EPISODE 1: DIAGNOSIS

Emma B: It can turn your life upside down. So how do you deal with a cancer diagnosis?

Hello, I'm Emma B and welcome to Talking Cancer, a podcast from Macmillan where we'll be meeting real people to have honest conversations about living with cancer. I'll also be meeting Macmillan professionals, who will be sharing advice and information to help anyone living with or affected by cancer, to find their best way through. In this episode, we're talking cancer with Chloe.

Chloe (clip): Once you hear the C word, you think, ah God, this isn't good…

Emma: In 2017, Chloe Dixon was extremely tired after the birth of her baby girl. At first, she thought nothing of it, but it kept getting worse.

Chloe (clip): Then I started having these headaches and it was like an elastic band around my head. So then I thought right, I better go to the GP.

Emma: Blood tests revealed Chloe had chronic myeloid leukaemia or CML, which is a type of cancer that affects her white blood cells. I'm talking to Chloe about her cancer, but particularly her diagnosis. What does it feel like waiting for the news? How do you tell your family? And how does having cancer affect your daily life?

Chloe (clip): It was horrific. I mean, holding my little girl and thinking I might not see next year, it was awful.

Emma: Plus, later in the podcast I'll be having a coffee with Dany, one of Macmillan's fantastic professionals, to give her thoughts on what to do when someone says those three fateful words - 'you've got cancer'.

Dany (clip): You could actually have a conversation with someone and even if they seem silly questions to you, the professionals at the end of the line will not mind in the least.

Emma: We're Macmillan, and we're Talking Cancer.

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Emma: Chloe, welcome along. It is lovely to have you with us.

Chloe: Thank you.

Emma: Now, I want to try and get to know Chloe Dixon before your diagnosis. We've spent a little bit of time together this morning. I think I could probably kind of sum you up in a nutshell. But that would be presumptuous. So, tell me about you as a person and life before this diagnosis.

Chloe: Well, I'd say I used to be, I still am but used to be, a very confident individual, very outgoing, loved travelling. I was a full-time teacher in a primary school.

Emma: Oh right, what was your specialist subject?

Chloe: Art.

Emma: Oh fab!

Chloe: So, I did an art degree alongside teaching, happily married to my childhood sweetheart.

Emma: Are you serious?

Chloe: Yes.

Emma: What is his name?

Chloe: Jack.

Emma: And how old were you when you met him?

Chloe: 13.

Emma: Are you absolutely kidding me? Oh my goodness me.

Chloe: No**.** So we went out when we were 13. And then we broke up at 14, as you do. I mean, I can't remember why we did but it must have been bad.

Emma: Yeah. Did he not talk to you at the bus stop?

Chloe: Yes, possibly! And then got back together when I was 15. And then we broke up a little bit whilst I was at uni, but apart from that, yeah, we stayed together and yeah, happily married. We bought our own place, got our own house, we're doing that up, our first build, and we're planning on having a little baby, which we were lucky enough to conceive straightaway.

Emma: And this family, this picture was always part of your plan.

Chloe: Yes, definitely.

Emma: What did that look like then in your head?

Chloe: I wanted a big family, I'm one of seven children actually - five from my mum and dad and then my dad remarried, had another two and we’re fiercely close, all seven of us. And I'm very close to my mum as well. So, I come from a big family, I've got a great group of friends so for me in a house, it's a big family with open doors, you know, friends and family members coming all the time. So that's what I always wanted to create. And that is still what I'm planning on doing - but it's just kind of gone a different route to how I planned.

Emma: Was there a moment that you said ‘right, okay, let’s do this family thing’ or did it just happen?

Chloe: Nope, my husband said we're not having children until I turned 30. He said that from about 25 when I was ready to have my first child, he was like nope, we're going to save up, we're going to get our own place, going to get married and I was like ‘okay, all right’. I respected it; I knew that he wanted to do well in his to his career so literally on my 30th birthday I was like ‘Hello! I'm 30!’.

Emma: No pressure!

Chloe: No (!) and he thought it would take months, he'd heard from people it was going to take months to conceive, and we fell [pregnant] first time.

Emma: First time! So is Darcey a birthday baby?

Chloe: Yes!

Emma: No!

Chloe: Yes!

Emma: Oh my gosh!

Chloe: Literally!

Emma: I'm going to fall off my chair with romance, this is incredible.

Chloe: And I had an amazing pregnancy, to the point where I had to have an early scan because I had no symptoms whatsoever. No sickness. My mum was like, 'hang on, this doesn't sound quite right'. But she was fine.

Emma: So this pregnancy is going super well.

Chloe: Yes.

Emma: The plan is coming together nicely. You're ticking off all those things that are on your list.

Chloe: Yes. House is ready. My nursery is how I wanted it.

Emma: What does the nursery look like?

Chloe: It's all cream with pinks and greys, it's lovely.

Emma: So, due date, Darcey arrives…

Chloe: Oh man…

Emma: How was the birth?

Chloe: Horrific.

Emma: Good grief.

Chloe: Yeah. I mean, it's not safe to say on microphone, just how awful it was.

Emma: Were you induced, or did it start normally?

Chloe: It started normally but she was back to back.

Emma: Okay, ouch.

Chloe: Yes. I got my first contraction at 11pm at night and at 6am I woke my husband up. I knew I was in labour, but it was just so slow. And then I went into the hospital and they're like, 'yeah, you're five centimetres. But she's not going come for at least another 12 hours.'

And then I end up pushing for three hours, which was horrific and some damage was done. And the recovery was really bad, as well. So, lots of aftercare was needed.

Emma: Was Darcey okay?

Chloe: Absolutely fine. She came out screaming but gorgeous, so I'm so thankful that she was great, but to be honest, that for me was the start of my journey because the day before I went into labour I had my bloods done as you do when you're expecting a little'un and my bloods were absolutely fine. So, at some point between having Darcey and nine months down the line when I got diagnosed, at some point, my body created an abnormal cell which then multiplied and turned into, you know, the leukaemia which I have.

Emma: How are you feeling in the weeks following Darcey's birth?

Chloe: I was absolutely exhausted, but I put everything down to the fact that it was the labour and being a new mum. My anxiety went through the roof. I said to myself, you know, I'm a new mum, I'm experiencing all these things. I've got this little tiny thing that needs me to look after it and I started having quite irrational anxiety attacks, actually. I didn't talk about them, which I should have. I kind of just swallowed it up and carried on - but because of this, I didn't sleep so well. Even when Darcey was sleeping. I didn't sleep that well, so the tiredness got worse. And I was at a low point. I mean, I love her - she's my absolute world. And I connected with her fine. So, in my head, I was like, 'it can't be postnatal depression because I love her, I don't want to be apart from her'. It was almost the opposite to what I thought postnatal depression was. But anything to do with her, leaving her alone with somebody, even if it was someone like my mother-in-law or whatever, it just caused me anxiety. I mean, I'd check our temperature constantly. I even at one stage, I actually went into her bedroom and closed the little window because I was so frightened that someone would get through that and take her - completely irrational. But I thought it was just my hormones, and it'd settle down. So, I wasn't taking very good care of myself. I lost a lot of weight, which I put down to breastfeeding. Yeah, you know, losing the baby weight and -

Emma: And everybody around you at the time was trying to reassure you with 'this is really normal' and 'don't worry about it'.

Chloe: Yeah. And they say, 'go and have a nap, I'll look after Darcey' and yeah, that's great. But I'm up there thinking, 'Oh, goodness, she's crying. I need to be there. Oh, I hope they're not doing this. I hope they're doing this'… not resting.

Emma: And at this point, was anything that you were doing or anybody else was doing making any difference to your levels of your exhaustion and your stress?

Chloe: No, I was just getting worse. I had so much support, my family are incredible. My husband is incredible. They were so wonderful. It was just something that was going on in my own body and, little did I know, I was sick. So the weight loss was - obviously, I had to lose the baby weight - but yeah, it was my body dealing with this illness and also me not taking very good care of myself.

Emma: So what happens on the day that somebody says, 'do you want to go and get checked out?'?

Chloe: The tiredness got worse and worse. But then I started having these headaches and that was like an elastic band around my head. So, a real tension headache and I had it for about five weeks, almost daily. I just put down to being exhausted and stressed and I went to the opticians, I thought 'well, you know, better check it's that before I'-

Emma: Had anybody else suggested? Or is everybody in this ‘it’s just baby’ thing?

Chloe: Yeah, ‘go and have a seat’ because I was exhausted, and they just put it down to me being tired. And if I'm honest, I didn't complain about it very often, I mean I just didn't want to be portrayed as a mum that was struggling.

Emma: So awful isn’t it, really.

Chloe: It’s so bad, but I’d wanted this my whole life. So yeah, I was so thankful that it happened but I didn't want to complain.

Emma: And the opticians, you start there – ‘might be my eyesight’…

Chloe: Yeah – ‘absolutely fine, your eyesight is wonderful!’. So I’m like, ‘oh. I was kind of hoping I needed glasses because then that would make everything better…’. So then I thought, ‘right well, I better go to the GP’. And it was actually a supply GP, it's not the one I usually see. And he was fine, but he was very much like, ‘you know, you're a new mum and you obviously look exhausted, you say you're not sleeping well, but I will just check your levels’.

Emma: Okay, and in a blood test?

Chloe: Yeah. And so I do the blood test, and then I get a call the next day from my GP, saying ‘would you mind coming in this morning for a nine o'clock appointment?’ and I thought ‘oh God, that doesn't sound good’.

Emma: And what did you think? Was there anything specific that you jumped to as an explanation?

Chloe: I thought maybe an iron deficiency because I didn't know! I thought maybe I had a low level of something, I thought maybe that's why I was tired.

Emma: But there was nothing in your family or previous experience of your mum that would have sparked an alarm?

Chloe: Nothing, we've got no cancer in our family.

Emma: Wow.

Chloe: Nothing, neither side. So the GP, I go into the GP and she first of all says, ‘you know, how you feeling?’ I said, ‘yeah, tired!’

Emma: ‘I’m at the GP!’

Chloe: And she did a full body examination before she told me anything and then she said look-

Emma: And what was that, was that feeling around for whatever she wanted to, pulses?

Chloe: That's it. Now that I know more about it, she was examining my spleen. She was trying to see if my spleen was inflamed. But yeah, she checked my blood pressure and everything else and my glands.

Emma: Were you on your own at the GPs?

Chloe: Yes, my husband was at home with Darcey, I didn't think it was going to be as severe as it was. So then she said, ‘basically your blood test has come back and in an average body, your white blood count - so your soldiers of your body - should be between 4,000 and 10,000 and you know, if you've got a bad infection or something, it might go up to 13/14,000. You're currently at 44,000.’ I was like, ‘errr, OK…’

Emma: I mean, obviously, we can all recognise that there's a huge difference in that number. But what does that mean? I mean, so you're given that bit of information - where's the explanation, does she sit you down and tell you what that means?

Chloe: So I said, ‘what are you telling me? I don't understand, I understand that my body is obviously fighting something but I feel fine apart from, you know, the headaches and the tiredness’ and she was like, ‘it could be that this is a wrong result. The best-case scenario, the data is wrong’. I was like, ‘yeah, okay, and the worst-case scenario?’ and she said, ‘blood cancer’. Yeah, once you hear the C word you think, ‘oh God, this isn't good’. And it’s at this point that she called my husband and explained to him what was happening.

Emma: Did you speak to him on the phone?

Chloe: No, I didn’t because I got upset at this point. But he was at home, I didn't want him to come with Darcey. I didn't want her to see me that way. I wanted to just calm myself down and then drive home, I was fine to do so. But at that point, she had to call the haematologist explaining what had happened, and I then got an emergency appointment with him, at the hospital, so I kind of got myself together and I drove home. And he bear-hugged me and he was as confused as I was if I'm honest, because we were in limbo. We didn't know at this point.

Emma: So, you've left the GP with a partial diagnosis of something that's not really been explained to you.

Chloe: Yeah.

Emma: How did you drive home?

Chloe: Well, I phoned my mum. She talked me through all the different possibilities that it could be and ‘we'll deal with it’ and ‘medicine is amazing’. You know, she's like my best friend. She's incredible. So she calmed me down and from that point onwards, my mum and Jack came to every appointment with me.

Emma: I mean, when you are your lowest, energy wise and you've had no sleep at all, and you've got a baby that you love more than anything in the world and are overwhelmed with emotion, how do you try and cope with that? I mean, what was going through your mind?

Chloe: I didn't cope with it very well. From seeing the haematologist and having extra tests done – I had a biopsy done, another blood test done –

Emma: What was involved there to confirm the diagnosis?

Chloe: That was horrific. A bone marrow biopsy, they're very painful. I was told it was going to be uncomfortable. My goodness, I would have preferred labour again, it was pretty awful.

Emma: What did they do?

Chloe: They put some anaesthetic in my hip to numb the skin. And then they put a needle into my bone to extract some of the bone marrow. It wasn't great, but it needed to be done in order to clarify exactly what condition I had. I didn't get the results then and there, it all needs to be sent off.

Emma: So how long did you wait? So, you saw the GP, then you went straight to the haematologist the next day? That's good –

Chloe: 11 days, and I have to praise the NHS because they were phenomenal. They were in constant contact. They were really reassuring. And yeah, I was diagnosed in 11 days, but those 11 days for me and my family were the worst.

Emma: What did you talk about with your other half and your mum in those days?

Chloe: Uh, well, we Googled it, obviously.

Emma: Is that a good thing?

Chloe: It was for me. When I started Googling, if you're having a bone marrow biopsy done, what are people looking for? I started seeing the word leukaemia a lot, blood cancer, bone, cancer, that type of thing. And I started reading up on all the conditions and started to understand the kind of chronic illnesses and acute illnesses. Then I started thinking, right, if I've got one of these things, I'm better off having a chronic illness which is slow growing, rather than the acute. We kind of got through it in a bubble, just trying to support each other. They were incredible with me. I never saw them emotional; they then must have had support elsewhere. And we just bumbled our way through it. But it was horrific. I mean, holding my little girl and thinking I might not see next year, it was just not great. It was awful.

Emma: It's cruel. I mean, you would have been emotionally vulnerable anyway. And I can't imagine how you must have felt. It's like the cruellest news to have at that particular point. And I guess you Googled it and approached it the way you would in your classroom in the morning.

Chloe: Yeah, exactly. I got it in my head, because it was at this point that I actually went back to the GP and I discussed my mental health. And I said I haven't been coping. I should have been more honest about it. This has come as an absolute shock. I needed help with it. And she was so lovely and so understanding and she put me on a tablet medication that's helped me with my anxiety. Once I was on that and my body got used to it, I was able to process information a little bit better. I just needed a bit of clearance, you know, a bit of support.

Emma: Was there an element of you being quite frustrated that you had to find out so much yourself?

Chloe: Yeah, the problem is that because there's so many different things it could be, the doctors don't want to give you too much information, until you've been diagnosed, and I understand that they're covering their own backs. They don't want to say 'it could be this and it could be that' because then that would worry the patient. But for me that's actually more concerning because I was killing myself thinking I was going to be dead in the next year. It's hard for the professionals because they've got to keep things, well, professional. But extremely hard for a patient who's waiting for a diagnosis. I knew something was coming, because the bloods had come back. I should have said, I had a second blood test to check whether the data had been wrong, and it wasn't. I knew my body was fighting something, I just didn't know what.

Emma: And then you get the results from the bone marrow biopsy back?

Chloe: Yeah.

Emma: What have you got Chloe?

Chloe: I have got CML, which is chronic myeloid leukaemia. So I went to the diagnosis appointment with my mum and my husband. And it's strange to say, but I was very relieved when I was given the diagnosis because I knew that it was chronic, so it was slow growing. I knew that there was medication that I could take that would mean that my life would be hopefully the normal lifespan. I was able to live a normal life – well, a new normal, if you will. I was incredibly thankful that it wasn't more severe. So I went home and me, my mum and husband went to the garden centre after, to a cafe. It was the nearest thing and I had a glass of prosecco.

Emma: Good for you.

Chloe: Yeah, after 11 days of hell, it was like, 'right, I know what I've got, I know what I need to do'. So I was back in my teaching mode and back on my anti-anxiety tablets. I was like, 'right, let's sort this out'.

Emma: And after everything that you've been through, of not knowing the worst, do you relive that bit?

Chloe: Yeah, sometimes that's the worst. That's whenever I talk about it, that's the bit I get emotional about, because it's just the uncertainty of it. It's like living in limbo. Horrible. Whereas when I was diagnosed, I knew they would finally talk to me about it. Like, 'this is what the stats are. This is the medication that you can take. This is what you need to do'.

Emma: Stuff that you can hang on to?

Chloe: Yes, and stuff, especially with my husband, that he could help me with. Finally, he was like, 'right okay, these tablets need to be taken here then, this appointment we have coming up', and he could take charge as well. Whereas for him, living in limbo was so hard, he's like me, you know, super organised. He's a construction manager –

Emma: Oh my gosh, yeah, project Chloe!

Chloe: Yeah, he's so lovely, he went into Paperchase, or somewhere like that and bought this bright pink diary that I can make notes on of when I need to take the medication. He bought me a notepad, a pink pen, a folder for my doctor slips. Literally, he had me organised. But that was him helping in the way that he knew he could.

Emma: Was there an opportunity through those 11 days, that hideous part, where you looked at the ripple effect for the rest of your family as well? That must have been hard for you to watch.

Chloe: Yeah, it was. I mean, they put on a brave face for me. But from what I heard from other members of the family and things that they had, like for example, my mum I think, used my sister and other people to get comfort from. But then you feel guilty. You feel guilty that you're causing other people pain, which is the reason why I didn't open up very much when I was struggling with all the anxiety earlier on. I didn't want to rely on other people. And when you get a diagnosis like this, you have to rely on others, because it's such a huge change to your life. You need to embrace the support and love from others.

Emma: It's difficult because it was such an unknown quantity, but would you do anything differently about the way you approached those initial steps going to the GP?

Chloe: Oh, yeah, I would have gone earlier. If I could go back, I would have got my anxiety sorted earlier. Which would have made me think more clearly. And then I think I would have thought to myself, ‘hang on, something's not quite right’. I got into the habit of ignoring my body, which was awful. And because of that, I left it later than I should have. I mean, I had headaches. Yeah, five or six weeks –

Emma: That's a long time.

Chloe: Yeah. It is intense, you know, daily headaches. But even the fatigue, I should have gone to the GP about my anxiety, got that sorted. They may well have even given me a blood test then, just to make sure.

Emma: I think it's difficult isn't it? Because in one way I guess, and we'll talk about this shortly, but through treatment and going forwards, Darcey, your gorgeous daughter, I guess is a great distraction. But in the earlier days, during diagnosis, it’s so difficult to distinguish. It's so hard to distinguish –

Chloe: Yeah. She's a fantastic distraction. You know, I'll spend the day with her and even forget that I'm poorly, but at the same time I can't rest when I need to as I've got a toddler. And people have been amazing, you know, all my family and friends helping out, but it's one of those things that you know, I'm still proud. I didn't want to rely on them too much. You know, and I didn't want to not spend time with her. Because if anything, it's made me want to spend every minute of every day with her.

Emma: Of course!

Chloe: So yeah, I found a balance. It took a while and the medication helped because once my anxiety kind of levelled out, I was like I feel more comfortable leaving her with people. So yeah. I found my balance but it took a while.

Emma: Was there an official moment where you told your family, or did you let them do that work for you?

Chloe: No, my mom was very good at this. I wanted to keep it a secret to everybody until I had a diagnosis. Her view was, our family being so close should know that I'm going through this, the 11 days. And that something may be coming of it. We knew that something was going to be diagnosed. Actually, we told my immediate family straight away in the 11 days and so they were ready for the diagnosis when I was. But when it came to outside, the family and friends, it took me a while to open up and that's why when I started this blog, which I will talk about later, I was anonymous on it. I wanted to do the blog, I want to write about it, but I didn't I didn't want to put a face to it. I think that links to the teacher thing, I wanted to carry on teaching, and I was adamant that I was going to go back to school and be me, not be the sick teacher. So, I only told a few members of staff – my head teacher and a couple of the people that I'm close to. I didn’t want people knowing.

Emma: I understand that completely. Meanwhile, I suppose there's a level of expertise about your own condition that you want to achieve, so that you can answer questions, and stop people kind of, you know, faking news-ing it.

Chloe: Yeah, exactly. I didn't want the sympathy either. I'm not really one for pity. I didn’t want a ‘I’m so sorry to hear that’, I wanted a ‘hey, are you watching Love Island’? ‘Yes, yes, I am watching!' You know, I didn't want to talk about it. But as my journey has gone on, I've become a lot more vocal about it. For the reason that I want to raise awareness.

Emma: Is that for you about, you want an element of control about your story?

Chloe: Yeah, exactly. Yeah. And I think my journey has been a positive one, the initial stuff was very hard. But once I was actually on the medication, and the results started coming in, I took control of my life again, and I thought, you know what, I might not be here or I could get hit by a bus tomorrow…

Emma: That would be really annoying! After all this, could you please look left and right before you cross the road Chloe? (Laughs)

Chloe: Yeah, I just thought, 'you know what? Life's for living and why am I being ashamed of this? You know, why am I hiding behind this boundary that I've put up, this barrier?'

Emma: Well, we have talked a little bit then about how you felt when you were told. Let's talk about where you are now.

Chloe: Okay.

Emma: Are we in the R-word phase?

Chloe: We are! The remission phase!

Emma: I should have a t-shirt saying remission.

Chloe: Do you know what? It's really complicated with my condition because it's not officially curable. So, it is more complicated, but my levels have reached such a low stage that they class it as remission. So, if I was just continuing my tablets, as I am doing, my chemo – I'm on a chemotherapy type of medication that's taken orally - to continue that and my body's meant to kind of get used to that level of cancer. And then they're currently doing trials in London, after people have been in remission for a certain amount of years, they're taking them off the tablets and 50% of them are staying in remission. So, it's almost like dormant, you know, the cells kind of just kind of plod along and don't increase, but 50% of the cancer does start to grow, but once it's been put back on the medication, it goes back down again.

Emma: So, it's very responsive to the medication which is really positive.

Chloe: Yeah, so I'm at the lowest stage I can be, which is fantastic. I'm in remission.

Emma: How many zeros have you got there?

Chloe: 0.0007, I think I am.

Emma: Round of applause for the zeros!

Chloe: Thank you. I've worked hard for them. Every three months I when I have a big test, I think, 'come on zero!'.

Emma: So, you just mentioned briefly as well that you get your diagnosis and you go straight into treatment. And that's what? Just an oral tablet?

Chloe: It's an oral tablet, four a day.

Emma: And how did it make you feel?

Chloe: It was bad initially. And it's hard as well because I've got to fast for them, so I do two in the morning and two in the afternoon, but I can't eat two hours before or one hour after.

Emma: Well, how do you build that into a busy life?

Chloe: I know! So I take them as soon as I get up, so I've already had two hours, so I just don't have breakfast for at least an hour after and then in the afternoon, I've just learned to be good and not, you know, snack on a biscuit late afternoon.

Emma: But generally, the treatment for you has been bearable?

Chloe: Yeah, I mean initially it was hard. I felt like I had constant flu and my limbs would just ache. It felt like, especially my left arm, it felt like I'd been lying on it and when you wake up it's kind of floppy. And my spleen really hurt, almost like I had a constant stitch.

Emma: Yeah, I heard that. You describe this feeling of it being really painful!

Chloe: It's because my body was getting used to processing this toxic, very toxic drug. But it all calmed down. You know, the one thing I still struggle with is fatigue. I can't get away from it.

Emma: So for that year, what was the biggest impact that it had on you, on a day to day to day basis?

Chloe: The fatigue actually.

Emma: What did you do?

Chloe: So, I would go to bed very early, I'd always nap with Darcey. She luckily would sleep for a couple of hours in the day and as soon as she's down, I'm down. I am able to sleep very deeply now which is great. And I'd go to bed at eight o'clock if I had to, and I'd you know, wake up at six and just get my sleep however I could. And once again family and friends have been amazing with coming over and playing with her for a couple of hours. Some days I've got more energy, some you know, I'm exhausted. So, for something like this, coming into London - which I absolutely love doing and I would do again - but tomorrow or the next day, I know that I will need a restful day. I need to just take it easy so that I can kind of get my energy back up. So, I don't overdo it.

Emma: Has that been tough for you, to kind of get to that point where you're going, 'Chloe, tomorrow is going to be a rest day'?

Chloe: Yeah, it is. I run on adrenaline, and I've got to calm myself down. I've got to be like, 'yeah, that was really fun'. And I want to shout about it. I want to go and tell whoever, but I know that I've actually just got to take a step back and think, 'right, my body's telling me that I'm tired. I've got headaches coming on, I need to rest because I've learned to listen to my body'. It's taken a while, but I'm back, you know, trusting my instincts and listening to what my body is feeling.

Emma: Emotionally, do you think it's changed your perspective about being a parent?

Chloe: It's just made me even more thankful, so thankful that I've got her. Because we may not be able to have another one, we'll have to see in the future. Fingers crossed. It's changed my perspective on life. You know, I just don't worry as much. I used to worry and stress a lot about stuff that were out of my control. Like things at work that popped up, or my social life or little dramas. I just don't care anymore. I value the things that I love in life and the people I love in life and the rest of it I've just haven’t got time for.

Emma: It's just such a massive turnaround from describing that person beforehand who was so in charge, to kind of voluntarily letting that go. That’s quite a journey.

Chloe: Yeah. Just going with the flow, because tomorrow isn't promised. So, what's the point in worrying about stuff that really just does not matter?

Emma: Have you ever explained to your two-year-old?

Chloe: No. I hope she doesn't need to know. When she's older I might explain to her because I may still have the condition, but I'm hoping it won't have any impact on my life at that point. And God forbid any impact on hers. If I can protect her from it, I will. But at the same time, I will educate her on it because I do think it's important. Cancer is so horrifically common. One in two people are diagnosed. So, it's important that she understands that people are poorly, people can get poorly – no one's invincible. It doesn't exclude anybody, cancer sadly. So, I want her to be educated on it and be prepared for things that might come in future. But for her to know that it's not scary and that there is medicine and fantastic people to help.

Emma: In your blog you talk about being kind to yourself. Is that something you think you're going to encourage her to do?

Chloe: Definitely! Yeah. Self-love is something that I've really learned to do over the last year and a half. And I try to instil that in her now. You know, giving her lots of love and kindness and hopefully modelling to her how she should treat other people too. And yeah, have that love for herself.

Emma: You must have found some strength and feedback from social media?

Chloe: Yes. I think it's important to say that during those 11 days, the doom days, I searched the internet not just for stats and NHS news etcetera. I looked for anybody in social media that could give me an insight to living with this condition. And I didn't find very much at all. And it's because CML in my age group is actually quite rare. So, the reason I started the blog was one for self-help, you know, therapy, I used to write a diary myself. So, I wanted to write about my journey, but anonymously initially. And two, to help anybody that was getting diagnosed, or that was in that limbo land, that could hopefully give some insight into what it was like living with this condition. And actually since I’ve started the blog, people have got in contact, that had private accounts, and I'm chatting to people in Canada and America that have been diagnosed, and it's amazing the support network that social media has created for me. I know that it can get a bad rep, social media, but for me, it's been it's been a huge part of my journey, a huge part of my recovery.

Emma: You mentioned a bigger family. How does that pan out? What's that looking like?

Chloe: Well, initially in the grand plan before the big C was that I'd have my children quite close together. That hasn't worked out. But now my journey has changed and now I'm in remission, which is amazing, because I now have a better idea of timings. My consultant said I need to stay on the tablets for at least two years of keeping me in remission and then they'll be willing to take me off the tablets temporarily to try and conceive for a baby –

Emma: Which you'll do about 24 hours after of course! Your efficient fertility!

Chloe: Fingers crossed! And then once I have baby they'll obviously monitor through my pregnancy. There's other medications that can they can put me on that’s safe, but just not ideal if you're carrying a little’un and so once I have baby, I'll no doubt go back on the medication because the cancer may have grown during the pregnancy, but they'll keep a close eye. But I think that will probably be where we stop, you know, waiting another two, three years. I think one more and we'll be very happy with the family of four.

Emma: And looking forward for you and your lovely family, how do you feel about what the future looks like?

Chloe: It looks bright, it looks exciting. I want to say yes to any opportunity for me and my family, I want to be able to travel with my child or children. And I want them to be brave and have courage and to speak up. That is one of the biggest things I've learned through this whole thing, is to talk, whether it's mental health or postnatal, or illness, whatever it is, talk about it and get support if you need it, and I'm going to hopefully instil that in my children.

Emma: It's so lovely speaking to you. Chloe, we wish you all the best and good luck in the future for you and your family. Thank you so much for having a chat with us.

Chloe: Thank you.

Emma: Dany Bell, Macmillan professional. Hello, welcome. It's lovely to have you here. Thank you so much for coming in for a cuppa and a natter. We've heard from Chloe, and the thing that we all sort of connected with was that she mentioned the importance of not ignoring your symptoms and going to the GP. That seems so sort of obvious in retrospect, but actually, how important is it? We're always told by the GP don't come to us if it's just a cold, we are encouraged to sort of look after ourselves a little bit more and think about it before we go. How do you balance that? Between that and going when you think something is seriously wrong?

Dany: I think the thing to note is persistent symptoms. A lot of symptoms for different cancers are the same as other conditions that are not cancer, but generally they're not persistent. And a lot of the guidance is, if you have a symptom that's persistent, for a few weeks, then you need to go and in some of the guidance, something that goes on for three weeks or longer is not normal. But obviously, for other types of symptoms, the guidance says that if you've had that symptom for six weeks, you need to go and see someone. So, it is difficult, but my advice is, there's phone lines that people can ring to get advice without going to the GP. And if they're worrying, then they just need to seek help.

Emma: And you're not expected to know the difference between a headache and a headache that might be something much more serious. What's the language that we should use then if we're phoning up, and we're worried? How do we know the difference?

Dany: Well, the thing with ordinary headaches, even migraines is they don't last and so if somebody has a headache for a protracted period of time, or nothing that they try to relieve it takes it away, then that should trigger really seeking some help.

Emma: And what I hear of are those levels of tiredness that are very common in everybody type symptoms, like sleeping? Your normal length of sleep and not feeling refreshed…

Dany: Yes. And we all feel tired. We all have busy lives sometimes and we feel tired, but we know that if we go to bed early and have a lazy day, we will feel better. But if it's not relieved by that, then that's not normal. If it is persistent every day and nothing you do seems to take that tiredness away, then that's kind of a warning sign.

Emma: Chloe had linked the discovery of her cancer to a trauma like childbirth that she went through, and that was her surmising. But what do you make of that?

Dany: Pregnancy and childbirth in itself doesn't cause cancer, but some cancers are linked to hormones. And so, it's certainly possible that all those hormones during pregnancy and then the change in that when you have childbirth, trigger how the cells grow if you've got an underlying cancer. So, whilst it's not a cause, it can impact on how the cancer’s behaving.

Emma: And I guess therefore, being particularly aware of your condition and your state of being and how you're feeling post childbirth is important. You need to look after yourself.

Dany: Absolutely. And it is a very difficult time because a lot of people feel awful adjusting to things after childbirth. So yeah, it's a tricky one.

Emma: So, once you get to the GP, and they've agreed that what you're displaying is not normal, who arranges tests and diagnosis, what happens from that GP moment?

Dany: If the GPs pretty concerned and sure, then they will fast track you for assessment by a specialist at the hospital. But sometimes GPs do a blood test or an x-ray just to get some baseline information while they do a referral. But the kind of the more major tests and what we call staging – so that's to find out at what stage the cancer is – generally happens once somebody is under the care of a specialist team.

Emma: I guess this is a really good time to ask lots of questions about the process, what the scan is going to entail. Is it a big tube? Is it a blood test? Those are lots of questions that you can ask then.

Dany: There are hundreds of different types of cancers and there are different tests. A CAT scan and an MRI scan are fairly standard for staging. So, most people are likely to experience that sort of test, but there are different tests for different cancers.

Emma: Chloe talks in quite some detail about the bone marrow biopsy, which sounded quite uncomfortable.

Dany: It's interesting because with all of the information about a punch biopsy or a bone marrow biopsy, which is just literally taking a little bit of the bone marrow, and the punch goes in and out, that shouldn't be painful, but it's uncomfortable. But I suspect that we're all different. And you know if Chloe was anxious that may have heightened her pain. But I'm sure it is painful for some people. We’re all different.

Emma: So, you've gone from the GP, who suspects and would like to know a little bit more, to the test, the staging, which kind of heightens the level of seriousness a little bit more. And then Chloe was really emotional about that 11 days that she had to wait. And returning to that, describing it, it’s obviously quite traumatic for her to even talk about it, because it was so awful. How long should you be waiting and what should people try and remember, if they are in that situation, in that waiting time?

Dany: Ideally you want it turned around in a week, but we often have to warn people that it might be two weeks, just because the pathologists that do that analysis, are as stretch as any other part of the workforce and there are vacant posts. And that's a really sad thing to say. But you have to manage expectation and actually waiting those two weeks won't change the outlook for the cancer. It's just the emotional impact on the person. And so, it's about what you can do to help the person manage that. So, managing the expectation and trying to plumb them in or give them some advice about how they can manage their own anxiety, but 11 days is within what you would expect, but it’s not ideal.

Emma: And in that time, however hard it is, probably stay off Google.

Dany: I think it is difficult because some people are automatically…I mean, I would be exactly the same. But I guess one of the positive things is, if you google things, Macmillan Cancer Support tends to come in the top five hits and so therefore if you go to a reputable site, and also the number to our support line would be on there as well, where you would actually reach someone who understands. And therefore, you could actually have a conversation with someone. And even if they seem silly questions to you, the professionals at the end of the line will not mind in the least.

Emma: Now Chloe is massively upbeat, hugely positive character, absolutely lovely to hang out with. And she really prefers to talk about Love Island than her cancer. What would you say to somebody who is dreading telling people? She didn't want a big sort of curtains and music and ‘tell everybody’ moment and I can't imagine many people do?

Dany: It is very hard because it's quite draining because you're not only dealing with your own emotions, you're then having to tell people that means something to you, and then you get their reactions and that that is quite a heavy burden, really, when you're going through that period. There are ways that you can do it. I mean for people that are used to using iPhones, there's a recording option on there. And we do sometimes see people ask if they can record the consultation. There are a couple of cancer apps out there that do that and then allow you to share, very securely, the recording but equally having somebody else with you. It's what works for you. And it's actually okay that you can't do it and you haven't got the emotional strength to do it.

Emma: How quickly do most people start receiving treatment after they've been diagnosed?

Dany: It depends, again, on the type of cancer because some cancers like acute blood cancer, so someone who's acutely unwell, you would need to start it pretty quickly. And they may actually have had everything done and be starting their treatment within a week. And very similar for brain cancers. But for other cancers, it's more difficult because the staging tests are more complicated, but I would say that within four weeks, somebody would have gone through the diagnosis and the staging and the treatment plan and be looking towards starting treatment. Or at least if its surgery, have a date for treatment.

Emma: Chloe was also very honest about her mental state after she'd had her baby. And that actually, that was something that was dealt with by her GP and gave her the space to be able to approach her treatment with a clearer head. What kind of emotional, physical and financial support can you expect? And where would you find that?

Dany: A GP is a good place to start. They used to managing all sorts of conditions where there's an emotional impact, also pain – so there's lots of things that GPs are well used to supporting people with, and also knowing the local services that they can refer to, to help somebody manage what they're struggling with. But equally, the specialist cancer teams would have that knowledge as well. So, if you're in an appointment with your consultant or your nurse specialist, you could bring it up there as well. And they may liaise with your GP to work out the best course of action, or they may themselves refer to a service to support you if that's what you need. We in a lot of hospitals or communities, we have information and support centres, and they are quite a good place because they focus on wellbeing and generally, lots of those professionals that help someone with their physical and mental wellbeing interact with the Information and Support Centre. So, there are lots of different places. If people didn't feel they wanted to go and have an appointment with the GP or their specialist team, they could just walk into somewhere like that and explain what the problem is to an expert Information Manager.

Emma: I think something that as well is of an immediate concern when you know that you're going to be receiving treatment that might knock you out for however long, it’s going to make you feel terrible, is the financial impact. Is there information around as well about how you deal with work? How do you talk to your bosses? How do you start that conversation about the time off that you will need?

Dany: Certainly, at Macmillan we've done a lot of that. And we've ensured that a lot of the posts that we fund like nurse specialists or support workers have that information and they know what the local resources are in their area. So, there is lots out there. There's also lots of information on our website, and even Citizens Advice bureaus will be able to give people that sort of advice and support if that's what the nearest local support is.

Emma: Dany, you're a minefield of wonderful information. Thank you so very much, and my thanks to Chloe again for sharing her story. To get more information about what we've talked about in this episode, then go to our website at macmillan.org.uk/talkingcancer. Next time we're talking treatable but not curable cancer with Adam.

Adam (clip): We've identified something in your brain, but we don't know where it is. So, we're going have to operate on you tonight, and then do a biopsy on you. And I just look at her, and she's like really solemn and upset and I was like, ‘we're talking potential brain tumour, right?’ And she just went yeah, potentially.

Emma: You'll find that episode wherever you listen to your podcasts. I’m Emma B and Talking Cancer is a Macmillan podcast.