

### Series 3, Episode 1: Talking to children about cancer

**Angie:** Being told you have cancer can be life changing, but how do you break the news to your children whilst you figure it all out yourself?

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**Angie:** Hello I'm Angie Greaves and welcome to Talking Cancer. A podcast from Macmillan sponsored by our friends over at Boots where I'll be meeting real people to have a frank discussion about living with cancer. I'll also be speaking to Macmillan professionals who'll be sharing their knowledge and advice to help anyone living with, or affected by cancer to live a life as fully as they can. In this episode we're talking cancer with Toria. In February 2020 just before the pandemic, Toria Pickering noticed a lump in her stomach. Now at the time she was training for the London marathon and believed that the exercise was to blame for her symptoms, but multiple scans and blood test results indicated Toria had a rare form of ovarian cancer.

**Toria:** I was very tired, but I was training for a marathon. Everybody's tired, aren't they?

**Angie:** I'm talking to Toria about her cancer diagnosis, but particularly how she broke the news to her 5-year-old twin boys William and Tobias. How did her children accept the diagnosis? What was it like receiving treatment during the pandemic? And what impact did this have on her children?

**Toria:** I said to my husband we need to talk to them. They've heard us saying things. We've got to talk to them.

**Angie:** After watching the difficult journey that her young boys went on during her illness, Toria published a children's book Butterfly Boy , about keeping hope whilst coping with an illness.

**Toria:** I was working on it one evening, and one of my little boys saw the pictures and he said that's me mummy.

**Angie:** We'll also be speaking to Azmina Rose, Macmillan cancer support and information specialist for some expert guidance on speaking to children about a cancer diagnosis.

**Azmina:** We do recommend direct language and also we totally respect that you are the ones who know your kids best and how they react.

**Angie:** We are Macmillan, and we are talking cancer. Toria, thank you for talking to me today. Remind me, how old are your twin boys?

**Toria:** They're five now. They had just turned four when I was diagnosed

**Angie:** That in itself must have been quite a nerve wracking experience, but tell me what was life like before diagnosis?

**Toria:** Life was just busy, go, go, go. My husband worked away a lot. I was working shifts as a nurse. Twin boys who I had at home with me and worked my shifts around them nights and weekends until they were two-and-a-half three, and then they did start preschool. Just really really busy, we've got dogs and we love all things outdoors, sporty. Life was just busy and great

**Angie:** Brilliant. I'm sorry, how long were you married before you decided to start a family?

**Toria:** Good question. I think we had been married about a year. We'd been together about five years before we got married, and I had always wanted children. I used to have a dolly called Helen from when I was about three, that's my granny's name so I think that's where that came from, that I pushed around in a buggy. It was just something that was super important to me. At the time it was like we weren't in a position to buy a house, get married, have kids like boom boom boom. It wasn't going to work. My husband said what do you want? What's most important? I said I would really have always wanted children. It's something that I don't want to wait, because what if, and now looking back I'm like that's good.

**Angie:** Are there twins on either side of your family?

**Toria:** I get asked this loads. I'm a twin myself.

**Angie:** Oh lovely.

**Toria:** Yes. I'm non-identical, and my boys are non-identical so it is genetic. My sister has two boys but has not had twins, but was fairly nervous for each of her scans.

**Angie:** It must have been interesting to see four legs and four hands on the scan.

**Toria:** Yes, so we miscarried our first pregnancy and I think I just knew something was different this time and I said I don't know if it's because it's right, you know everything is good or it's twins. My husband was bit pale.

**Angie:** It's been so lovely to hear how you and your husband planned for your future, but I'm sure cancer didn't quite feature in that plan. Can you talk me through telling your husband first?

**Toria:** I had just put the telly on for the boys and come upstairs to make the phone call and my husband was in the office making a work phone call. I just hung up and sat in the bedroom crying, how do I walk out this room now? Pretend everything is normal to the kids and go and tell my husband. I just knocked on the door and he was on a call and I was like, "You need to come out." He was like, "Okay." I can't even remember what I said. I just said, "It's not good news," or something like that. He could tell, he knew. Looking at me he knew I was making that phone call. He was just-- like he is practical mode. "We'll be okay. It'll be okay. Think of it like marathon training, we've just got to get through it." Then I just walked downstairs, we had a moment and tried to compose myself and the boys were left watching CBeebies. I just thought, I don't know how to even go down to them. They knew I'd been poorly with my surgery, but that had been five weeks ago, and I just sat down and cuddled them on the sofa but I think I was crying. They were like, "Why are you sad mommy?" And, "Oh it's okay." Sort of ignoring

it. Just thought I need to leave this for today, I wasn't in an emotional state to talk to them at that point.

**Angie:** I want to ask you, how do you tell your children that you have cancer. Sometimes because of life, sometimes because of health issues. Sometimes we have to tell them something that is quite fearful but we have to tell them.

**Toria:** Yes.

**Angie:** How do you talk to your children who were very young at the time? How do you tell them about that.

**Toria:** Yes I think for me this was always the thing that they were my focus, and then to think, "How do I tell them?" It was something that I really overthought, like in all parenting you overthink every situation, but this was a really serious situation. I did really need to think about getting it right, and talking to different people. I spoke to my best friend who's a primary school teacher. I spoke to the preschool that they were at and just said, "Have you got any tips? Have you got any hints?" I thought, "Take your time," and I was waiting for the right moment. They were little, but also they're very aware of everything that's going on and they must have heard us talking even though we tried so hard, we were in the house, it was lockdown. They pick up on your emotional state. One of them just said to me, "Mommy are you dying?" It just threw me because I guess ultimately when you hear you have cancer, that's the one thing that you fear the most. Am I dying? I didn't know at that point. I just knew I had cancer, and I had ovarian cancer and I didn't even know am I dying? I was a bit panicked of how to answer that. I said, "Not at the moment. No." It was at bedtime and I had put them to bed, and I said to my husband, "We need to talk to them. They've heard us saying things. We've got to talk to them." I think ultimately when it comes to talking to children, you know your own children best, and like all parenting we are kind of winging it, aren't we? We overthink everything and ultimately you do what's best for your children. I just thought given their age, they did not know what the word cancer meant. They knew my tummy had been bad, they didn't know what cancer meant. For us I think it was really important that we used the correct terminology because they will hear that. Cancer although hopefully you get better, it doesn't go away. It was really important that we just said it how it is without too much complication. Literally the next morning they came tottering in way too early and hopped into bed. We all just lay there and I said, "Boys mommy has got cancer." I just said it because I was like, "We just need to put it out there and say it." They said, "Oh, what's that mommy?" I said, "Well you know, my tummy has been poorly," and, "Yes." "It's still a bit poorly on the inside even though you can't see it. Mommy's going to have to have some medicine that's going to make her better." That was it, because I actually didn't even know at that point what the plan was. I just knew they'd heard me talk about it and we needed to say something. It's really funny, they went, "Oh, okay." Looked confused, looked at me, looked at my tummy, silence. I was thinking, "Oh, what's coming next." "What's for breakfast mommy?" And that was it, and that was great. It just changed the mood. It was just typical four year old boys. They are resilient. They don't overthink things like we do, and they didn't really know, so that was that conversation. We needed a plan as well, we needed to know what was going on before we could talk to them anymore.

Really then it was waiting to see what was the plan? What was my treatment going to look like? Then we could think about other ways where they could understand how it might change how I look, or I might not be around as much, because I'd have to be going to appointment and things like that.

**Angie:** Now that you are in remission, do you ever think, and this is hypothetically speaking, that you could have kept this away from your children? To be going through this and not tell your kids. They would have seen changes in you. They would have felt changes in you. Having now found yourself cancer free do you ever think, should I have told them?

**Toria:** I never ever ever have I once questioned whether I should have told them or not, it was really important for us to be open and honest. They would've picked up on it. Like you said, they feed off the energy around you. I think that's the other thing that's so important about, it's not just about now, it's about the future and them learning about their bodies and what's right and wrong and the terminology. It's not just talking, saying the word cancer, it's talking about body parts and them being able to talk about that. I think that's also really important for me and for us to say the words. They have to learn about their bodies and they have to learn the correct terminology but I've never questioned that. I think it's really important to be open, to be honest with them. I want them to be open and honest with me about their bodies, about their feelings. So, no, I've never questioned that.

**Angie:** Now Toria, you've written a book about your experience, haven't you? You go into schools and you talk to children quite openly about your journey, your health journey.

**Toria:** Yes, so I think with the boys being such a young age, I found using books a really good tool for them to discuss things. I looked up books, my friend who's a primary school teacher helped me find books that might help them understand the situation. That's where my idea for my book came from. I wanted a story to help them understand their emotions and other children in a similar situation. The book is a really uplifting story about coping with illness, but the theme around it is hope, so it makes for a good read. Although I say so myself [chuckles] Whether you are going through illness or not, the underlying point that I wanted to get across was hope and keeping hopeful. That's something that with COVID and cancer, I think we all need to have in our lives and it was something that I really felt important for the boys. I didn't know how the future at that point was looking and I just thought I would want them to always be hopeful.

**Angie:** You've got this book great, and I love the ethos, you say we've got to always have hope. What's the book called?

**Toria:** The book is called Butterfly Boy.

**Angie:** Ah, and you must have read it to your boys?

**Toria:** Yes, so I wanted to keep it a secret into till it was already and arrived in the post. I was working on it one evening and one of my little boys to venture out of bed when he's not supposed to. He crept into the kitchen and he saw the pictures and he said, that's me mommy, because the picture of boy on the front is supposed to look a

combination of the both of them, and so I read it to him and he said, "Will you read it to me again." That was so lovely. My other little boy, William, they're very, very different and he actually got quite upset the first time I read it. I just think it brought it back again, and he didn't want to read it then for a little while because there's little bit-- It's based around our journey and he warmed to it and now he does love it and he's very proud and of it I think, now.

**Angie:** That's beautiful. That's so lovely. Toria, having been through what you've been through, what advice would you give anyone in your situation? Having young children, talking to children, how would you hold someone's hand through this?

**Toria:** I think the biggest thing is you know your own children best and you know what they respond to and what will help them. For us, it was books. I do think looks a really good way to understand things. I think just gathering information, talk to their teachers, their friends, or people who are in their lives who might be able to help you. I think ultimately you know them best. Finding the right time when you are feeling positive like we said earlier is really important, and just try not to overthink it. You will, because we do as parents, we overthink everything, but I think just being open and honest and having the conversation with them is really important.

**Angie:** You'd advise other parents to be as open and as honest, obviously, based on the relationship you have with your child.

**Toria:** Yes, I think it's what works best for you. I think being open and honest is really important because they pick up on things on the radio, don't they? They pick up on things on the telly, in magazines, depending what age they are. They hear their friends talking, their dog might have cancer. Their grandma might have had cancer. It is everywhere and I think if I hadn't spoken to the boys about it so honestly. They came home and said, "My friend at schools grandmas died of cancer, but you didn't die mummy." It's there. I've noticed as they've got older, their understanding become more and they're seeing it around them more, so I think it was really important for them to know what was going on.

**Angie:** Having come out of the other side. I know you said that the word cancer is always there, but you are out the other side in this period of your life. What does life look now?

**Toria:** I think anyone who's experienced this will say it's changed you forever. There's the not so nice parts of that where it's fear, and health anxiety is always there. The really good bits is just that feeling of a deeper appreciation, and also I just feel so much more determined to do more, make the most of everything. I don't think I would've had the confidence to write a book before. Just things, when you're tired and the kids are driving you mad, and your husband is leaving things lying around. I'm just like, "It doesn't matter." It's the small things that bother you don't matter, and the small things that make you happy are everything. I think just soaking up every bit of life is so much more important to me now.

**Angie:** Toria, it was lovely to meet you.

**Toria:** And you.

**Angie:** I just wish you all the best.

**Toria:** Thank you.

**Azmina:** Questions about cancer, Boots or Macmillan are by your side from the moment you're diagnosed through your treatment and beyond. Our Boots Macmillan information pharmacists are on hand with specialist support, from helping you make sense of your diagnosis to advice about living with cancer. You can now access this specialist cancer support at every Boots pharmacy in the UK, visit [boots.com/mscmillan](https://boots.com/mscmillan) for more information, subject to pharmacist availability.

**Angie:** Azmina, welcome. Now, this is your first time on the podcast, so can you tell me a bit about your role?

**Azmina:** I'm Azmina and I'm a Macmillan professional working in the NHS, and my specialty is support and information. What that actually means in practical terms is that every day about 20 people who are affected by cancer will come into my center to talk to me, not just for the person who has it, but also for their family, friends and loved ones.

**Angie:** Thank you for that. We just heard from Toria, who spoke so beautifully about talking to her twin boys about her cancer diagnosis. How can parents or loved ones prepare for a conversation with children about cancer?

**Azmina:** Well, Angie you've said the key word there, which is prepare. Preparation is absolutely key for very difficult conversations like this one, and generally what we say to people is you do need to practice beforehand. If somebody comes into my cancer support center, I would offer them the opportunity to rehearse with me. To practice, not just what words they're going to use, but essentially I would offer the person a chance to practice the whole conversation with me before hand, including thinking about things like when to have the conversation and where to have it.

**Angie:** What are some of the things that you could say? I know we've just said, you might not want to say the C word, you might want to use another word. Also, what kind of language do you use, is it an empathetic language, an emotional language? What kind of language would you suggest?

**Azmina:** We do recommend direct language wherever possible. Also, we totally respect that the people having the conversations, you're the ones who know your kids best and how they react, but to avoid uncertainty and misunderstandings and confusion, we suggest very direct plain language, not using euphemisms or surrogate words. We suggest that when you're first telling the kids about what's wrong, you keep that first conversation quite short because they will have difficulty remembering it. There's always time for further conversations once you've actually got the message across to them.

**Angie:** Azmina, how can you advise people to explain a cancer diagnosis to a child with learning difficulties?

**Azmina:** When a child has learning difficulties, it can be very difficult. Before you have that conversation, it's understandable that you would really feel quite anxious. What we

would suggest is that if the child already has a trusted caregiver, perhaps at school, or somebody else, another adult, who they trust and who they relate to. For a child with learning difficulties, we would actually often suggest maybe involving that other adult to help you to have the conversation. Again, we would just encourage to use very simple language. In the case of a child with learning difficulties, it may be a conversation that needs to happen more than once in slightly different ways each time.

**Angie:** Azmina, what are the things to reinforce during conversation? Is there anything that you suggest we avoid?

**Azmina:** The things to reinforce to children are the fact that even though a parent is poorly and is having to go to hospital, perhaps. That the doctors or nurses who are looking after that person are very nice, and they are going to do their very best to make mommy or daddy or whoever the loved one is, better. The key message to reinforce if possible, is actually a message of confidence, a message of hope, a message of optimism, and a message of faith. Actually, this illness, or this cancer, if you have named the word, is going to be temporary, is going to be something that as a family you're going to get through. The key message really is to try to avoid communicating any sense of this being a catastrophe. Even though we know that having a cancer diagnosis does hit us like a sledgehammer, and it can feel like a catastrophe.

**Angie:** Azmina, is it necessary to tell the child's school about the diagnosis?

**Azmina:** We wouldn't say that it's necessary to tell the child's school, but it can definitely be helpful to do so. It is something that we would encourage. Particularly because teachers have often faced a situation like this before, and they can be on guard and on the lookout for any changes in behavior that may indicate that the child needs extra help to understand what the parent is going through. Teachers can also be there to just provide an extra listening ear if the child is of the age where they might want to talk to somebody about it. We would encourage you to tell the child's school if you would feel comfortable in doing so.

**Angie:** Azmina, thank you so much. What a moving story. Huge thanks to Toria for sharing her story, and to Azmina for her expert advice. For more information about what we've talked about in this episode, and for more information about how to donate, please visit our website [www.macmillan.org.uk/podcast](http://www.macmillan.org.uk/podcast). I'm Angie Greaves, talking cancer, is the Macmillan Cancer Support podcast. [00:24:49] [END OF AUDIO]