970

Who knows? But I did need to write down that paper and that did give me a little bit of a lift.

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00:04:27,510 --> 00:04:34,050

And Christmas was tough. Really tough. We eventually get out of the snowbound house and found our way home.

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00:04:34,200 --> 00:04:40,409

And early in January, I went to the consultant, and the, Oh family,

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00:04:40,410 --> 00:04:43,559

I should have said. Family. Vital. Talk to your family.

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00:04:43,560 --> 00:04:47,520

Keep families in touch. You need your families, your friends.

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00:04:47,760 --> 00:04:52,440

When you're on the cancer journey, don't be amongst the huge number of people I come across

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00:04:52,440 --> 00:04:57,360

who say "shhh don't tell anybody, my partner, my wife doesn't know I've got this cancer,

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00:04:57,360 --> 00:05:02,040

but I wouldn't, couldn't possibly tell my kids." Personally that is almost a criminal offence.

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00:05:02,250 --> 00:05:09,920

So keep them on board because you need them. Anyway. I went to see a fantastic consultant and the support team there

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00:05:10,740 --> 00:05:14,200

And I had my lovely wife with me and she took notes.

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00:05:15,420 --> 00:05:18,719

I've got those notes and they're blooming good notes.

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00:05:18,720 --> 00:05:25,740

I was stunned because as the patient at that time probably I absorbed 1% of what was said to me.

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00:05:26,550 --> 00:05:30,000

I can see people nodding, I think 1% is probably an overestimate.

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00:05:30,300 --> 00:05:31,709

So I'm very grateful for those notes.

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00:05:31,710 --> 00:05:37,380

And I actually looked at them the other day and I was quite surprised by some of the things it said, like don't eat seafood.

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00:05:37,620 --> 00:05:42,200

I'd totally forgotten about that, I do eat seafood occasionally.

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00:05:42,210 --> 00:05:44,370

So yes, take notes, take somebody with you.

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00:05:44,520 --> 00:05:54,720

And the support people I first met, like the various haematology nurses and support people I was given and the care and the love and the attention,

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00:05:55,170 --> 00:05:58,980

and I tried to respond with mutual respect,

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00:05:59,310 --> 00:06:05,580

to establish a relationship with those other people because I knew they were going to be really important to me on my journey,

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00:06:05,700 --> 00:06:08,130

which led, of course, to my first chemo session.

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00:06:08,550 --> 00:06:16,410

And they say to you, this is the room you'll have chemo in and you can bring your own music and you bring your own DVDs.

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00:06:16,410 --> 00:06:20,879

And I thought this will be alright, it's like going on a nice, nice chilled afternoon.

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00:06:20,880 --> 00:06:25,950

Well, I went in. No bloody DVDs, no music, thank the Lord!

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00:06:26,790 --> 00:06:35,190

But I did find a really comfortable throne. It was a big comfy chair and that became my habit and that was really nice to have that chair.

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00:06:35,940 --> 00:06:39,780

And I haven't got my glasses on so I can't see the nurses but I know there are a couple of nurses here,

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00:06:40,050 --> 00:06:43,590

who will say "John and his bloody chair", if you're looking for that chair.

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00:06:43,980 --> 00:06:50,130

And it was great because it was a superb position because I could see everybody else and keep an eye on what was happening to them.

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00:06:50,760 --> 00:06:55,139

But, but then I took a book with me first time, as I thought well that would keep me busy.

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00:06:55,140 --> 00:07:02,310

But the thing that, the person who was the absolute worst were visitors, people came with visitors.

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00:07:02,310 --> 00:07:08,970

Now I understood why people had visitors, and I know why people would love to have visitors, but I hated visitors.

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00:07:09,240 --> 00:07:13,170

So what I used to do is I used to have a little iPod and I do mean iPod.

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00:07:14,140 --> 00:07:19,890

You know, the earlier version of the iPod about that big. So I listened to music so I didn't have to hear those people.

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00:07:20,310 --> 00:07:24,350

And to be honest, I've done a lot of hospital visiting, by 10 minutes

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00:07:24,360 --> 00:07:27,780

I've kind of run out of words anyway with people you know really well.

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00:07:27,780 --> 00:07:34,230

It's hard work, isn't it? So I personally loathe visitors, but I understand perfectly why they were there,

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00:07:34,710 --> 00:07:44,430

but as well as the fantastic people who work there and use catheters, because I've got, not catheters,

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00:07:44,430 --> 00:07:50,009

wrong word! Who's listening? Nobody's listening. Catheters, catheters. That's entirely

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00:07:50,010 --> 00:07:54,360

different than any of those other things that they stick in your arms

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00:07:54,360 --> 00:08:00,360

and sort you out. Cannula! Thank you very much. Cannula, because I've got world class veins.

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00:08:00,360 --> 00:08:03,839

It's the only decent thing about me. So it always brought a smile to haematology

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00:08:03,840 --> 00:08:13,260

nurses. They thought well it's a warm day, John's nurse, at least he's, he'll probably carry on talking until he falls asleep, but his veins,

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00:08:13,260 --> 00:08:16,589

his veins will be alright. And so that was great.

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00:08:16,590 --> 00:08:21,090

And one of the fantastic things that happened to me there as well, if it's ever offered to you,

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00:08:21,360 --> 00:08:26,310

was a Red Cross nurse would come around and offer you a hand massage.

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00:08:26,670 --> 00:08:31,440

And that was the most wonderful thing when you're having chemo, somebody's nodding there.

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00:08:31,440 --> 00:08:35,759

Yeah. So, you know, I'd love to meet the lady. I don't know who she is or where she is.

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00:08:35,760 --> 00:08:40,740

One day I come across her and she, and that was just, I was in heaven when that was happening, that was just brilliant

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00:08:40,980 --> 00:08:46,640

as part of the process. At the end of the session, the used to give you happy pills.

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00:08:46,680 --> 00:08:49,620

They do have a proper name. Steroids, is it?

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00:08:49,920 --> 00:08:55,799

And they were either pink or white and then the colours changed, and one colour was much better than the other.

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00:08:55,800 --> 00:09:05,760

And I used to have about 21 because I think they're sort of weight related and so I'd be able to cut anybody's lawn for the next three days after I'd had these happy tablets.

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00:09:05,760 --> 00:09:11,910

So they were really good, and they made me happy and it enabled me to get a bit more energy.

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00:09:12,120 --> 00:09:16,290

And energy is really important and as is fitness.

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00:09:16,290 --> 00:09:23,910

So what I started doing was I started chopping wood because we have a wood burner and that was good exercise.

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00:09:24,300 --> 00:09:30,420

And as things got better, I thought I might get arrested bringing this in.

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00:09:30,600 --> 00:09:32,520

This is a log splitter, I'm told.

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00:09:34,050 --> 00:09:44,490

I daren't use it now, having had a couple of other little operations in other regions which would discourage me from using things like that.

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00:09:44,820 --> 00:09:52,230

But yeah, it was great. Also on the journey, I had quite a number of CT scans because the,

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00:09:52,290 --> 00:09:59,400

the cancer was focussed largely in this zone and I didn't like CT scans, particularly

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00:09:59,610 --> 00:10:08,310

because I don't like aniseed. And at that stage, you had to drink a virtually a jug full of horrible aniseed.

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00:10:08,730 --> 00:10:13,230

And my tip to anybody if they still use it, I don't know, you can actually get orange juice instead.

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00:10:13,530 --> 00:10:14,850

Which wasn't offered to me.

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00:10:15,330 --> 00:10:24,000

But I have to say that the kindness that I received throughout the journey from everybody was amazing.

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00:10:25,020 --> 00:10:33,330

And so I always used to make a point, if erm, when I was going for my six monthly check to try and buy raffle tickets.

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00:10:33,510 --> 00:10:36,710

Yeah, I know there were, are the two nurses still here?

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00:10:36,720 --> 00:10:41,380

Are either of them still here? Or have they gone home? Oh, there you are.

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00:10:41,400 --> 00:10:44,940

Those are for you, by the way, those are for you.

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00:10:44,940 --> 00:10:48,030

That's my thank you. You won't get much next time I come and see you.

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00:10:48,840 --> 00:10:54,380

I did say I'd embarrass you. That's your box of biscuits, so it's important,

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00:10:55,140 --> 00:10:58,350

You keep the people that matter, you know? You look,

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00:10:58,380 --> 00:11:06,390

you look after them. One of the other things that I'd also pass on as a valuable tip is how you pace yourself.

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00:11:07,080 --> 00:11:13,710

I decided that when I was doing activities, I'd have a magic half hour. You do half an hour, and then you stop.

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00:11:14,280 --> 00:11:19,350

However wonderful you may be feeling, do life in kind of half hour chunks,

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00:11:19,680 --> 00:11:27,420

and that made a huge difference in terms of building up stamina and exercise, and that was to do with self preservation.

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00:11:27,810 --> 00:11:31,230

And the other process I went through was kind of reconnection.

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00:11:31,350 --> 00:11:34,079

I don't know about you folks, but I'm still of an age where I send

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00:11:34,080 --> 00:11:39,750

Christmas cards, the numbers get slower and slower and the book that has people's addresses, gets more and more depressing too.

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00:11:40,560 --> 00:11:47,880

But I've been guilty and maybe one or two of you have, you send a Christmas card out and said, well, I'll send the Christmas card to them, probably won't,

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00:11:48,000 --> 00:11:51,659

I know I won't see them this year, but I still send them a Christmas card.

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00:11:51,660 --> 00:11:56,620

And you think, why? I've done quite a lot of reconnecting and that's really quite nice.

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00:11:56,640 --> 00:12:06,030

It's not saying I see closure coming on. Oh, it's inevitable to all of us, but that reconnection is quite refreshing and quite healthy.

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00:12:06,510 --> 00:12:08,070

And I recommend it to you.

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00:12:08,520 --> 00:12:18,179

One of the things that was also mentioned to me, indirectly, was something called the haematology support groups and I thought haematology support

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00:12:18,180 --> 00:12:27,540

groups, don't know about that, especially when I met the woman in charge, my God, Carol! Who's a superstar, who is an absolute superstar.

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00:12:27,550 --> 00:12:34,440

She knows I'm pulling her leg. And I really recommend that the value of haematology support groups I know there

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00:12:34,440 --> 00:12:38,880

are a lot of people in the audience who attend haematology support groups,

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00:12:39,150 --> 00:12:42,390

whether it's the one here in York or the one here in Northallerton.

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00:12:42,630 --> 00:12:51,630

I do both. Even though it's a while, I'm not a masochist, but it's a wonderful process of sharing that goes on.

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00:12:52,290 --> 00:12:56,639

The challenge is timing. When do you join a haematology support group?

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00:12:56,640 --> 00:13:00,930

And there is no answer. Sometimes people say I should do it early on my chemo journey.

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00:13:00,930 --> 00:13:04,319

Some people say later, but whatever works for you. But I wouldn't,

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00:13:04,320 --> 00:13:13,340

I really would recommend the friendship, the joy, the sharing, the generosity that you get out of the haematology support group.

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00:13:13,420 --> 00:13:21,850

The York one tends to be a very broad range of cancers that's represented, and the Northallerton guys are going to say,

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00:13:21,990 --> 00:13:23,700

"You're a myeloma group, aren't you?"

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00:13:23,820 --> 00:13:30,660

And yes, they are very much a high percentage of myeloma, it's by chance isn't the two groups, both entirely different.

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00:13:30,930 --> 00:13:39,810

But if you could, you know, take one nugget away to pass away to colleagues, I really would encourage you to contemplate using the haematology,

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00:13:40,980 --> 00:13:45,270
the haematology support group, both as give and take, because it works really well.

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00:13:45,270 --> 00:13:48,780
And I can think of lots of occasions where people ask questions

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00:13:48,780 --> 00:13:55,200
and one is very clear in my mind, because I can relate to this and I don't know who asked it but somebody said

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00:13:55,440 --> 00:13:59,190
"do your fingers ever freeze up, do you hands ever freeze up and lock?"

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00:13:59,910 --> 00:14:03,960
And we went around the room. Yes, yes, yes.

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00:14:04,110 --> 00:14:09,360
Did your consultant say it was to happen? No. No. No. But that sort of sharing,

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00:14:09,360 --> 00:14:10,770
you think, well, I'm not nuts.

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00:14:11,100 --> 00:14:19,470
And it's an enabling process where, for example, you think, Oh, well, who do I ask, you know this could be like a really dumb question.

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00:14:19,780 --> 00:14:22,380
But you can ask anything and you get so much back from it.

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00:14:22,710 --> 00:14:31,620
So that would be one of the really key things I would recommend to you as part of the journey.

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00:14:32,470 --> 00:14:36,090
A bell rang for me this morning during one of the slides.

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00:14:36,300 --> 00:14:44,370
Well, one slide, not only did I see two doctors, but I was in fortunately having Rituximab in 2012 I had the expensive version.

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00:14:44,610 --> 00:14:50,009
So I'm the Â£18,700 and whatever it was guy who had that.

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00:14:50,010 --> 00:14:55,620

And that also made a very big difference in terms of my progress.

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00:14:55,860 --> 00:15:01,260

Now I did threaten that I wouldn't talk for very long, which I've tried not to do, but I hope some of the tips are useful.

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00:15:01,500 --> 00:15:06,149

There's one tiny little thing I want to finish with, and that was the slide.

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00:15:06,150 --> 00:15:09,180

It's the only piece of technology I think you're going to introduce for me,

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00:15:09,180 --> 00:15:14,550

which is a welcome bit, and that is a quote from George Bernard Shaw that I quite like,

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00:15:14,850 --> 00:15:20,820

and that is I want to be thoroughly used up when I die, for the harder I work, the more I live.

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00:15:21,030 --> 00:15:27,000

I rejoice in life for its own sake. Yes, it's part of a longer quote, those of you know George Bernard Shaw.

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00:15:27,390 --> 00:15:30,420

But I quite like that. Thank you very much for your time. Keep well, folks.