



Life Long Caring 'You cannot retire' "I want another 20 years"

Family Carer: Brenda Quick
Age: 92
Cared For: Karen
Situation: Lives in own home with support next door to Brenda
Age: 66
Other children: 3 daughters (one deceased, one lives locally and one lives out of county)

Years of caring: 66

The second world war broke out when Brenda was 14 and at the age of 17 she joined the land army and moved from Sheffield to Oxfordshire where she met her husband who was in the RAF. She has lived in the same house for 50 years. Her daughter Karen lives next door with support from a live in carer, Brenda and one of Karen's sisters.

Karen who is Brenda's second daughter was born profoundly deaf. For the first years of her schooling Karen attended a specialist school in Newbury as a weekly boarder. At the age of 14 she then went to a school for the deaf in Birmingham. Brenda drove her daughter to both schools on a weekly basis whilst also caring for her 3 other young daughters and working a number of different jobs in order to earn an income.

She said leaving Karen every week at the school was the hardest thing that she has ever had to do.

At the age of 17 Karen's schooling ended. Brenda was told 'that's your lot (now) get on with it' so she found Karen a job in Witney which she enjoyed although Brenda would often have to go in and intervene as Karen would get teased by the other employees. Karen also had a volunteer driver who would take her to and from the deaf center. One-night Karen came home in hysterics. Although it was never clear what actually happened Brenda believes that Karen was abused. This had an enormous impact on Karen's mental health and from then on, she refused to go out. It has taken a lot of support from Brenda to help Karen achieve what she is able to do today.

Looking back Brenda does not feel that life was particularly hard and that the support she has provided for her daughter is no different to what family carers have to do today. It's a case of 'taking it in your stride – you don't stop to think about it – you just keep going'. However she recognizes that Karen's disability did have an impact on the rest of the family and after divorcing her husband she had to rely on her other daughters to look after Karen whilst she was working.

However even at the age of 92 she says you cannot retire and Brenda is proud that it is because of her carrying on that Karen has been able to stay in her own home. The compensation for her far out ways the hard work and both the gratitude in Karen's face when she is not well and sees her Mum or the little gift that Karen brings back for Brenda every day is reward enough for Brenda.

Brenda does not regret one minute and is very proud of what she has done. However her biggest fear is when she is no longer around. "The worry and stress is far worse than the 66 years of caring that I have done – I don't sleep at night. I can't as I am so worried that Karen will not be able to stay in her own home". "The thought of Karen being uprooted from all the things she loves, to go where she doesn't know anyone and where they do not understand her" fills her with worry. She worries about Karen's screams being mistaken for

bad behavior and that she will be sedated. Her greatest wish would be to have another 20 years of life so she can continue to look after her daughter.

She is still very involved in Karen's day to day life. She goes to see her every morning. She cooks lunch for her every day. She helps her with her knitting and she is still helping Karen with her personal care during the week. 'It is the little things that matter to Karen' 'Karen is my life – always has been – when she is happy I am happy'. Every day Brenda stands at her fence to see Karen walk by on her way out.

One of the hardest things about being a family carer for Brenda is all the paper work that has to be filled in. "Not a day goes by when one form or another has to be filled in – there is stacks and stacks of it!" She doesn't think that anyone other than a family carer can appreciate the amount of paper work that is involved.

Brenda's advice to other families is not to let their family member be sent out of county. Every child needs their Mum. She is very grateful for the help she has been given and feels that with the right support anyone can lead a normal life. Since been in receipt of a Direct Payment, Brenda says Karen has been very happy and this is due to the fact that she has the right support and feels very secure. Brenda's advice is 'go ahead and do it.... I'm proud to think I've done it". If she could have done anything differently it would have been to get a Direct Payment earlier and choose her own carers for Karen. Getting the right support has made a huge difference. She is grateful for all the help she has received both from OCC and other organisations.

Her hopes and dreams are that Karen can stay in her own home for the rest of her life.

She feels that having a child with a learning disability makes you stronger but sees her life as 'just a life I have led' which 'I would do all over again'

Her words of wisdom: 'Keep going.....never stop...and don't look behind!'