Matthew and Diane’s sepsis story – audio visual video transcript

Audio

(Background music plays)

**Visual**

**Text appears on screen accompanied by a female voiceover which says, “Matthew and Diane's sepsis story.**

**This video contains content and images that some people may find distressing.**

**Matthew Ames was 39 years old when he suffered a life-threatening reaction to what started as a sore throat. The father of four developed sepsis leading to the loss of all of his limbs.**

**Matthew and his wife Diane share the story of his illness and recovery.”**

**We see a close-up photo of Matthew’s face. He is sleeping, with his head on a white pillow.**

**A photo shows a younger Matthew wearing a cap, on a boat with water and mountains in the background. He is smiling and looking directly at the camera.**

**A photo shows Matthew and Diane when they were younger, dancing at a party and smiling at the camera.**

**A photo shows Matthew and Diane holding walking poles, at the top of a glacier.**

**The picture changes to video. We see Matthew and Diane Ames sitting in a room with a green wall behind them. They are sitting behind a table. We can see them from the waist up.**

**Matthew, who has short dark hair with a hint of grey, is on the right-hand side of the screen and is looking towards an interviewer who is just off camera. Matthew is wearing a grey, short sleeved shirt and has artificial limbs.**

**Diane is on the left. She has shoulder length dark hair and is wearing a white blouse with a red, pink and blue floral design. She is looking at Matthew as he speaks.**

Audio

(The music fades down)

“I first went to a doctor with flu-like symptoms and thought I was okay. Kept going to work for that week, and then that following weekend my condition deteriorated.

I had fevers, rigours, shaking and ended up being nauseous and dehydrating. And on the Sunday evening, I reached out to the emergency department to see how I was going and was diagnosed at that time with a viral illness; I went home.

For me, unfortunately, things continued to deteriorate. And on that Sunday afternoon I noticed a small rash on my left arm, which was non-blanching - it didn't go away when you kind of pushed it.

So that rash continued to get a lot larger over the course of the next couple of days.

Tuesday evening, because of a deterioration a number of my symptoms, I felt that I was really not, you know, feeling as well and asked for an in-home doctor to come and see me.

That doctor also said that I had a viral illness. And the following day the rash had got worse again and my symptoms had deteriorated; painful to move as well. So, I went to my local GP. Again he thought I had a viral illness.

I continued to deteriorate during that day and attended the emergency department that evening; it was a Wednesday night. And I remember sitting in front of the emergency department nurse sort of running through my symptoms and really that's the last thing that I remember until I woke up from my coma about three weeks later.”

**Visual**

**A photo shows Matthew in a hospital bed, intubated and in an induced coma.**

**A second photo shows Matthew in a hospital bed, with fewer tubes but still unconscious.**

Audio

(Music plays)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Matthew was put into an induced coma to give his body a chance to fight the infection.”**

**We return to Matthew and Diane sitting in the room with the green background. Diane is looking towards Matthew as he speaks.**

Audio

(The music fades out)

“It turned out to be a group A strep infection; you know, strep throat is fairly common.

The same bacteria went invasive into my bloodstream. So in an effort to try and stem the infection on the Thursday morning they debrided my arm where the source of, you know, site of the rash was.

But unfortunately for me the intravenous antibiotics didn't stem the infection. So the following day they thought the only course of action left was to remove my left arm, which happened that afternoon.”

(Music plays)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Matthew's wife Diane describes how despite the amputation of his arm, Matthew's condition continued to deteriorate.”**

**Only Diane is on screen, with the green wall behind her. She is speaking to an interviewer, who is just off camera).**

Audio

(The music ends)

“And then on the Saturday, they came to me to say that there was nothing more that they could do for Matthew and that he was going to die that night unless they operated to amputate his remaining arms and legs. And even then, there was only a 1% chance of surviving.”

**Visual**

**A photo taken before his illness shows Matthew, Diane, and their four young children – a girl and three boys – smiling at the camera.**

**We then return to Diane in the room being interviewed.**

Audio

“So that's when we then brought all the children to the hospital and sat them down to explain that their dad was really unwell and that despite the doctors trying everything that they could, there was a chance that he was not going to live.

So we then had to go in to say goodbye, which was extremely hard. Our elder son refused to come in to begin with, and then Matthew's best friend then said ‘You know, Luke, don't worry about it. We'll just sit down. We'll have a game of cricket with a banana and some nuts.’ And so that lightened the mood for a little bit, and he was able to come in.

But it was it was the hardest thing bringing the kids in to say goodbye to their dad.

(Music plays)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Diane remembers the sensitivity shown by medical staff when she was faced with tough decisions about Matthew's treatment.”**

**We then return to Diane in the room being interviewed.**

(Audio)

(The music fades out)

“When the doctors came to us, they were very caring in the way they delivered the news, which made a big difference to me.

They explained that this was the only option to save Matthew and there was only a 1% chance of him surviving.

And not only was Matthew the love of my life, but he was also a fantastic dad to our four children.

**Visual**

**A photo shows Matthew and Diane on their wedding day. Matthew is wearing a black suit and white shirt and tie and Diane is wearing a white dress and veil.**

**A photo shows Matthew sitting outside with his arm around one of his sons as a toddler.**

**A photo shows Matthew sitting cross-legged with his arms around two of his young sons and a third looking over his shoulder.**

**We then return to Diane being interviewed. She is using her hands as she speaks. Matthew is looking towards her.**

Audio

“And I knew that our lives would never be the same after this operation.

But I would never want to go back to the children and say in time there was a 1% chance of saving your dad - his life would be tough forever - and I didn't take it.

I knew that it really wasn't an option.”

(Music plays)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Diane was supported to deliver the news to Matthew about his amputations when he woke from the coma.”**

**Diane and Matthew appear on screen. Diane is speaking.**

Audio

(The music fades out)

“I wasn't doing this alone. I was there with Matthew's mum and dad, the social worker who was dedicated to our family, the ICU doctors, the ICU nurses.

There was a huge team of people around this bed that were all there to support me. And the thing was it was to be me who was to lead, but when it was too much for me, then I had other people that could step in.”

(Music plays)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Matthew's recovery.”**

**Matthew is looking towards Diane as she speaks and is smiling.**

**Diane alternates between speaking directly to the interviewer and looking towards Matthew.)**

Audio

(The music fades out)

“It was so lovely. When Matthew woke up, all we had to communicate with were his eyes - because I, everything else…”

(Matthew interjects, laughing)

“I had tubes in me.”

**Visual**

**A photo shows Matthew in a hospital bed, intubated.**

**We then return to seeing Diane speaking, with Matthew seated next to her, looking towards her.**

Audio

“He couldn't talk.

And I knew straight away that we had Matthew back.

And I could tell from his eyes that he clearly understood even though he'd been in this drug haze.

I just stepped him through what had happened and how he progressively got worse. And he was very accepting of everything that I was telling him.

I explained that we had to amputate his arms and legs and he's almost nodding, not that he could move his head.

And so I knew that he understood what had happened. And then the only time that it was tough for him was when I had to explain that the kids came in at that time to say goodbye to him. And then he cried with that bit.

Apart from that, I knew that I had Matthew back.”

(Music plays).

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Lessons learned and opportunities for improvement.”**

**We see Matthew speaking to the interviewer, while Diane looks towards him.**

Audio

(The music fades out as Matthew begins to speak).

“I think from my perspective when you're receiving bad news, you know, really bad news, it's not really the specific words that you necessarily pick up. It's the intent that the other person has for you.

So, I don't remember the exact words, but the overwhelming feeling that I got from Diane on that day was that everything was going to be okay. And no one else could have given me that message.”

**Visual**

**Diane brushes away her tears. Matthew continues to speak, looking at the interviewer.**

Audio

“When I think we're designing things about people delivering bad news, we really need to understand that's what the receiver is going to be seeing in the words is actually that intent.

And it really made a huge difference, I think, for me about how I could start that journey of acceptance.”

(Music plays).

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Matthew's healthcare team would talk to Diane and the children about how Matthew was doing, improvements he was making, and involve them in his care.”**

Audio

(The music fades out as Diane speaks).

“Medical staff would sit there. They would bring up scans on their phone and show our kids what was happening to show positives.

Allowed them to suction Matthew's mouth out…”

(Matthew interjects)

“..my tracheotomy. Yeah, down my throat. So they were involved, you know, really.

(Diane continues)

“Yeah. They were involved in every way that they could be.

“Nursing staff would sit there and they'd as they come in from school every day, they'd be like, ‘How was school?’

**Visual**

**A photo shows Matthew awake in his hospital bed following his amputations, with one of his sons beside him holding up a colourful picture he has drawn.**

**We then return to the room where Diane is speaking while Matthew looks towards her.**

Audio

“You know, it was not a quiet ICU environment when we were there, but nobody ever seemed to worry about it for us.

Our kids felt fully involved. And then when Matthew moved from ICU to rehab, the involvement was exceptional again.

(Matthew speaks and Diane turns towards him smiling).

“Again, I don't know if there were rules broken, but they were…

(Diane interjects, laughing)

“…I think they probably were”

(Matthew continues)

“They were really flexible, and it made all the difference.”

(Music plays)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Matthew ended up spending about 9 months in hospital. Being able to stay connected to his children gave him the drive he needed during his recovery.”**

**We see Matthew sitting in the room next to Diane.**

**The music fades down as he begins speaking).**

Audio

“When I got to rehab, there was a fairly big room and it had a one of those beds that pulls out of the wall for a visitor to be able to sleep in. It was a double bed.

So, we hatched this plan to see if the three boys could sleep in that bed overnight, with me, on a Friday night.”

**Visual**

**(Matthew and Diane are smiling as he recounts what happened).**

Audio

“So we had a chat to the nursing staff during the day and, you know, had a chat to the doctor and he was great. He said, "Look, the more kids we have in here, the better.” The age in a rehab facility is pretty high, and he wanted to kind of lighten up the place and get a bit of joy happening. So, so he thought that was fantastic idea.

So we just, you know, executed; the kids are being dropped off, the three boys could all fit in the double bed.

And then was probably about half past four, five o’clock….somebody had forgot to actually inform the director of nursing.”

(Diane starts laughing as Matthew continues the story)

“So she came in, Diane was no longer around, the kids had already been dropped off. I told her the plan and she said, ‘Who's looking after the kids?’

And there am I lying in bed with no arms and legs, not able to move.

And I just turned to her and said, ‘I am’."

(Matthew and Diane laugh)

“So she then, just she looked at me, and she knew him pretty well by this stage, and she just went, "Okaaay." And then walked out.

So I think somebody might have got in trouble, but that happened every week.

So they would come for Friday night ….”

(Diane interjects)

“…and the boys would look forward to that and they ended up being on a roster system as to who could have a sleepover. And it was the highlight for them of probably the whole experience, because they had movies on demand, food was delivered directly to them...”

(Matthew interjects)

“…..breakfast in bed…”

(Diane continues)

“…they had a great time.”

(Matthew picks up the story)

“Then on the Saturday morning after they had the sleepover, they'd come down to the rehabilitation gym with me. And you had everybody trying to, you know, get around and we're on the floor trying to play soccer and rolling around and wrestling and stuff like that.

It made it so much more important for me to get better. It gave me a huge drive to make that difference.”

**Visual**

**A photo taken before his illness shows Matthew, Diane and the four children lying on their backs on the grass, smiling up at the camera.**

Audio

(Music plays)

**Visual**

**Text appears on screen accompanied by a voiceover which says “Matthew recalls a time when he was supported by his medical team to push the boundaries, to aid his recovery.”**

**Matthew begins to speak and Diane looks towards him.**

Audio

(The music fades down)

“I think one of the other really important things for me in the way that the hospital approached my recovery was the ability to take risks in hospital.

It's much more important to take risks where you have a support mechanism to deal with things that go wrong - because if you don't do it in a hospital, you're going to do it at home.

So for example, you know, falls prevention - I am quite a falls risk, but I also need to do cardio activity.

And we were really struggling to work out how do I actually get cardio, a bit of exercise and core strength back up again.”

**Visual**

**Video footage shows Matthew in his bed at home. He is wearing shortened artificial limbs. He tilts his electric bed up. The camera zooms out and we see his dog lying on the floor of his room.**

**The shot changes to Matthew wearing his shortened artificial limbs walking down his hallway at home.**

**We return to seeing Matthew being interviewed, with Diane sitting next to him.**

Audio

“So, an example of that, we decided that a trampoline would probably be a bit of a good idea.

So, as you can imagine, you know, with my no arms and legs jumping up on a trampoline, the falls risk kind of escalates a little bit more.

But that's an environment to do it in. So, we worked out how do we do it? What kind of matting do I need around me to make sure if I do fall that I'm going to be okay?”

(Diane interjects)

“You had a helmet on.”

(Matthew continues, smiling wryly as he recounts what happened)

“And as it turned out, I fell. So, my head hit the side of a wall and I slid down onto the mat.

I was perfectly fine. The risk was managed well.

And that's probably an extreme example, but there are lots of others where I was able to take those risks to find those boundaries because if you don't know where those boundaries are, then you're probably not trying hard enough.

So how do you do that in an environment where it's well supported and those risks are well managed.”

(Music plays softly)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Reflecting on what happened in the lead up to being admitted to hospital, Matthew says there were a number of occasions when his illness could have been diagnosed.”**

**We Diane looking towards Matthew in the interview room as he speaks.**

Audio

(The music fades down)

“The core thing for me is that there were multiple opportunities to intervene and in my view there was facts there that were able to be read.

They may not have said this is exactly what the diagnosis is, but there was an alternate there.

(Music plays softly)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “The importance of adverse event reviews.”**

**we return to Matthew speaking to the interviewer with Diane looking towards him).**

Audio

(The music fades down)

“The adverse events in New Zealand highlight that there are issues around either, you know, making a diagnosis too early, you know, or making it the wrong diagnosis or diagnosing too late.

So, I think taking that time to really understand what these set of facts in front of us could be and not explain it away too early with something that's convenient.”

(Music plays softly)

**Visual**

**A photo appears of Matthew in a rehabilitation centre. He is upright, dressed in a red sports singlet, and not wearing his artificial limbs. He is surrounded by his family and medical staff. They are all smiling at the camera.**

Audio

“And I think in that scenario, the care that will be given to patients will significantly improve.”

(The music continues to play softly)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Matthew saw a range of health professionals before he was admitted to hospital. He believes had they had access to all of his health records, he may have been diagnosed earlier.”**

**We return to Matthew speaking to the interviewer, while Diane looks towards him.**

Audio

(The music fades down)

“I saw a GP, then a hospital, um then an after hours doctor, then another GP, then a hospital.

So for me, the continuity of care wasn't necessarily there, and access to history is critically important.

Now, I think it's very important that the patient, as I did, gives the history. But I think it's also helpful if the system actually supports the right type of decision making.

So to have all of those records available to people.

I've seen pretty much everybody except maybe an obstetrician and gynaecologist.

(Matthew and Diane laugh. Matthew continues)

“I think I've seen pretty much everyone else. My records are everywhere.

You know, the specialists and you know trying to bring all those together, my scans and my blood results and I think …. trying to manage those records is quite difficult and then it's very difficult to then make decisions.

I think you also end up with duplication of testing and the quality of care would be improved by being able to connect all those things together more effectively somehow.”

**Visual**

**Diane begins to speak and Matthew turns to look at her.**

“Matthew's a very capable person, so he can explain his history, but not everybody is in that position.”

**Visual**

**Video footage shows Matthew in a wheelchair, using a ramp to exit an accessible van.**

**We then see Matthew outside in his electric wheelchair speaking to a man who is walking beside him.**

**Matthew and the man are then shown talking and laughing, seated inside a café.**

**The footage then changes to Matthew in his wheelchair inside an elevator, selecting a floor number. The elevator doors close.**

**We then return to the interview room.**

Audio

(Diane continues speaking)

“And when you have to go through your history, you're reliving it to a degree.

So it would be better if there were systems there ..

(Matthew interjects)

“…to help”

(Diane continues)

“…so you didn't have to explain every single time.”

(Matthew picks up the response)

“Every time I go to hospital, you know, I sit out filling out those admission forms, asking the same 26 million questions that I've been asked the last 15 times I've been to hospital.

And there's more chance of error because I'm getting complacent.

And so I think, you know, how do we actually help patients do that kind of stuff as well?”

(Music plays softly)

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Matthew talks about the importance of adverse event reviews and the work being done by Te Tāhū Hauora Health Quality and Safety Commission to improve them.”**

**We see Matthew and Diane seated in the interview room, with Diane looking towards Matthew.**

Audio

(The music fades down as Matthew begins to speak)

“It does remind me a lot of the things that I've seen over my career. I worked 20 years in the oil and gas energy industry where unfortunately things, you know, have gone wrong on many occasions.

One of the things that I do see is that there is a conglomeration of what is happening.

So what are the actual things that are happening? And you know that's always the first step, which I think is fantastic.

**Visual**

**Video footage shows a close up of a screen on a device used to open the side door of the wheelchair accessible van.**

**A wider shot shows Matthew use a ramp to get into the van on his wheelchair.**

**We then see Matthew driving along a suburban street.**

**Then the visual returns to Matthew and Diane in the interview room.**

Audio

(Matthew continues speaking)

“I think the challenge is simply going to that why. Why are there problems with diagnosis?

And also continuing to ask why.

So I have no idea the answers to those questions, but you know, why may that be misdiagnosis? Well, ‘we didn't have enough information’. ‘Were you given enough training to ask the right information?’ And then if you have enough training, do you then have enough resources? Is there enough equipment there? Or, you know, are there enough people there?

And then you say, ‘well, if there aren't enough people there, why?’ ‘Well, our budget constraint is there.’ So, well, why is the budget constraint there?

It’s like well, somebody very much removed has set that, probably not understanding the implications.

What I've experienced historically is the deeper you go in those why questions, the more impact an action coming out of that investigation will have on more people.

The difficulty is there's always multiple things that are happening; it’s never, in my experience, ever been one.

So how do you get a consistent view? There might be the top three, look for themes. You know, ‘are we resource constrained?’ ‘Do we have an issue around training or competency?’. Those kinds of systemwide changes I think is the real challenge to find - and I don't underestimate the difficulty of doing that.

But I think it really starts at the top, you know, where people who are hearing the information must not accept simple answers to the investigations; they're always complex things, there's never a simple answer.

And it's not about finding blame. It's not about finding who did this wrong. It's actually about preventing things in the future.

And to do that, you've really got to find those deep root causes, which is the needle in the haystack, and it's hard, but it's very much worthwhile doing.”

**Visual**

**Video footage shows Matthew at home in his wheelchair, with his daughter off to one side of the screen.**

**He’s then pictured coming down the hallway in his wheelchair, being met in the entranceway by Diane and his dog.**

**Diane and Matthew hug.**

Audio

Music plays softly.

**Visual**

**Text appears on screen accompanied by a voiceover which says, “Thank you to Matthew and Diane for sharing their story.**

**Find out more about sepsis on the Te Tāhū Hauora Health Quality & Safety Commission website, hqsc.govt.nz”**

**The Te Tāhū Hauora Health Quality & Safety Commission logo appears on screen. It features the Commission’s name. Alongside is a stylised version of a wharenui (meeting house) in a triangle shape, with the tāhū (ridgepole), heke (rafters) and niho taniwha (triangle pattern) beneath.**

**The Te Kāwanatanga o Aotearoa New Zealand Government logo also appears. This logo is made up of the coat of arms of New Zealand on the left and the words Te Kāwanatanga o Aotearoa in bold letters alongside it, with New Zealand Government written beneath.**

Audio

The music fades out.