



Family Carer: Pat Purkis
Age: 83
Cared For: David
Situation: Lives in Supported Living near family home
Age: 54
Other children: One daughter
Years of caring: 54

'Every time the post comes I think, what is it now?'

Pat is originally from Plymouth and after marrying her husband Tony 59 years ago spent a number of years living abroad. David who was born in Singapore was three when they moved back to live in the UK. He was a very happy toddler and got up to the same mischief as any other infant. It was only when he started school that Pat became aware that David was not at the same level as his peers. They home schooled him for a while, then he attended a school for children with special needs. They moved to Oxfordshire when David was an adult but found the transfer between counties 'a mess'.

Pat like many others in her situation does not see herself as a family carer but is in fact still very involved in David's life and is still dealing with his day to day finances and supported living arrangements. She has also up until recently being a carer for her husband aged 84 who moved out to a care home because of dementia. Whilst David has been living independently for 21 years he still comes home every week for his 'coke and custard tart'.

For Pat the best thing is when life is running smoothly and you have time to relax. When you are a family carer you are on the go the whole time and when things go wrong it can be devastating. Despite David living in his own home with support Pat is still very involved and is still continuing to sort out Fairer Charging as well as any unforeseen issues that occur. David has had to deal with the unexpected death of one of his care workers as well as his Dad moving in to a care home.

Having David has meant that he has bought a lot of understanding about people who have learning difficulties. He is well known in his local community and Pat is often told by people that he makes them laugh. He has a great willingness to help, he is easy to be with (as long as he has a coca cola and custard tart) and he is able to plan his own activities.

One of the biggest impacts of being a family carer on Pat's life however is that 'your time is not your own...a lot of the things you want to do you just can't do as it clashes with you caring'. Not only is Pat still having to help David with his finances but when her husband was still at home she could not leave him alone. She was also accused by the Doctor of meddling when David needed surgery. Her response was 'he is my son and if it's going to get him to the hospital quicker I don't care'.

One of her biggest worries is who is going to deal with all this when she is not here. She sometimes wakes up at night worrying about David's financial position. 'There's always something!'

Looking back however Pat doesn't feel that she would do anything differently – perhaps be more challenging with the support provider who she feels are not as good as they used to be.

However, she knows that David is 'sublimely happy' and that living in his own home was the right decision. When it finally happened he gave Pat a really big hug.

Pat trained to be a teacher and taught for a while in various schools up until David and her daughter were born. She then stopped working as she could not have done a full-time job and even though David had a learning disability Pat does not feel that it was the reason for her deciding not to continue working.

Her advice to others is 'Start as you mean to go on'. By that she means not giving the opportunity for statutory organisations to be difficult and if you don't succeed "Go to the Top." She wishes the statutory agencies would be more transparent

Her hope. 'That David will continue to live in his own home spending his time as he wishes visiting car museums'.

Pat's husband Tony passed away a few weeks after this interview.