

Radio Ombudsman #30: Melissa Mead on raising awareness of sepsis after the loss of her son

Melissa's son William died from sepsis in 2014. In the ten years since, Melissa has dedicated her life to raising awareness of the condition. In 2019, Melissa was awarded an MBE for her efforts. In this podcast, Ombudsman Rob Behrens speaks to Melissa about the loss of her son, campaigning to raise awareness and what needs to change going forward.

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- Rob Behrens:** Hello everybody and welcome to another edition of Radio Ombudsman and today we have a very special guest. It's a privilege to talk to Melissa Mead, who has done more for education about sepsis than anybody else in Europe and maybe in the world. She has brought the spotlight onto the issue of sepsis through tragic personal circumstances and those of you who were lucky enough to be at the PHSO conference last year, will remember the wonderful impact she had on all of us in explaining what had happened and what she wants to do. So, Melissa, we're very privileged to have you. Thank you very much for joining us.
- Melissa Mead:** Thank you so much for that lovely introduction, Rob. It's wonderful to be here and to be able to talk to you today, especially about sepsis, of course.
- Rob Behrens:** I will get on to sepsis, but could you just start off by telling us a little about yourself and your background when you were growing up and what you wanted to do?
- Melissa Mead:** Well, that's an interesting question. So, when I was a little girl, I actually wanted to be a train driver, but I haven't quite accomplished that yet. One day I found myself in the world of financial services and that is what I was doing prior to what we're going to go and talk on today. And I live in Cornwall and grew up in Cornwall, and that's where I am now with my husband and son Arthur.
- Rob Behrens:** And what sort of values were instilled in you when you were growing up?
- Melissa Mead:** Well, I think honesty and integrity and to I think work hard and achieve whatever you need to achieve. You know, it's set your sights high is what my dad always used to teach me. And that, you know,

anyone can achieve anything if they put their mind to it. So that's the kind of mantra that I've had throughout my life and something that I continue to instil in my son that he can achieve anything he would like to achieve.

Rob Behrens: Well, you've certainly done that. So, thank you for that. We know that in 2014 your son William very sadly died from sepsis. Could you tell us just a bit about what happened please?

Melissa Mead: So William, he was born a healthy baby, so he didn't have any sort of other illnesses or chronic illnesses that would impact his day to day life. And shortly before his first birthday, we had taken him to the doctor's a number of times about a cough that was seemingly just a normal day to day cough. You know nothing, nothing serious.

But over time, and I'm talking a couple of weeks, it had worsened. He coughed more frequently for longer periods of time, and it did get to a point where it would keep him up at night and things, and in the course of about six weeks we took him to the doctor's four times more frequently.

Towards the end of that, and then the weekend that he died and we had taken him to the GP on the Friday and he had a temperature of over 40, he was very combative and not himself at all, and he was examined by the doctor and at the time I didn't know anything about the type of examinations that a doctor would do, like blood pressure and things like that and or what would be required.

So when we were told that he just had a viral cough and, you know, viral infection, we believed that because we didn't have any reason not to believe it. And unfortunately, this was a Friday night. And so we're heading into a weekend over, you know, just before Christmas, it was icy. We've only got one acute site down here in Cornwall. And I said to the doctor:

"What should I do if he gets worse?" And he said, "Don't worry, it's nothing grizzly." We took him home and we topped up on supplies of Calpol, Nurofen and the next day his temperature seemed to come down but he seemed worse. The one thing the doctor had said to us was get on top of his temperature.

So I was sort of confused by the fact that he seemed worse, but his temperature was coming down. So anyhow, I decided to call 111. They asked me to take a temperature three times during that phone call and it was 35.4, so they reassured me that I'd got his temperature down and that was good.

Now at this stage I didn't know anything about a low temperature being dangerous. I described through this phone call nearly every symptom of sepsis. So he wasn't wetting his nappies. He was quite cold to touch, so like I couldn't get any clothes on him because he

was quite upset about clothing touching his skin, it's difficult to explain.

But for that reason they said if he hasn't got clothes on him - he had a vest on his arms - his hands, you know, feet will be cold. So he was making a funny, whining noise.

He had, obviously, this very high and then very low temperature and he was very, very pale and I explained all of these symptoms, probably not in the same use of words of I've explained them now because at the time I didn't really know that mottling was a thing of the skin, for example.

Anyway, the phone call was say a non-urgent 6-hour callback and so I hung up. And Williams sort of didn't get any better, certainly, and he was just very weak, very lethargic, very, very tired. I couldn't placate him in any way. I couldn't tempt him with food. I couldn't tempt him with any sort of liquid milk or water or even an ice pop anything, and I put him to bed.

And anyone that's a parent will know that when you put a child to bed, you stealth out of the room because you don't want to wake them up. But I just stood at the end of his cot and I looked at him and thought something is just not right. And so I went downstairs and I called 111 back and I asked to speak to the doctor. And we had to be patched through to a little local cottage hospital as we call them down here.

And I can recall this, this doctor telling me that he was very, very busy this evening and I thought I felt a bit of a nuisance. And I reeled off all of these things. He had this very high temperature yesterday. Now it's sort of 35.4 again, I was falsely reassured that that was a good thing, that I'd got on top of this temperature. I said that he was very, very tired. I said that he hadn't wet his nappies or he hadn't eaten, hadn't gone to the toilet. And this phone call was actually played out at the inquest.

And I said: "In your professional opinion, what do you think I should do?" Because listening to it back, I was leading all of the questions. I was proactive and the doctor was reactive at the time. That was obviously subconscious for me. It wasn't something that I was doing on purpose, if that makes sense, and the doctor reiterated that the best place for him was in bed with Calpol, fluids and plenty of rest, and that he'd be right as nine pence in the morning.

And we checked on him during the night and he was snoring softly. And at about sort of 5:30am in the morning. I heard some rustling and could see on his little monitor that he was sort of just trying to take a drink from his sippy cup. So I thought I was good. He's, you know, he's thirsty. He's wanting something to drink.

And I went into his room just after 8am and we have blackout blinds and I didn't have my glasses on. I can't see very well without them, and I was talking to him and I was calling his name and he was just there. I had no response and I walked over to his cot and I stroked his cheek, which was warm and he didn't move.

And then I put my arms through the bar of his cot and I stroked his side and he was stiff and I shot up and I opened the curtains and he was staring straight through me and I could tell very obviously that he had died.

And then the nightmare began.

And we obviously contacted immediately 999. The ambulance and the paramedics were there really, really quickly. But within 7 minutes of that phone call, they turned to me and said I'm sorry, my love, but he's gone and that is where for us my life was completely stopped and redefined from that moment. And because I just didn't understand why and what had happened to him.

Rob Behrens:

Thank you for telling us that. Other people in that situation, which you know, I can't countenance because I've not been through it, would want to concentrate on grieving. And clearly you have grieved and you are grieving, but you decided to take action as well, which is immensely difficult to do. There was no question about going on and trying to take action to find out what had happened. Did you have any reservations about doing that?

Melissa Mead:

No, none whatsoever. I tried to make sense of something in my head or tried to accept in some way what happened, but how can you accept the unacceptable and it was at the moment the coroner called me on Christmas Eve and said, "Did William have a cough? and I sort of had a nervous laugh and I said, "Yeah, he'd had a cough for weeks. I've been to the doctor about it," I said. "Why? How do you know that?"

And she said, "Well, he had pneumonia."

And I said, "Well, what do you mean he had pneumonia?"

And I catalogued all of these times we would have been to the doctors and it obviously transpired that William had had a bacterial chest infection and it had developed into pneumonia, which gave way to sepsis in those last few days of his life.

And she said, "He died of sepsis."

And I thought, goodness me, I've never heard of that. And so I did what everyone does - I Googled it and I literally ticked off every single symptom that he had that I had explained to the 111 call

handler and the doctor and I didn't understand how they hadn't picked it up because whilst it might be rare that thankfully children don't die very often, it isn't that uncommon. And he had a known cough. He was quite clearly unwell when we took him to the doctors.

I didn't understand how we arrived at the position we were in, and so rather than get angry, I suppose I got active and it wasn't easy. It was probably an indescribable journey of survival, and in part probably what kept me alive for a period of time. My mental health was very, very poor during that period of time because I wasn't allowed to grieve because I had to look at everything objectively.

I'd received his post-mortem report and I would take to my bed for a couple of days and then I would have to look at it almost from a third person perspective and try to pick apart exactly what had happened.

And unfortunately, the moment that from our experience, the moment that we started to ask questions of those involved as in the doctor's surgery, 111, South West Ambulance Trust and the others, the doors were shut in my face and I didn't understand because all I wanted was answers. All I wanted to know is how we had got to this position and Paul, my husband, and I are fairly well educated and we didn't understand that if we could be in this position then so many other people could also be in this very vulnerable position.

Of course, William was nonverbal, being one year old. So he couldn't tell me, "Mummy, it hurts here," or, "This is how I'm feeling." So I thought, well, his voice wasn't heard when he was alive and I'm gonna make damn sure it is after he's died.

And that was kind of how I set about ensuring that his voice was heard and that he was remembered because he's not just a number or a statistic. He's a person and you know, we grieve for him now, 10 years on. His brother born after him is grieving quite profoundly at the moment, trying to understand and comprehend missing something he never had.

So we ended up having an inquest and the inquest found that William could have and should have been saved with better care. And it was following that that I managed to get NHS England to start a report which ended up being a root cause analysis report which found 16 failings in his care and four missed opportunities to save his life.

And I don't think there's anything worse than losing your child. But to know that they could have and should have been saved with even basic care is very, very difficult to live with. And I just knew that I needed to do something for him. I needed to still be his mum somehow and I think campaigning over the last ten years or so has allowed me to still be an active mum to him.

Rob Behrens: And could you just tell us a bit about that campaign for which you've received a royal honour? I think you went to Buckingham Palace so that must have been an amazing experience. But when did you sign decide to make it a more institutional focus than just you campaigning?

Melissa Mead: It's a very good question and something that over the last 10 years you kind of realised that lay people in the public who access services within the NHS can somewhat be blindsided by the Goliath that is the NHS and it's actually, we found out very quickly, very siloed.

And if you go to your GP surgery and you ask them to put up a poster about sepsis or a leaflet to help other parents, that's not going to happen in every other GP surgery because they are simply not linked. So I thought we need to go right to the top and this needs to be cascaded down.

There needs to be some mandated education, clinical awareness, public awareness, because if we, like I said, if we can go through this, so can anyone and obviously the more I got involved and more I heard about other people having experienced the same thing and sort of what you talk about, when Williams report was released back in January 2016, I decided that what I would do is use that report as a pivotal moment to push it out into the media.

And on that day I did, crikey, 30 television interviews, including news, radio and Jeremy Hunt, the then health secretary was recalled back to Parliament on an urgent question about Williams death. And he apologized to us on behalf of the government and the NHS for allowing Williams death to happen.

And so I tweeted him and I said, "How about we have this chat face to face?" And I met him and I recall saying to him, "Jeremy, the best apology is changed behaviour." And it was at that moment I think he realized that I didn't have an ulterior motive. I didn't have or want anything other than something I could never have back. I just wanted this to not happen to anyone else and so I was just persistent and I think I was called a 'constructive nuisance' at one point, which was a bit of a compliment, but it doesn't feel like it.

Because we have the right to make informed decisions about our care and the right to have knowledge about making informed decisions about our children or loved ones that have don't have capacity, for example. And so I just didn't think it was very equal or fair the treatment that we had received and wanted to change that for others.

Rob Behrens: It's rather patronising to describe you as a nuisance, even a constructive nuisance. And that does say something about the culture of the NHS that the way in which patients and families are regarded by clinicians, which I think it remains a very a significant

problem in trying to change the culture of the NHS.

We published our report on sepsis ten years ago and we're going to produce another report in the next couple of months about sepsis, the issue as it stands today, but in your reading how much has changed in those ten years.

Melissa Mead:

I think it would be unfair of me to say that nothing has changed because it has. There's been significant advances in sepsis awareness, sepsis education, clinical advances. Awareness of the public has skyrocketed somewhat, but again, one in three still don't believe or understand that it's a medical emergency. So there's this so much still to be done.

The difficulty is in - you know, I'm obviously nonclinical - but it's difficult sometimes to diagnose sepsis because of a multitude of factors. However, what we want to be able to do, and what I think we have semi-achieved to a fairly good success is knowledge amongst the public to say, "Just ask, could it be sepsis?" if they have an infection or a known infection and when they present to healthcare say, "Could it be sepsis?"

The difficulty, and you touched upon it just then, is culture and attitude and behaviour and we sort of go back to the 'doctor's know best'. And the thing is, is that sometimes they don't. The doctors didn't know William best, I knew him best. I knew what normal was for William and William wasn't normal and whilst I might not be able to put that in the right medical terminology to trigger a thought process, well, I was telling you, is that my child is not right.

And I've approached you as a healthcare professional to help me understand why he isn't right, and certainly something with sepsis and something that we that we encountered is we were just told, oh, it's just a viral infection without really doing any tests. You cannot physically tell me it's a viral infection. I know that now.

But what we would ask is that health care professionals say to you, "It's not sepsis because..." and don't just fob us off with, it's just a viral infection, tell us why it isn't something, or why it is something. Help us to take more responsibility as well.

And you know, we have the right to have an understanding of what's wrong with us or what isn't wrong with us rather than just being told something mundane because we haven't gone to Med school. I don't think that that's right.

And I think you know the NHS is, what, 75 years old Roughly thereabouts? And it's taken 75 years to build up this culture and this sort of negative behaviour. And I think it's going to take 75 years to undo. I think that's the biggest issue that we have nowadays is you can mandate protocols, processes that sequencing and do whatever

you want in terms of quality directives. And you can lead a horse to water, but you can't make it drink. And if that clinician does not think sepsis, he's not gonna treat for it. And that's the biggest difficulty that we receive that that that we face nowadays.

Rob Behrens: I'd be interested in your view about the second opinion. Clearly, that wouldn't have an impact on changing the culture, but it would give people the opportunity to challenge in a way which wasn't there when you articulated it and certainly doesn't seem to have been there when Merope articulated it. Could you say something about that?

Melissa Mead: Yeah, I mean, what happened to Martha Mills, the young girl that lost her life is absolutely devastating and abhorrent in all honesty.

The right to a second opinion I believe is something that we should be able to do and I think what Merope is trying to achieve is an urgent second opinion. Because I think most, if not all people, would know that if you're not happy with your care, you can go and challenge it. Do people actually do that? I don't know

But in emergency care, what are the chances that if you're speaking to a consultant or a senior clinician that you challenge them and say I'd like a second opinion? That what you're not going to get is - well be treated like a nuisance, or the process being made very, very difficult to achieve that.

You know, at the end of the day, when we are - if I put myself in that position, if I wanted a second opinion, it's because I'm concerned, it's because I'm worried, it's because I'm vulnerable. And I have concerns that I don't feel are being answered and I think actually that should be reflected back upon the clinician because they've not reassured that patient enough that they would like a second opinion. And perhaps over time, the bedside manner, has eroded somewhat. I don't know.

The time being able to spend with a patient has declined. But I do believe that if we are unhappy with the quality of care that we believe we're receiving, or the the diagnosis that we've received, or lack of diagnosis in most cases in terms of sepsis, we should be able to ask for a second opinion.

I know talking very candidly, if you went to a car garage and you weren't happy with the service, you'd take your car and take it to another garage. Why should we not be able to do that with our health?

Rob Behrens: It's a good point. Thank you. Just as far as the UK Sepsis Trust is concerned, what are your ambitions going forward given how much progress you've already made in raising awareness about the issue?

Melissa Mead:

I think, you know, the objectives of the UK Sepsis Trust are to support people affected by sepsis and to continue to drive forward awareness and education around sepsis. And I know that they're educating thousands and thousands of people every year. Clinicians, healthcare professionals from you know the front door right up to the surgeons or the senior consultants.

And I think there needs to be some kind of shift change in the way that sepsis is treated in a holistic view because it isn't just one person's problem, it's everyone's problem. It's every speciality right from ED through to euro sepsis, neutropenic sepsis, all of the above.

So I think there needs to be a spotlight on it and you know your report combined with other reports that I know of that are coming out later this year in terms of children's deaths is just going to highlight more and more the need for education and speed around the diagnosis of sepsis.

And it would be good to see the government standing up and doing something about this in a cohesive manner, in a cohesive way and with the same shared objective, because I don't think there's anyone out there that's suggesting that there's a different way to do it.

We just need to stand up and be heard and for the government to help, and I know that they have a five year national action plan on sepsis and antimicrobial resistance and they might be listening, but we don't want it to just be lip service. We want it actually to be tangible changes that are going to affect every single process, whether that be pandemic preparedness, hygiene, you know, filtration in the hospital, infection management in the hospital and post sepsis syndrome, you know, right the way through from the moment someone could potentially have an infection to the moment they hopefully walk out of a hospital alive.

It needs to be dealt with in a really holistic manner and I know that the infection management coalition is something that's being put together to try and manage that that process.

Rob Behrens:

Thank you. I've got two final questions for you, if I may. I'm interested in whether you think that advocacy on behalf of people who aren't as articulate as you clearly are would help people raise the issues that clearly need to be raised in the unequal relationship between clinicians and patients.

Melissa Mead:

I deliver a number of talks every year - probably going into the hundreds and I always share Williams story and I always help people to understand that they are also patients at the end of the day, those clinicians at some point in their life are going to need and require NHS treatment for whatever it might be and we are brothers and sisters and mothers and friends. And it goes back to the old adage, you know, treat people how you want to be treated.

And there are some people, as you say, that that cannot stand up for a number of reasons, rightly or wrongly, and advocate for something that's gone wrong.

And you know, this is why I wanted to be - I didn't want to be angry. I don't want to be consumed by anger because I know that if I can speak up for those that have been treated like us, then hopefully other people will not be as scared to speak up either.

And a lot of the time, people don't speak up because they weren't listened to in the first place.

Rob Behrens: So that brings me on to my last question and I could go on for a lot. Usually I ask people what advice I'd give to young people coming in to the Ombudsman profession on the basis of your experience. But for you I think it's more relevant to ask, what about people facing the same situation that you faced? What advice would you give to them now?

Melissa Mead: Well, I think I would give people the voice to be able to - the confidence to speak up because you know your loved one and you know yourself and you know what is right or wrong. And if you don't feel that you're getting an explanation that you don't feel reassured, just keep asking. Ask for a second opinion.

And I think it also goes into what you commented about - you know the Ombudsman and whenever we speak to anyone in life, you just don't know what impact you're going to have in that five minutes or ten minutes on anyone.

And if I came and sat in front of a doctor or GP surgery, what he says to me in those ten minutes, and certainly what he said to me in those ten minutes when I took William in for the last time, has stuck with me for the rest of my life. I can remember his clothes. I can remember his smell. I can remember his words and the sound of his voice.

Any clinician is in a privileged position to be able to help and treat vulnerable people at their most unwell, their most vulnerable time. And sometimes it isn't going to be a positive outcome because naturally not all healthcare attendances are positive, but you can still be and have a positive impact on that person and that goes for you guys at the Ombudsman when you are speaking to the members of the public, you're speaking to them about probably their most horrific experience they've ever had in their life.

And we have the ability to be able to be positive and have a lasting impact on them that they're going to remember in a way that is not going to hurt them because we're all people at the end of the day and it's, you know, kindness and respect is free.

Rob Behrens:

Thank you very much. It goes back to your point about respecting people on the basis that you expect to be treated the same as people would treat you. And I think that's a consistent theme.

Thank you for joining us today. Thank you for the work that you've done. You made your son immortal in a way that is just a deep consolation for something that shouldn't happen to anybody. So on behalf of all our listeners, I want to thank you, Melissa, and to wish everyone a good day and take care.

This is Rob Behrens on Radio Ombudsman signing off and saying all the best.