



Family Carers: Rachael and Ian Scott-Hunter

Ages: 72 and 74

Cared For: Alexandra

Situation: Lives at home with her parents

Age: 47

Other children: One son

Years of caring: 47

'Family Carers are unsung heroes...you don't have a retirement'

Rachael and Ian met in Wales when they were 15 and 18. Ian's family who were from Aberdeenshire were on holiday at the hotel that was run by Rachael's family. Rachael is adamant that when they first met, Ian stuck his tongue out at her – Ian – ever the gentlemen denies it vehemently. The rest as they say is history. They were engaged when Rachael was 20 and married when she was 21. Ian moved to the hotel to work. Their son Paul arrived, followed three years later by their daughter Alexandra. The birth of Alexandra changed their lives forever - in more ways than one.

Alexandra was only 4 days old when she suffered a massive brain hemorrhage. Rachael had known however as soon as Alexandra was born that there was something wrong as she would lie there like a rag doll. What followed were years of visiting specialists as well as many emergency trips to the hospital often during the night to get a full diagnosis. During this time they came in to contact with a multitude of professionals. Some whom Rachael remembers as being fabulous – others who accused the family of 'causing a lot of fuss' and a consultant who told them he hoped Alexandra would die.

Their son Paul was bought up with all of this and accompanied them on all of the hospital visits with Alexandra. This is why, Rachael feels, that he has developed a real care for others. It was during one of these trips to the specialist unit at Great Ormond Street that Ian was also to discover his next job. He happened to spot a job vacancy for a butler, applied and has spent the rest of his working life as a royal butler for the Queen and Buckingham Palace. This not only took Ian away for months at a time which meant that Rachael spent much of her time as a single carer but they also moved a great deal which meant starting all over again with new professionals and schools.

Despite everything both Rachael and Ian feel incredibly honoured to have Alexandra as she has taught them so much about life. In her 47 years Alexandra 'has had so much to cope and deal with' as she 'has so many medical problems'. Yet in her own way she is so inspirational. 'She makes us laugh'. 'She is a proper flirt' and she has taught them both to be more patient. They love Alexandra's strong personality and despite being nonverbal is certainly able to make her feelings known.

The hardest thing about being a family carer for Rachael is the trust she has to put in to others to take care of her daughter especially when Alexandra goes in to respite. Rachael is terrified that Alexandra will die there and that she will not be with her. At home they still use a baby monitor to listen out for Alexandra in case she needs them and often have to get up to her during the night. Previous bad experiences means that 'they cannot say they 100% trust people.'

Rachael and Ian also now find it more difficult to physically take care of their daughter who needs a hoist to be moved. They have had to adapt their home and employ a team of carers who are in their home every day – something they find very intrusive. This has meant Rachael has had to become an employer on behalf of her daughter, paying wages, income tax and pensions – something she was never trained to do. The even greater worry is staff calling in sick or leaving and the stress that comes with finding a suitable replacement. It takes a minimum of 6 weeks to train them up and for Alexandra to get used to someone new.

When they were younger they were under enormous pressure to put Alexandra in to residential care. They tried it for a while but it had such a negative impact on Alexandra that they knew they could not continue. Despite that knowing that they have to prepare Alexandra for a future with them not in it, they have continued to use respite but find it very challenging.

Rachael has managed to juggle being a family carer and work but with Ian often away for months at a time she has had to fit it around caring for Alexandra. When Ian started working only at weekends it meant that Rachael could develop her career but 'wouldn't be able to do it without Ian who is my anchor'. Neither of them would have thought however that at the ages of 72 and 74 they would be starting out on their biggest journey.

Ian and Rachael have big plans. As a result of the amalgamation of Day Services within Oxfordshire in 2017 they started to think about an alternative place for people with learning disabilities and their vision for the 'Alexandra House of Joy' was born. Two years on, they have the land, the plans and are a registered charity and are raising two and a half million for the building work to commence. They see it as a legacy to Alexandra.

Their advice to other family carers is to take it a day at a time and to recognize that nothing is set in stone. 'Don't be afraid to speak out – stand up for what you feel is right for your son and daughter'. No family carer they feel, should live in fear and should be allowed and encouraged to say what they feel. 'Family Carers are the unsung heroes' as other people do not realise what impact looking after someone for all their life is really like. Looking back Rachael feels she should have stood up more to the authorities than she did but has found her voice now.

Rachael's hopes and dreams – 'for Alexandra to be taken before us – I can't bear for us to be taken before her.'

Alexandra died peacefully at Sobell House surrounded by her family on March 26th 2019, a month after interviewing Rachael and Ian.