

I'm Cindy and I was sixty-nine when I was diagnosed with multiple myeloma.

## Diagnosis

**Interviewer: Did you want to know Cindy how long you had? Did you ask then?**

At, in that very beginning I didn't particularly want to know. I was caught up in this idea of treatment, which was largely chemo and a lot of uncertainty, rather than death itself.

**Interviewer: Can I ask you something horrible?**

Yeah.

**Interviewer: But it is uh, did you know then from when you were told this that this was going to kill you?**

I knew it was going to kill me because of the research that I'd done myself um that this was terminal, but then also the lymphoma had been um, when I had the lymphoma which I still do I was told that that was incurable. So I was pretty well um, what's the word, I was kind of working with death [laughs] for quite some time. I'd had the lymphoma for about ten years, something like that.

So when the myeloma came um uh I knew it was going to kill me, and I knew it was going to be quicker than the lymphoma. One of the things that happens with myeloma is that your bones are badly weakened and your immune system is badly weakened as well, and so I do, I have had broken bones. I, my ribs seem to keep breaking [laughs]. Um my spine collapsed quite badly early on and, and they put cement in it which is kind of cute. Um so it's not [laughs] collapsing at the moment. Um so yeah those, those things are there.

I'm having to [clears throat] stop some of my more heavy physical activity [laughs]. So I don't break too many more bones.

Interviewer: Like scything your garden, Cindy.

Like scything my garden yes, I, I think I've given that up [laughs] now [laughs].

## Treatment

My treatment has been totally awful [laughter]. Um the chemo; I had [pause] with myeloma you have different combinations of chemo [clears throat] that work for a little while for some people [laughs], um and then stop working, and so then you do another combination for a little while and that stops working, and, and usually there are three modes of it.

Um every single one of those I had severe side effects with, severe meaning [pause] neurological damage, not just nausea [laughs], and you know the normal stuff. I could kind, could work with that. I was shaking so uncontrollably through most of it that I couldn't pick up a pen. Um it just, I won't go into all the details, but it was terrible. And I did go through those three cycles, or not cycles.

There were three different bouts of, of chemo over about two and a half years, and um when I came to the end of the last one I said that's it, and was fought and still am being fought by the haematologists who want me to do trials and all sorts of other stuff, and I'm very clear that I don't want any more chemo. I want to, I feel better now [laughs] than I have for three years or whatever by being off the chemo, even though my, my illness is progressing.

Um I'm not having the side effects and I'm being with my illness as it is which seems right to me, rather than poisons that make me feel worse. So I asked the haematologists at that point what would happen in their opinion um when I, if I would stop all chemo at that point and there was shock and horror on their faces [laughs], not what they wanted to hear, um and I was told at that point that it would be probably a matter of weeks rather than months that I would have to live, which did shock me, um because I didn't feel that bad.

I knew that death was coming, but it was ooh, weeks. Ah. It was for me very much a choice of quality of life, and that was far more important to me than how long my life would be, particularly when I knew that the chemo, whatever I have is going to, I'm going to have terrible reactions to it. So it was a no-brainer for me.

I've stopped all chemo treatment. I'm still having um pain relief, and I am having to up that. I've always, I've always, this might sound perverse but [clears throat] I've always wanted to have some pain so that my body speaks to me [laughs]. So my palliative care consultant is wonderful on this, and she um very early on she said I think we have different goals [laughs]. She said my goal for you is no pain, but that's clearly not quite yours is it!

So we work very well together and she listens to what I feel I need and we're working on getting the pain just manageable.

## **Telling people**

I can sometimes be quite um flippant about my death [laughs], or joke about it or... not treat it lightly, but to not make it always heavy, and that sometimes is very difficult for the people around me, and I've had to learn to be careful not to throw that out very much... around certain people anyway.

I've learned so much uh, uh even technical stuff about this illness and bodies and all of that, but also about how I approach things, how I relate to people. Um one of the things that first struck me when I was first diagnosed and I told people about it was the absolutely outpouring of love and concern from people.

It really, my, my illness opened their hearts. Wasn't that amazing? And then their open hearts kind of opened me further as well. So I, my relationships with people [pause] developed in ways that I don't think it could have any other way, apart from this death sentence [laughs]. So that's been an adventure. It's all an adventure. Some of it is difficult, but it's always an adventure.

## **Coping mechanisms**

I get very angry with the whole sense of fighting cancer or fighting illness or fighting death um... on a couple of different levels. One is that there often seems to be a, a sense that if you haven't fought well enough you fail [laughs]. There's also a similar one with being positive. If you aren't positive enough and you die there's something wrong with you, which is really abominable.

Interviewer: Do you think you're better equipped than many at dealing with your impending death?

I think both the [clears throat] the, Buddhism and the mindfulness have really honed my tools [clears throat], my, my way of being with whatever happens in life. Um there's no doubt that I, I don't know where I'd be without either of those. Buddhism helps me in [clears throat] um [laughs] more ways than I can say and probably in words that I'm not going to be able to find. First of all um... Buddhism doesn't make a big distinction between life and death [laughs].

**Interviewer: That's helpful [laughs].**

That's a big help, but also a sense of um how everything is impermanent. If you really are attuned to looking at impermanence which we do in, as Buddhists, um the fact of death isn't a big shock [laughs].

## **Intensity**

### **Interviewer: Do you still enjoy your life?**

I enjoy my life incredibly, yes. In some sense I enjoy it far more than I ever had before.

I remember uh parts of my life before I had a terminal diagnosis when I would be just overjoyed with life, but it isn't sustained in the same way as it is when you're very conscious that the life is limited. I also have some incredible joy at everything that is new and wonderful every day uh which I didn't have the ability to notice so much in the past, and I think having a death sentence really helps me with that, to recognise um the smallest things that are gorgeous and spacious and new and exciting, and wonderful.

I've had some incredibly tender [sighs] connections with people that wouldn't have happened. I've got a, a more of a sense of freedom somehow [laughs]. It's, it, yeah it's great, it's wonderful.

### **Interviewer: Really?**

Yeah.

Just walking down the street in the sun, or being at my cottage with, I've lots of wildlife there and just, last summer I got involved with counting butterflies.

## **Brave face for others**

I frequently feel I have to put on some kind of face for people [laughs]; um brave, um steady, whatever, and it is, it is a burden. But it's something that I've probably had to do in my work anyway, but I resent it more now that I'm ill, and I should be allowed to just be as I am.

I've found it incredibly difficult to know how to... be with people [laughs] [clears throat] and there, there are a lot of different categories of people in my life as there are with everyone I guess, but um a lot of the people who care very much about me are my students [clears throat] or people that I supervise. And my relationship with them has been of my being strong [laughs], and um guiding and advising them, and for a lot of them that doesn't change with my being ill.

So they can be quite a burden when I'm exhausted [clears throat] and they want to come and see me because they love me so much and they [laughs] wear me out. They have tremendous needs of their own around my giving them something that I often can't give any more. So it feels, it often feels like a burden. In fact I, I've had to um set up boundaries for myself around a lot of the people that I want to be in touch with but I, I need to have boundaries.

So I started writing a blog at the beginning of um 2016 to keep people like that, keep in touch with them so they knew what was going on with me, um but without my having to carry them.

### **Support - hospice and new friends**

Uh there is a big assumption from a lot of people around me that um because of my background as a counsellor, a psychotherapist, a Buddhist, a mindfulness teacher, a supervisor, all these things that I couldn't possibly need any help [laughs].

Well right from the start of my being diagnosed with myeloma I pretty much knew I wanted to die in a hospice, and there I met other outpatients, and that was a revelation to me that there were people like me who were, who have a terminal illness and we could communicate and talk just like normal people without my having to worry whether they were going to try to take care of me or depend on me or whatever else. We could just be normal people together.

And that is such a gift. I had no idea that I needed that so much, and I don't have to worry about their wanting to take care of me or um all of those other burdens that come up with all the other people who don't know what it's like to be with a terminal illness. It's very simple in some way. I mean I can't define it, but it's so relaxed being with other people like me [laughs].

We laugh a lot. We might cry too, but you know it's just normal somehow. It's a bit of normal. So there's something just about a normal simple [sighs] relationship that has no, no strings, no, no heavy cloud over it. I, I hadn't realised how much I needed that.

### **Sadness**

**Interviewer: Do you feel, I mean a lot of the people that are in the film or that I've talked to I mean they have families, they have partners, [C: Mm] they have children. You don't. [C: Yeah] Does, does it feel lonely or alone or do you quite like it that way?**

It can feel incredibly alone without having [pause] a partner alive and my family [pause] has never been one that I could count on for

anything [laughs]. [Clears throat] I have a brother in the States. Um there are times when that is so hard [pause] or feels so hard [pause]. That's the black times.

**Interviewer: Is it?**

The real black times, but I also know that... there's, that I have a sense of relief, that I don't have family right on top of me, that I would have to be taking care of or um [pause] tsk putting on some kind of act for, which I do with a lot of my friends actually. Um and what I've discovered is that [pause] this dying business is alone [laughs].

The bottom line you, we are alone [pause] and may-, maybe I get to that sooner than other people who have a lot of family around. I don't know.

**Interviewer: So in a funny way, correct me if I'm wrong, your aloneness makes facing all this easier?**

I think very definitely. My alo-, aloneness [clears throat] makes it easier for me to face all of this openly and as honestly as I can.

**Death and dying**

I'm not dead, I'm living [laughs]. I'm living at a phase that is closer to death. Um I wish that our culture allowed us to be more casual about death or to be more open about it. Maybe they're the same thing, I don't know. Um until that happens everybody's going to be frightened of death. I was terrified of death [pause] in relation to my husband's death.

The convoluted ways that I would not look at death because I was terrified of losing him and I think his death um which was probably the most horrible thing I've ever encountered for me and the hardest thing um in a sense that freed me not to be afraid of my own death.

Death and dying is totally lonely. Um that's the hardest part for me I think. Um really coming up, it's like you're faced right against a, a brick wall of 'this is it'. It is alone. And nobody else can understand it unless they're in the same place, and that feels very alone, even if you're surrounded by friends and family um and, and sometimes that makes it harder [laughs], we are alone.

I've had um a long life. I don't want it to go on indefinitely. I, I think a real horror story would be to live till you're you know a hundred and six [laughs] or something awful like that. Um I'm ready to die.