

Hi, my name is Kevin. I was forty-nine years old when I was diagnosed with incurable prostate cancer. That was two years ago.

## Background

So before I had prostate cancer my life was a typical forty-nine year old man. I went to work, I enjoyed my job, my job was pretty full on and it was possibly eleven hour days most days, and some weekend work. I came home. I had a family. I played football. I did a little bit of running.

I'm like my dad and my dad's side of the family and they live forever. You know my great grandma was a hundred and one when she died. I think my, my dad's eighty-five now and still alive. So I thought, I had every right to think I think that I would live to at least eighty-five because my dad's eighty five and all the men on his side of the family, and women in fact have all pretty much lived beyond that.

So to suddenly find out at forty nine that you're not probably going to make sixty and probably not even fifty-four and probably less than that is, that's quite a, a shock.

## Diagnosis

I don't think I'd ever had any time off sick working at the bank for about the previous ten years. Um I think I might have had one day when I had a dodgy stomach or something and then suddenly uh I had a, a symptom of going to the toilet a bit at night, and then a few other things down there if you like, in, below the waist that, that the, the sum of the parts made me think that maybe something wasn't quite right somewhere over quite a short period of time, over uh six weeks.

And then we came to November the 6th where after having loads and loads of tests and uncomfortable biopsies I then sat in front of another urologist who then said to me you've got between two and ten years to live, but probably think three to four. He actually made a real point of saying don't think ten, because he was quite blunt about it, um and he was very apologetic, but in hindsight I don't think there's a better way of telling you. He could have spent five minutes pussyfooting around but actually bad news is bad news. Let's get on with it and as you can imagine um lots of tears.

And then we went and saw a, an oncologist who then sort of said it's not all doom and gloom and there's lots of drugs out there nowadays

and we can do things to sort of prolong your life that are frequently successful, but not always successful. Um so we walked out that meeting a lot happier than we did uh the first one. In fact the first, we called the first doctor Dr Death and the second one Dr Life because they were just so chalk and cheese about the same situation.

The first thing I asked once I was told it was incurable was how long I had to live, and the urologist said you've got two to ten years, but think three to four. In my head straight away it was two years. It wasn't three to four, or ten. So that two year period started absolutely at that moment in time. So I saw my life ticking away quite quickly from then.

## **Treatment**

I thought after chemotherapy starts it's just going to be a neverending cycle of sadness, pain, feeling ill, everyone feeling sorry for me, never going to work again, never having fun again and then just gradually going downhill. I, I hired a house over on New Year that year and paid for my two best friends and their families. We went away down to Woolacombe Bay in Devon, because I actually thought it was the last holiday I'd ever have where I felt alright, and we went down and we just sort of partied like it was, as Prince would say, 1999 you know.

We went out there and just gave it large, because I knew that only five days later I'd be starting chemotherapy and that was the end of my living life as far as I was concerned. And I came home from the first dose of chemotherapy and I felt like I had to behave a certain way. It's almost like if I went and saw the Queen I know I'd have to stand up straight and only speak when spoken to and say ma'am and all that sort of thing.

And I came back from chemotherapy with this view that I had to be ill, and I shuffled out of the car, up the steps into my front room, sat in the armchair a bit like a really, really old person, no offense to really old people, but really old person. And my wife brought me my tea and I ate my tea and actually it tasted okay but I felt like it shouldn't.

I thought I was going to struggle to eat it but I didn't, but I felt like I ought to. And I, I watched a bit of TV and I went to bed and I think I cried a bit in bed. And then the next morning I woke up and I thought this is a defining moment. Now is the time that I either lie in bed or get up and do something, because I could have quite easily lay in bed for the whole day.

In fact everyone expected me to lie in bed for the whole day.

## **Treatment & relationships**

I like to think that my wife and I had a fairly uh active physical relationship. One of the things that changes with prostate cancer is you are effectively chemically castrated. And so one of the first things they do when you get diagnosed is they give you drugs that, that block your testosterone, and they basically start to turn you very, very slowly into a woman or you find your feminine side. So things happen like your sexual function disappears straight away.

You start to grow man boobs or moobs. As a man you know we're all a bit devious and there are things that you might have occasionally done to make sure that your wife or partner was, was very happy so that you could um have a good as time as possible that night should we say. [Laughter] One of the lovely things about having my situation with prostate cancer is those urges have gone. I couldn't do anything any more if someone wanted me to, if someone begged me to I couldn't do it. So it takes all that pressure away. So you know the reason I'm always the way I am with my wife is because I love her so much. I just do it because I love her and that's just really nice.

## **Telling the children**

I have three children. My eldest children live with their mum. My daughter Hayley, she's eighteen, just started at university in Swansea, reading History. Um Ben is sixteen. He's just started uh college doing Engineering. And Ollie's eleven, and he's just started uh high school.

Before I told them I didn't really know what to say or how to say it. And I went on to one of the charity's websites and it talked about how you tell your children. And it said tell them all together at the same time. Um don't hide it from them, don't, don't keep it too long because they'll find out from someone else beforehand, if someone tells them, that's not good. If you tell them individually the danger is they hear different stories and put different spins on it and have different questions and then they're not hearing the same message.

They knew there was some bad news coming, and then thought I was going to tell them that my grand, their granddad was going to die and they were quite shocked when I said it was me that actually had prostate cancer and that I was going to die. Um actually that's not quite true. I didn't say I had prostate cancer and was going to die. I said I had prostate cancer and it wasn't curable, and we cried a bit and you know lots of big hugs, a bit like Tellytubbies really. [Laughter]

So it was all very family fun and friendly and had a, and had a bit of a smile and a joke and then I went to the park with, with the three kids and played football, just to prove to them that even though I had this sort of rubbish disease it didn't mean we had to stop doing things we always did.

### **Coping mechanisms - being positive**

When I was first diagnosed I was sad about everything all the time, um and I cried a lot. Most nights I'd cry in bed. I'd wake up at one in the morning and just cry for three hours, and I always remember being very conscious that I mustn't wake my wife up because I didn't want to share the burden with her. So I'd just lie there and sob quietly to myself. As time has gone on I've got better at not crying.

I just think I've decided to do three things in my life. So you could argue these are three bucket list things. The first is to enjoy myself all the time, but never at the expense of someone else. The second thing is to create the best memories I can for my friends and family. And the last thing is to raise awareness and money for the Prostate Cancer Charities because it's just so important that other people don't end up sitting where I am today.

### **Coping mechanisms - running**

And I came home from the first dose of chemotherapy and the next morning I woke up and I thought this is a defining moment. It was January and it was cold and I got up and I said I'm going to go for a run. And my wife looked at me and said no you can't go for a run, you just had chemotherapy. I said why can't I? No one said you can't go for a run after chemotherapy. And she said oh no, no don't do it, and I said no I'm going for a run. And so I got all my gear on and off I went.

And I ran three miles, and you know that's not as far as I could run, but that was as far as I could run that day. And I was very slow and I walked a bit, and I felt awful running, but mentally I felt absolutely elated cos I felt I could still do something. From then on I decided that actually being told you've got a terminal illness hasn't got to be a death sentence. It can actually be a 'live' sentence. Running is my salvation really. No matter how bad I feel I will go for a run, and within twenty minutes I feel better. It's like a miracle cure. Running is the only time when I actually feel I'm not ill.

People have started calling me Forest Gump now because I love to run so much. There, there is some evidence that running actually helps fight cancer, but mentality it's good. I've, I'm actually doing

something to fight the cancer. I may not be really but I think I'm doing something.

In my heart I definitely feel the changes I've made are going to prolong my life. They won't make it, won't be, maybe not forever, but they will prolong my life definitely. I'm absolutely a hundred percent convinced of that. How long is the bit I don't know.

## **Project management**

So when you're given some really bad news and you understand its terminal and time could be short your priorities change massively. So one of the things that makes a huge difference when you get a terminal illness diagnosis is how well you're treated by your employer and I'm really lucky. My employer have done absolutely everything they could for me. So looking after my family was the most important thing. I was lucky, I don't know if that's the right expression, but I feel very lucky that I had the forethought to take out an insurance policy and it enabled us to pay the mortgage off for example. So one massive worry I haven't got is that I know my wife and kids will not be destitute.

So right or wrongly as the, the man of the house I've always felt it's my responsibility to do certain things, and of course once you have a terminal diagnosis you realise that you can't do it all, not forever. Day to day things; like getting the car serviced you know, the electricity bill, what about the grass being cut. All those things are my jobs.

Getting rid of spiders is a job that's definitely my job. There's no one else in the house that will get rid of a spider. So that's something my wife's had to come to terms with. And as silly as it sounds right now that's becoming really important to her is how she's going to deal with a spider and she knows she's got to cope with that spider one day that she's going to find in the bath.

But she's absolutely petrified of it. It's probably one of the biggest things in her head about what she'll do when I've gone, is how to get [laughs] rid of the damn spider.

## **Family**

Interviewer: Do you think as a result of, of your diagnosis you've become a better dad?

[Blows] Mm. [pause] I'm not kind of sure what father I was like before I was diagnosed, but since I've been diagnosed I really try and make their time as good as I can. Am I better dad? I don't know. I can give you my opinion of that. I think I'm a better dad. I think I spend more

time with them. I feel a bit guilty now sometimes about not spending as much time as I should have done with them in the past, but now I definitely do all I can to do the important things for them with them.

So watch my little boy play football, um going to parent's evenings, that sort of thing that maybe work would have got in the way of before and now I'll make an effort and actually if it's important I'll go and do it no matter how dull it might be to my mind. If it's important to them it's become important to me. Silly things like uh Pokémon hunting. So I go Pokémon hunting with my eleven year old, Oliver, because right now that's important to him and when I do go to work, cos I work in London he asks me to go Poké hunting for him on his behalf to get the ones he can't get himself.

So I do that sort of thing now, um which before I would have just turned my nose up at it, but now it's quite key to make sure that I um do whatever he wants me to do. They also understand that it's sort of now or never. So I've probably had a better with my kids now than I ever would have done if I hadn't been diagnosed with a, a terminal illness.

### **Achievements - bucket list**

Now what's the average person achieved in their life? They achieve a family, yes and that's important, but if you go beyond the family what have they achieved? And surely we're not just on the planet just to have family and reproduce. So you know the, what have they done for themselves that they can look back on and say well that was great, I loved that.

The race that I always wanted to do, so the one thing on my bucket list which I wanted to do from the age of twenty is a race called the Marathon Des Sables. So in simple terms the Marathon Des Sables is a marathon on Sunday, a marathon on Monday, a marathon on Tuesday, a double marathon on Wednesday. Thursday you get off, a marathon on Friday and a half marathon on Saturday.

Interviewer: You're kidding.

You do all of that in the Sahara over sand dunes carrying twenty four pounds on your back with limited water. All your food for the week you've got to carry, your sleeping bag, all your clothes. It is absolutely full-on hardcore.

I never really thought I would make it. So getting to the start line of the Marathon Des Sables was actually my bucket list thing. It wasn't about finishing it. I didn't think I'd ever actually get to the start. I thought I would be so ill at that point in time that I wouldn't be able to go and tough it out, and even go to the desert, let alone go and do

the race. As it turned out I did do the race and I actually ran the race quite well. And I thought there's no way I could put my wife through this again by doing it all over again even though I kind of wanted to I thought I can't tell her.

And I got back and within two days she said you've got to go and do it again, and I said why. She said because it changed your life. It gave you purpose. If you look around my house there's, there's pictures and things and there's photographs of, there was only one thing on the wall that actually is from me that really matters to me, apart from the family and that's the shirt in the middle. I've never washed the shirt. It's framed and it's there cos to me it's the thing that means most that I've actually achieved.

I don't know what my wife will do it of course when I'm gone. She'll probably throw it away, but uh [laughs].

### **What have you learned?**

Interviewer: Do you, are you surprised at how strong you've been in the face of this pretty major adversity?

I don't think I've been that strong. I think that if anyone was in my situation they would go one of two ways. They would either just give up or they would try and carry on the best they can and have a good life. That's not necessarily being strong. That's just doing what you want to do.

The obvious thought when you get told you haven't got that much time to live is there's nothing good about it, but actually there is. The good is that it makes you really focus on what's important. The thing I've realised is you only have one life. That's what I've discovered. I think we all live as if we're immortal. I thought I was quite uh weak and I thought I wasn't very, I don't think, I don't, I don't like the word brave cos I think brave is a word you should use when you put yourself in a situation and I haven't put myself in a situation.

I have no option, but I think I'm quite tenacious and dogged about making sure that the life I still have is a life I want to have. So I will keep on doing things I want to do until I absolutely can't. And the third thing I've learnt is that if ever you have anything below the waist that changes go and see a doctor [laughs] cos it might just save your life.

### **Denial and hope**

Interviewer: How important is hope?

Um I don't really have any hope. I know it sounds quite strange, and I think that there will be some changes that will make some difference. I suppose I could say I hope there will be ones that will make a massive difference, but that hope is almost ridiculous, and that's not me. I don't deal in ridiculous. I deal in factual things and probability. So the probable situation for me is that there will be something that will come out that might give me another few months but is never going to cure me and it's never going to give me a whole more load of years.

Hey if something does that's fantastic and I'll have to say something again to you that's different, but uh right now hope is a wasted emotion.

## **Sadness**

I'm not allowed to dream any more. That's the problem. That's the biggest negative thing about my life is I, I can't dare dream. So for example I hoped to have see my daughter's twenty-first birthday, my son's eighteen and twenty-first birthday, and my younger son's eighteenth and twenty-first birthday, see them potentially graduate from university or college, um maybe have grandchildren, in my retirement hire a campervan and go around Europe. Suddenly all those dreams stop and you have to think really short term.

The dreams I have are for other people. So they don't involve me. That's hard.

## **Death and dying**

I panic every time I have another blood test. I sit in the waiting room waiting for the result thinking the doctors are going to come in and say sorry the test has gone the wrong way, and that would be the end of, or the start of the end. I feel more sorry for my wife than I do for me, cos I have the easy cop out. You know I'm the lucky one cos I'm just going to be dead in X month's time or year's time. She's got to live beyond that. She's got to watch me go downhill and then she's got to cope with it afterwards, and cope with the kids afterwards. And everyone else is going to expect her to be strong and all that sort of stuff and that's going to be really hard for her.

Having any terminal illness has to be lonely at times and it, and it is and there are times that only you've got it and no one else understands, and you just feel absolutely on your own. [Sighs] ] I guess when it's terminal as well it makes you realise that when you go out of this world you'll be on your own as well.



It's a bit like jumping off a cliff. Sometimes you want to hold someone's hand when you do it, and I think death can be like that. You want to be with someone else that's dying, and your family can hold your hand as you die, but they don't jump [laughs].

I think when the, you know the, the last days are there [sighs] I think I can be positive about what I have done, but not positive about what's to come because [sighs] apart from avoiding pain and hurt ... [Kevin becomes emotional] Sorry.

Interviewer: I'm sorry too.

It's alright. [Sighs].

I'm not [sighs], its not about me. It's about um my family I suppose at that point in time [sighs] in my example I've got three days, a week. By then I'll be drugged up, won't really care, but my family have to watch that and that'll be hard. [Kevin becomes emotional]