

Transcript Module 2



Michelle's Story



Michelle's story – Introduction 1 min 28 sec

Michelle: It was such a shock to hear the doctor say that I had breast cancer.

That was two years ago now, my whole world turned upside down. The initial treatment was really full on, not to mention losing my hair and everything that goes along with chemo, but I got through it all. The cancer responded well to the chemo, and I'm feeling great. My life's balanced again, Pete and I are happy, the kids are great and they're doing so well at school. I love my job, teaching is fantastic, and my boss was brilliant. Everyone has been so supportive. A month or so ago I noticed that I had this nagging cough and lately I've been feeling a bit breathless. I did wonder if the cancer had come back, they said it might, but no, I've just been overdoing it. The kids have been sick; you know it's just a viral thing. Anyway I went to see my GP last week just to have it checked out. She did a whole load of tests. I'm just waiting now to hear back about the results. I'm sure everything will be alright.

Michelle's story – Receiving distressing news – 3 min 4 sec

Doctor: It's lovely to see you again; I just wish it was under better circumstances. I've got your results.

We'll talk about that, then if you've got any questions or concerns I'll tend to those as well is that okay?

Michelle: Nods

Doctor: I was hoping to have good news for you today, but unfortunately Michelle your cough's not a virus. I'm really sorry to tell you but the cancer has spread.

Michelle: Cries

Pete: What do you mean?

Doctor: On the CT scans we can see that it has spread to your lungs, that's why you're coughing and that there are a couple of spots in your liver. I know this is not the news that you'd hoped for, I wish I could tell you otherwise. It's a huge shock.

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Michelle's story – Receiving distressing news 3 min 4 sec *continued*

Michelle: I just don't understand, I've been so well and we lead such a healthy lifestyle now.

Everything's so good at the moment, this news, it's just devastating.

Doctor: It's really, really tough and you and Pete, you dealt with that first diagnosis just so well with such amazing, incredible determination and you put loads of effort into making sure that you built a healthy lifestyle and that you did everything you could to recover.

Pete: What exactly are you saying? We beat the first cancer, we can do it again. Michelle, she's fit and healthy, she can cope with whatever treatment she needs. We'll get through it alright. Please can you tell us what treatment she can have?

Doctor: Of course Peter, I understand that you need to know what happens next. Are you okay to move on then Michelle? Well the first thing I'd like to do is arrange a bone scan that will give us a lot more information. And our main priority is going to be reducing the size of the cancer in your lungs and in your liver with some chemotherapy.

Pete: Very good, so when can we start this chemo?

Doctor: Well I can try and arrange for the bone scan this afternoon, and then we can meet tomorrow morning to discuss the different options. We should be able to start the treatment as early as next week. I know this is really hard and really a lot to deal with. If you do have questions please ask.

Michelle: Can you still cure this?

Doctor: I wish we could Michelle, but now that the cancer's spread we can't cure it. It's there in your lungs and in your liver. We can give you some chemo to stop it from spreading further and we'll be looking after your symptoms like your breathlessness, and we'll be trying to give you as much time as you can have with the best possible quality of life.



Michelle's story – Understanding palliative treatment 2 min 35 sec

Jeremy (Radiation therapist):

Hi Michelle, I'm Jeremy, I'm sorry to see you back here.

Michelle: Yes, it's just the worst news. My breast cancer has spread now; it's in my lungs and my liver. Dr. North sent me for a bone scan and I've just found out it's in my spine. I had back pain but I just thought it was from the gym, I never thought it was something more serious.

Jeremy: I understand this must be very difficult for you, so what's your understanding of what we're going to do today?

Michelle: Dr. Maitland wants me to have some palliative radiotherapy. I don't know what he meant.

What is palliative radiotherapy?

Jeremy: Palliative radiotherapy isn't curative, but it's aimed to improve the quality of your life and we give it to relieve symptoms, like your back pain and the treatment will be different too. Now last time you might remember you had the six week course of short daily treatments.

Michelle: Yes.

Jeremy: Well this time the treatment will be different in the length of time that it takes, the dose of the radiation, and the area of the body that will be treated. Now any questions Michelle I'm happy to go over anything at any point if you want me to.

Michelle: Well not really, but will my treatment start today or will we just be planning today?

Jeremy: We'll be planning today but your treatment itself will start at ten o'clock tomorrow, okay.

Michelle: Alright that sounds good, I just don't remember too much about last time.

Jeremy: Well I can show you through if you want to come inside.

Michelle: That'll be great, thanks.

Michelle and Jeremy walk to the treatment room.

Jeremy: Well here it is, look familiar now?

Michelle: Yep.

Jeremy: So here's the CT scanner. First we'll get you positioned on here. You might remember last time we marked the area with some small tattoos. Well we'll do that again, and that way we can set you in the same position each time.

Michelle: I just hope the treatment helps; I guess I'm just a bit scared.

Jeremy: Well that's perfectly understandable Michelle, but remember you'll have your treatment team around you, if there's any concerns, anytime just ask us and we'll help you if we can. If we can't then we'll find the right person that can.

Michelle: Yep, thank you so much Jeremy, I really appreciate it.



Michelle's story – Michelle's illness progresses 3 min 50 sec

Doctor: You guys look exhausted. How are you going Michelle?

Michelle: Not good, I'm not getting any better am I?

Doctor: I'm sorry Michelle, I wish I could say that you were getting better, but your cancer is continuing to spread.

Pete: So, what are we meant to do? I can't just sit back and watch Michelle die.

Doctor: Must be really hard for both of you. Today we need to talk about a management plan and maybe look at some of your goals Michelle. Things that you may or may not want to happen in the future.

Pete: Yeah a plan would be good, we need a plan.

Doctor: We can keep on with some chemotherapy and try to get on top of the cancer in your lungs and your liver. Would you like to know more about that now?

Michelle: Oh yeah, I want to know as much as possible. I need to talk to you about my breathing, it's a lot worse than last time I saw you and I'm really struggling at times. I don't think I can wait for the chemotherapy to work. Is there anything that you can do to help with that now?

Doctor: Yeah, there's a couple of things we can do to make it easier. Can you describe your breathlessness for me?

Michelle: Well it's there most of the time now. But a few times it's been really frightening; I couldn't get my breath you know. It's an awful feeling and then I just panic and then that just makes things worse.

Doctor: But not being able to breathe is really frightening. Pete it must be scary for you too.

Pete: Yeah it's really hard to see her like this. She had a really bad episode while I was at work and I just feel helpless. What can we do to help her?

Doctor: We're going to put you on some medication today Michelle. We can monitor the dosage and adjust it if we need to. I'd also like to get some input from the palliative care team about how to manage it.

Pete: Palliative care, aren't they the people you see when you're dying.

Doctor: Well that is part of it Pete. They do give end-of-life care, so it's good for you to meet them and get to know them. The palliative care team is made up of a lot of different types of health professionals. They're there to support you through this really difficult time and they're experts as well in managing symptoms. How would you feel if I made a referral out to them?

Michelle: If you refer me to the palliative team, will I have to stop the chemotherapy?

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Michelle's story – Michelle's illness progresses 3 min 50 sec *continued*

Doctor: Oh no, not at all. We'll be working closely together, to keep an eye on things, adjusting as we go along.

Michelle: Okay then.

Doctor: Pete?

Pete: Yeah, that's fine.

Doctor: I don't know who you'll see, but they're all really lovely. Have you got any other questions before we move on?

Michelle: Yeah, I do. How long do you think I have to live?

Doctor: That is the hardest question Michelle. Studies that have been done with women who are at the same stage of breast cancer as you are, typically show that survival times are measured in months rather than in years.

Michelle: That's not very long.

Doctor: No, and at this stage, it's impossible to say just exactly how long.



Michelle's story – Raising concerns

4 min 20 sec

Nurse: Hi Michelle, hi Pete how are you going?

Michelle: Not bad.

Nurse: What are you looking at there, some diversional therapy for the morning?

Ah the kids, great.

Pete: Just sorting through the photos, we've got so many of the kids; we thought this would be a good time to do it.

Nurse: How are they?

Michelle: Oh they're good thanks. I just want them to remember me as their mum you know. I want them to look at all the pictures and remember all the good times we've shared.

Nurse: It must be really hard to know what to say to them.

Michelle: Yeah, we've tried to protect them from so much, haven't we? Glances at Pete.

Maybe that wasn't the right thing to do.

Pete: We want to do the right thing by them; we just don't know what that is.

Nurse: Well, you know I think, in my experience, I think children often know when something's wrong, so it's often best just to be open and honest with them. You know they can get quite anxious when they don't know what's happening, and then of course when they find out it can be quite a shock for them. It gives you guys a chance also to understand what their worries are and you know how to support them. What do they

know about the situation so far?

Michelle: Well not much really, do they? I mean they know the cancer's come back. It's hard to know what to do, you know.

Nurse: Well would you like to come in together? All of you together one day and we can talk about it.

Michelle: (Shakes head) No.

Nurse: Well maybe we could explore some ideas now, about how best to talk to Ben and Elyse.

Michelle: Yeah, that'd be good.

Nurse: I think it's really important to know that each child might see things a little bit differently, so a really good place to start is to actually find out what they already know. So you need to give them time to talk and to be able to express their feelings. It's really important that they know that it's totally okay for them to be open and honest with you, to ask you any questions that they need to ask you and that you are really there to support them. Have they asked you any questions so far?

Pete: Yeah, Ben asked me if you were going to get any better.

Michelle: Yeah, he asked me that one too. He said he's got a friend at school who told him people die if their cancer doesn't go away.

Nurse: What did you say?

Michelle: Well I told him that I really didn't know, and that everyday we hope the cancer will go away.

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 **Michelle's story – Raising concerns**
4 min 20 sec *continued*

Nurse: Michelle, do you think the cancer is going to go away?

Michelle: No, Dr. North told me that the treatments couldn't cure it.

Nurse: It might be a good time for you to tell the kids then I think, and start preparing them.

Michelle: Maybe you're right.

Nurse: I think sometimes children also need to know that your cancer's got nothing to do with them, that it's nothing they've done. Do you get a sense that, that could be worrying them?

Michelle: No, not really but we should talk to them more.

Nurse: Let them know how special they are to you guys, how much you love them and maybe also tell them that you're really sad that the cancer has come back.

Michelle: Yeah, we should do that shouldn't we Pete?

Nurse: Pete, they need to know that you're there for them and that life can just go on as normal as possible, so if you can try and keep the usual routines happening, that'd be really helpful. Something else you could do, I don't know if you've thought about it, but you could start a scrapbook for them.

Michelle: I wanted to do that for them, didn't I? I just don't think I've got the strength at the moment.

Nurse: What about a friend? Have you got a friend who could help you with that? Or actually, I could get one of our team to help you out in here. Would you like that?

Michelle: Yeah, that'd be good. I can do it when I come in for chemo.

Nurse: Yes, that'd be a great idea. Look I'll get onto that, arrange that and I'll let you know.

Michelle: Oh wait, I've got one more question. My sister and her husband are going camping with their kids next weekend and they've asked if they can take Ben and Elyse. Do you think that would be a good idea?

Nurse: I think it's a great idea for them to spend time with family and friends that support them; I assume they get on well with their cousins?

Michelle & Pete: Yes.

Nurse: Yeah, then I think it's a great idea. And I think it'll be really good because it will give you guys time to have the weekend together, just the two of you, which might be quite nice.

Michelle: Yeh, thank you so much.



Michelle's story – Responding to losses

5 min 21 sec

Nurse: So how are you doing Michelle?

Michelle: It's not a good day today. I feel like I'm losing control of everything in my life. I met with my boss last week and its official. I'm on an indefinite leave of absence. I'm absolutely devastated, my job is a huge part of me, and I'm a good teacher. I've made a difference to loads of kids' lives and it's over now and it's finished and my own kids want to spend more time at their friends' houses than they do at ours.

I don't even take them to school anymore, Pete does that. I can't do anything; even walking to the car in the driveway makes me breathless. Sitting in the car just makes this pain so much worse. I don't know. I don't even seem to get my mum hugs anymore. It's just breaking my heart, and then there's Pete. Spending time at his mate's house is clearly more attractive than spending time with me. I can't even remember the last time he gave me a cuddle. Cries

Nurse: You've really been holding on to so much haven't you.

Michelle: I'm really sorry to blurt it out like this. I just really needed to say it out loud and just have a good cry.

Nurse: Yes it's okay.

Michelle: I hope I've left you some tissues.

Nurse: Don't worry about it; I've got plenty out in the cupboard. You've been through an incredibly tough time Michelle, you've continued to work and be a mum, wife and friend and stay in control of everything. You've faced some terrible losses Michelle and its okay for you to feel like this. What do you think has been worrying you the most?

Michelle: I just don't know what to do next.

Nurse: Sometimes it's a little bit easier if we break things down into smaller pieces, so the whole situation doesn't seem so overwhelming. So if we did that, what would be top of your list?

Michelle: Pete, Pete and me. We're just drifting apart and I love him so much. I miss the beautiful intimacy; you know, the kisses and the cuddles, just being together.

Nurse: Yes, that special part of a relationship. You guys are really close.

Michelle: I just can't relax with Pete anymore. There are times when I don't even want him to touch me or even see me. I look at myself in the mirror and I don't recognise myself. I mean who am I?

Nurse: Have you been able to tell Pete how you feel?

Michelle: I've tried, the time just never seems right.

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 **Michelle's story – Responding to losses**
5 min 21 sec *continued*

Nurse: You can't find the right words either, I suppose. I'm guessing that Pete is finding it really hard to share his feelings with you as well. Maybe we could look at some ways that you and Pete might be able share your thoughts and feelings? Do you have any ideas about what you could do?

Michelle: Something simple, I don't know really. I know I really need to talk to Pete about it. But I just get the sense that he's scared to upset me and he keeps pulling away.

Nurse: Sometimes it might be helpful having someone break the ice for you. Perhaps when you're in next I could have a chat with Pete if you like. I can tell him what we've been talking about and to let him know that you'd really like to be talking to him as well.

Michelle: That would be so good, thank you.

Nurse: Do you think Pete would feel comfortable talking to me?

Michelle: I think so, he trusts you.

Nurse: Okay alright well I'll try and arrange it when you come in next. There are also some really good resources that we have on sexuality and intimacy for women with breast cancer and their partners that you might find really helpful to read. Would you like me to get some of that information?

Michelle: Yes, that'd be good.

Nurse: Michelle it's really, really good that you've been able to talk to me about this, you know. It's such a big burden for you. It's good for you to get it off your chest, I think, at times.

Michelle: Oh yes, I feel so much better. Thank you.

Nurse: It's my pleasure. I've just got one more thought. We have a psychologist on our team. I'm thinking it might be really helpful for you to talk to her she might have some other ideas that might be useful. So perhaps when you come in next if you're still feeling a bit concerned about you and Pete I can go and get her to see you if you like.

Michelle: I think that'd be good. It might be nice to talk about it some more. Thank you.



Michelle's story – Spiritual conversations

5 min 16 sec

Michelle: I know I'm dying, I'm scared. I don't know what it all means.

Palliative care nurse: What is it that scares you most?

Michelle: Not being prepared, does that sound weird. You know when you're pregnant you've got nine months to prepare for the birth. You go to information sessions and workshops and everybody wants to tell you their story, good or bad. The point is that they talk to you about it, but no one wants to talk to you about death and I need to talk about it. I am going to die soon, aren't I? I'm not a religious person, neither of us are. We bought the kids up with a set of values that I hope will get them through life.

Palliative care nurse: I'm sure you have, are those values helpful to you now?

Michelle: Definitely, they help me to figure out what's important and what it all means.

Palliative care nurse: So what is important to you right now?

Michelle: My family and friends, I don't think I could get through this without the strength that they give me every day.

Palliative care nurse: A lot of people in your situation feel the same. There's nothing quite like the support of friends and family. Your friends have rallied around, have they?

Michelle: I don't even know where to start; Liz has been bringing me two meals a week, for months now. Paul and Jen take our kids out every week, with their kids. Barb brings me the naughty things, gourmet chocolates and bubbles and even clothes that she's picked up on special. Then there's Meg, Meg she just fits in with wherever I am that day. Sometimes she sits with me and we say nothing, and it's just beautiful. She's so dear to me. I can see that everyone's worried about me; they know I'm going to die soon, but Meg is the only one who will talk to me about it. I think that's why it's been so hard lately. Pete and all my good friends are trying to avoid talking about it. What does it feel like, when I die?

Palliative care nurse: There are certain indications that will let you and the people around you know that death is getting closer.

Michelle: What are they?

Palliative care nurse: You'll start to feel weaker, you'll spend longer periods in bed, you'll be drowsy and you'll be less aware of what's going on around you.

Michelle: What about the medication and my breathing? What if I can't swallow? How will I take my medication?

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Michelle's story – Spiritual conversations 5 min 16 sec *continued*

Palliative care nurse: We can change the way we give you the medication if we need to. We can use a little machine about this big and what we'll do is we'll put a little needle under your skin; it's just like a pin prick going in. Then we'll attach some tubing from the needle to the syringe with your medication in it. A community nurse will come each day and change the syringe.

Michelle: That sounds good, but what if it all gets too much for Pete to take care of me.

Palliative care nurse: We'll be visiting regularly, reassessing things each day. If at any time you or Pete are having difficulties just let us know, give us a yell and remember we talked about the Palliative care unit, so that's always an option and wherever you are there's a whole team to look after you.

Michelle: Thank you.

Palliative care nurse: I know it's a really difficult time; you've got a huge amount on your plate at the moment Michelle. I'm here to listen and help as much as I can. But remember we've also got pastoral carers and social workers in our team and I can organise for one of them to come and have a chat, if you think that might help.

Michelle: Thank you and I really will let you know if I need more help.

Palliative care nurse: Alright.



Michelle's story – Preparing for Michelle's death

4 min 24 sec

Pete: It's so hard to see her like this. I'm really worried about her now. I can't get her to eat anything and she'll only take a few sips of water. Should I be trying harder to get her to eat and drink?

Palliative care nurse: I know this is really tough Pete. Michelle's body is shutting down now so she's probably not interested in eating or drinking. Just keep doing what you've been doing; the mouth swabs, the lip balm, that will keep her mouth moist and comfortable.

Pete: We've been using those mouth swabs you left us. It gives us something to do.

Palliative care nurse: So what's your main concern at the moment?

Pete: The noisy breathing, it started yesterday. I know you mentioned something to me about it a while ago, but I can't remember what exactly or if I should be doing anything about it.

Palliative care nurse: When people get to this stage, the secretions, the fluid builds up in the back of the throat. Michelle's not swallowing anymore so the fluid is there in the back of her throat and it's noisy. It's distressing to listen to I know but it's not distressing for Michelle. We could try some medications but it probably won't stop it completely. The other thing we could try is turning her on her side and making her more comfortable.

Pete: Could we do that before you go?

Palliative care nurse: Sure, let's do that. You know Michelle is deteriorating now. She's probably going to die within a couple of days, maybe a week at the most. She'll probably stay fairly peaceful and just quietly stop breathing eventually.

Pete: I knew that this was coming. Her hands and feet are starting to change colour, just like you said they would. All we can do is hang on to every last second, what else can we do? I feel so helpless.

Palliative care nurse: That's totally understandable Pete. The main thing is that you, Ben and Elyse are able to spend time with Michelle. Just tell her that you love her, be there with her. Even if she's too weak to respond she can hear what you're saying. So how are Ben and Elyse managing with it all?

Pete: They're okay I think, very sad. But they're okay. Elyse especially just wants to be with her mother as much as possible. I came in last night and she was painting Michelle's fingernails pink, chatting about her day at school. Begins to cry I'm so proud of my kids, they're my strength.

Palliative care nurse: You've got a really good bond with Ben and Elyse, and that's great Pete. The main thing now is that you all spend as much time with Michelle as you can. But you need to get your rest as well. Everything's in place just the way Michelle wanted it to be, you're all here with her at home.

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Michelle's story – Preparing for Michelle's death 4 min 24 sec *continued*

I'll be heading off shortly. You've got my mobile number if you need me. I'll give you a ring later in the day, see how things are going and remember we will be here for you after Michelle dies as well, okay.

Pete: Thanks James, I don't know how I would've coped without you.

Palliative care nurse: Let's go back in and reposition Michelle. We'll get her comfortable.