

Living with second-hand depression and the roller coaster ride that is being a full-time unpaid carer

One of our carers has written a moving piece about what it's like to care for his disabled wife and daughter for more than 20 years. Health problems have led to severe depression for his wife, which is very hard to cope with. He wishes to remain anonymous, but that does not detract from the frank and honest insight he gives, to which many carers will be able to relate



I've cared for my wife for more than 20 years now, since she has been registered blind. Over the subsequent years, her health has continued to worsen, partly because of the difficult birth of our daughter, but also from injuries inflicted when she was a child by abusive parents, both physical and sexual. She ended up needing catheters, which gave her repeated UTIs and even sepsis twice.

The urinary infections were slowly killing her. Eventually it was decided the only option left was to have an operation to divert the normal flow of urine from the kidneys. However, her bladder shrank and bowel collapsed, and in 2018 she had to have a colostomy stoma operation.

During this time, I was also caring full-time for our now young adult daughter, who has cerebral palsy and dysphagia. Dysphagia is when you cannot understand the speech you are hearing. She is still unable to talk, read or type, but has learned to read sign and body language and the auto-spelling on her laptop mean she can follow the things she loves: John Barrowman, Butlin's and Doctor Who. She also communicates via images to me and her friends. I cared for her until she was 23, when she moved into a care bungalow two years ago, the same day my wife went in for her bowel operation. There were lots of tears the day she moved out, but my daughter quickly grew to like the freedom, 24-hour care, a car and a bigger bedroom. She now considers this the time she grew-up, and loves it there.

My health was also starting to feel the strain of caring for two disabled people. I developed a chest infection and paramedics had me admitted to Bedford Hospital. While I was in the ward they discovered I had an irregular heartbeat, Atrial Fibrillation. They tried to stop my heart with defibrillators and then restart it. It worked, I had a steady heartbeat for all of five minutes and then it reverted back to my irregular beat. They said that it was too dangerous to try again so I am on several tablets to keep my heart going, as well needing four injections of insulin a day due to type 1 diabetes.

After the operation on her bowel, leaving her with two stoma colostomy bags, my wife's depression began. The operation had a huge effect on her, having to cope with the myriad of equipment needed to manage two stoma bags, while completely blind, and constantly worrying about leakages. I am always here to help and assist when bags need changing, but



having the stomas killed our social life. If we go anywhere we need a suitcase full of medical supplies and going to the theatre, which we both used to love, became impossible because she would spend the whole time worrying if the bag would fill or worse, leak.

The depression this caused by feeling trapped because of the bags, led to her hearing voices, flashbacks of the abuse inflicted by her parents, and then self-harm. Which is where

we are now.

She has lost all motivation and the inherent joy of living. Life feels meaningless and an unending struggle to her. She feels like 'what's the point of it all' a lot of the time.

Living with someone you love who has depression, is also devastating for their partner in life. I have always been someone who has an optimistic view of life, but I feel that slipping away, along with my motivation.

I feel exhausted most of the time, undervalued by the government and unappreciated by my wife, but I know that is the depression talking. I feel like I need a rest from the incessant gloom and despair, or I fear I will fall into the same deep well.

Deep down I know my wife loves me, and I her. I hate to see her suffering so. This summer will be our 30th anniversary and we plan to renew our marriage vows.

During the last 20 years or so, which sometimes seem like an unbelievable movie or soap opera script, I have always had the support of charities that have helped us carry on. Carers in Bedfordshire have been an absolute godsend in helping with the incessant forms regarding the different benefits that we can claim. CiB also provided me grants to allow me to have an occasional break in the Isle of Wight for much needed respite. The charity also enabled me to have haircuts and foot treatments during lockdown. Carers in Bedfordshire are wonderful and due some long overdue recognition.

Family Fund has provided us with a washing machine and fridge freezer. My thanks also go to Macintyre Care, for doing an absolutely magnificent job looking after my daughter, whilst I continue to care for my wife.

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