

Jill Fenton

Parents and Carers
Spotlight Profile



I have been a carer for forty years in total, both full time and part time at different junctures in our daughter's life. At six months of age our daughter Amy was diagnosed with a rare brain tumour that was surgically removed at the Maudsley Hospital South London. Since that date, her life has never been free of neurological-related conditions, medical and surgical procedures; she has epilepsy, recurrent brain tumours, acquired brain injury and, more recently, severe cognitive impairment.

At twenty years of age, having graduated from a specialist college, she decided that she would like to live with young people like herself who have epilepsy and learning disability. We found a supported living provider offering the independence that she desired but, six months into living there, one day she fell downstairs during an epileptic seizure and incurred major contusions to her brain; she spent a subsequent two and a half years in a brain injury unit. Since then, she has lived in a residential home that specialises in the needs of young people with intractable epilepsy, most weekends returning home to us her family. After neurosurgery to remove a brain tumour in November 2018, Amy experienced considerable loss of memory to the extent that sometimes she is unsure of where she is and who is her family. In November 2019, she had radiotherapy to treat a recurrence of the earlier

brain tumour, following which, further loss of her cognitive abilities.

Then came lockdown in March 2020. The care home and we agreed that Amy should live with her family because of the probable distress to her of being separated from us. Because Amy's immune system was compromised by earlier radiotherapy, we had to shield her and isolate ourselves from other family members, in fact, all visitors; we could not call upon carers to support us because of the risk of cross-contamination. We were completely alone, my partner trying to keep his business going and myself my teaching for the International Foundation Year (IFY), whilst sharing between us the care for Amy. In addition, I had to learn new programmes and technology to deliver my teaching remotely. But I managed, thanks to wonderful support from IFY colleagues at the School of Languages, Linguistics and Film.

That first lockdown, Amy was at home for four and a half months then returned to her residential home, however, not for long before the second lockdown in November - another month of living with her family - and now the current lockdown - she has been living with us since 24 December and will continue to do so until it is completely safe for her to return to her residential home.

In all three lockdowns, my partner and I have shared the care for Amy without support, sometimes working into the night to make work deadlines. We get tired and frustrated and at times utterly depressed because we love our daughter, but she also breaks our hearts especially when she has a vacant expression on her face and is unsure who we are. When education is so important to both of us, it is wrenching to see that it has become completely lost in our daughter whose language is limited to baby words and occasional moments of clear speech. When we are not working - thankfully, I am a part-time lecturer - we spend our time planning creative activities for Amy whether playdough, popping bubble wrap, making simple jigsaw puzzles, walks on fine days, colouring. At the end of each day, we sleep out of exhaustion and sometimes also with heavy hearts.

I do not know how I would be without my teaching for the IFY which has given me a space in my life for myself and enabled me to be creative. I have even recently managed with a colleague to have an article published in a journal. Also, working with the students remotely is a joyful experience and one I really appreciate. I teach human geography and many of the topics covered in the two modules are about social justice and human rights. The experience of caring for Amy as well as at times

fighting for her human rights has given me insight into how critical a discipline human geography is towards a fairer world in which all voices are heard as well as the voices of those who are unable to speak for themselves.

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