

Meningitis and Septicaemia 2019
November 5-6, 2019, British Museum, London.

Patient experience of meningococcal disease

Mike Davies, member of MRF

Mike became ill with meningococcal meningitis and septicaemia at Christmas 2017. He was wrapping presents on the afternoon of Christmas Eve when he began to get colder and colder, getting into bed didn't help. Mike says: "I looked like a ghost with blue lips. My family insisted on the trip to The Royal Sussex County hospital where the fantastic NHS clicked in. On Christmas Day my family were told I was unlikely to survive, but after I spent ten weeks in Intensive Care I pulled through.

During this time I began to look forward (yes, looking forward) to having my hands and feet amputated. Legs went one week - hands the next, and the hands took seven hours alone. Then I had weeks of recovery and wound healing. For a long time I had to have my blood detoxified three times a week at dialysis in hospital as my kidneys were so badly affected, but I could have died. One day I flatly refused to get out of bed to attend hospital for the necessary and life-saving dialysis I was having three days a week. The greatest thing to happen to me then was to be offered counselling through the hospital renal department. In my darkest moments I would think, how would I ever shower, toilet, eat breakfast, drink tea, go shopping, walk places, catch a bus? But overcoming each of these challenges was another little victory.

I feel lucky to have had my meningitis journey and support in a country where good aftercare is available. I learned to accept my situation and be at peace with it. I feel in quite a positive place in my mind about the challenges I still have to overcome. Support from other people has been key. I am a lucky man. There needs to be better recognition of the after effects, that's why I'm helping to raise awareness of the serious health outcomes, and how good aftercare can help.