

Steffi and Elayne Video – Audio Description

The video starts with an animated Bristol Myers Squibb logo.

Text then appears on screen which says

“The story and opinions shared in this video reflect Steffi and Elayne’s personal experiences. The list of symptoms mentioned here is not complete and experiencing them does not necessarily mean you have HCM. Consult with a qualified medical professional for an accurate diagnosis.”

“CV-GB-2400061 | April 2024” is included as text at the bottom left of the screen.

The video then cuts to a garden scene. Two women walk out of the rear of a pebble-dashed house. Steffi and her mother Elayne. They are holding mugs and begin to walk around the garden looking at plants.

Steffi speaking:

“My name's Steffi, I'm 26, I'm from Surrey and I'm currently a project manager.”

Elayne speaking:

“I'm Elayne, I'm Stephanie's mum. I'm 62 this month.”

[The video transitions to a living room scene. Elayne is seated on a stripey sofa with Steffi next to her on a matching armchair. A graphic appears on screen which says “Steffi. Hypertrophic Cardiomyopathy (HCM) patient.”]

Steffi speaking:

“I was diagnosed when I was 18. I was just sat on the sofa at home one day and I said to my mum I couldn't breathe. I felt breathless, just sat down. So my mum said, I think we should go to the doctor's.”

[The viewpoint cuts back to the garden scene where Steffi and Elayne continue to walk around looking at shrubs.]

“I went to the doctor's and they originally thought I had asthma, so gave me an asthma pump and gave me this lung monitor to see if it was asthma. I went I went back maybe a couple months later for an ECG.”

[The video cuts back to a close-up shot of Steffi sitting on the armchair.]

“And at the ECG appointment they found something that obviously concerned them because they then booked in an echocardiogram.”

[Camera switches to a different viewpoint of the living room. A wide shot where Steffi is seated on leather sofa and is looking through a photo album.]

“I had the echocardiogram and then they said, we need you to go up to the cardiology ward.”

[Elayne walks over to join Steffi on the sofa. They both look through the album.]

“And I was then waiting in the family room.”

[Camera changes to a close-up shot of Elayne and Steffi.]

“So, by this point I was in hysterics, crying my eyes out with my mum and my brother. The cardiologist did come into the room a bit later on.”

[View cuts to a close-up of Elayne.]

“And explained what cardiomyopathy was,”

[Video transitions to a view of Steffi and Elayne on the sofa still looking through the album, smiling and talking to each other. We do not hear what they are saying.]

“And that I had a version called hypertrophic cardiomyopathy. It was very difficult,”

[View switches back to Elayne and Steffi sitting on the stripey sofa and armchair.]

“But my mind switched when I found out I had something and I would be staying in hospital because I was of the mindset of, I can't fight something that I can't control.”

[The video cuts to a kitchen scene. Elayne is sitting at a table with a jigsaw puzzle in front of her. Steffi is standing next to her helping her with the pieces. Elayne points at the picture of the completed puzzle on the box and back to the pieces on the table.]

“Whilst I was there, I had visits from heart failure nurses, heart arrhythmia nurses, from local charities that didn't tend to have a lot of young people, but they were trying to get me involved.”

[Camera moves back to Steffi sitting in the stripey armchair.]

“It was very lonely at the start. So while I was in hospital and just afterwards, because there was no one to talk to, who was going through the same thing, and that can be very difficult, yeah.”

[The video switches back to the kitchen table scene with Elayne and Steffi working on the jigsaw.]

Elayne speaking:

“They sent her for gene testing later. When they did the gene testing, they found that she obviously had this gene, they wanted to then test the rest of us. I went for the testing and they found that the gene had come from me.”

[Camera zooms in on Elayne's hands on the jigsaw.]

“From my point of view that was much worse than having the condition.”

[Video moves to Elayne seated on the stripey sofa.]

“Because I feel guilty, any time she feels ill, I feel guilty. Any time she says I can't breathe, I can't do this, mum. When we're just going for a walk, I feel it's my fault.”

[Viewpoint cuts to Elayne and Steffi back in the garden.]

Steffi speaking:

“After the surgery, I lost my independence. My mum was washing my hair. I was sleeping on the sofa downstairs because I couldn't get comfortable in the bed. That was very hard. And adjusting to living with the ICD can be very difficult. The first things you notice is friends can sometimes disappear”

[Video moves back to the living room scene with Elayne and Steffi seated on the stripey furniture.]

“Because they're worried that you'd be out and something may happen, or they could be put in a weird position or they don't understand. But then you get the other friends that want to know everything, even though you don't know it, and they're asking you and you're trying to explain that you don't know something about yourself.”

[Camera zooms in on Steffi]

“Symptoms are elevated by the weather, by the seasons. And this is something I personally like to talk about because it isn't mentioned as much.”

[Scene changes to the kitchen, where Elayne is filling a kettle from a water filter jug and adding teabags to two mugs.]

Elayne speaking:

“What Stephanie didn't cover is the physical aspect of the operation. It left her with a very big scar, and also the device itself”

[View moves back to the living room with Elayne and Steffi.]

“Was quite frightening because you've had a big operation and then all they've told you is that it will last probably between 5 to 7 years, the battery, and then you'd need the battery changing and another operation.”

[The video changes to Steffi sitting at a desk in front of a computer screen, she is working on a document.]

Steffi speaking:

“Since my diagnosis, I did an apprenticeship in project management.”

[Cut to Steffi walking into her bedroom. She walks up to a dress which is in a cover and unzips it.]

“I also took up pageantry. So I compete in pageants. I've done one called Miss International and I'm currently doing another national one called Young European.”

[Viewpoint switches back to Steffi seated on the stripey armchair in the living room.]

“It's given me such confidence. I get on stage, I don't care now if my scar is out. None of the girls there judge me”

[Camera goes back to the bedroom scene. Zooms in on Steffi placing a pageant sash on a green sequined dress.]

“And you do get a chance to speak for those who can't speak for themselves or to talk about something different, and the dresses are an added bonus.”

With something like this, I do think you realise life can be short and that you need to, if you want to do something to try and just go and do it.”

[Video returns to Elayne and Steffi in the living room.]

“Whereas before, I had that drive, but I didn't have the big motive behind doing it, probably.”

[Camera cuts to Steffi in her bedroom with her dresses.]

Elayne speaking:

“I'm proud of her for using it as a platform, really proud of her for that, and proud that she likes to try and help other people.”

[View changes back to the women in the living room.]

“What she didn't tell you that she's also taken up is she does do counselling when she can, not obviously on a professional level, but she does it for other young people.”

[The video cuts to Steffi in another room. She is looking at her ICD monitoring device.]

Steffi speaking:

“Myself and my mum, we're living proof you can live with this condition. Yeah, it is limiting and you do have to find your way around it. But, if it did ever happen, we do have the knowledge to help other people to pass on the knowledge.”

[Cut back to the living room scene.]

“So I feel we're in a much better place now knowing it's hereditary, than we were at the start.”

[Viewpoint changes to a wide shot of Steffi and Elayne in the garden.]

If I could give advice to someone with cardiomyopathy, it would be talk to people. There are people out there with your experience, speak to them. There are positive experiences you can relate to rather than just all the negative ones you see.”

[The video cuts back to a close-up shot of Steffi on the stripey armchair.]

“Don't go on the internet and search up for your condition, go to the right places such as Cardiomyopathy UK and don't let it change your life, let it adjust your life to something that works for you with the condition.”

[Screen fades to white and the Bristol Myers Squibb logo animates on.]

Text then appears on screen which says “Could it be HCM is a disease awareness campaign that has been fully funded and developed by Bristol Myers Squibb.

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