



Family Carers: Derrick and Ann Sturdy
Ages: 85 and 80
Cared For: Kay
Situation: Lives at home with her parents
Age: 53
Other children 2 sons.

Years of caring: 53

'Everything finishes at 2'clock for us as we have to be back home for the bus.

Derrick and Ann are both from Oxfordshire and have lived in the same house for 61 years. They are parents to three children as well as being grandparents and great grandparents.

When Kay was about one, Ann had a sense that she was not developing in the same way as her other children but was told by a specialist doctor that Ann 'was expecting too much' and 'setting my standards too high'. It was only a chance visit from a new GP to see all three children who had chicken pox that Kay was diagnosed with microcephaly. She was 5 years old when she had the test. Consequently she did not go to a special school until she was nearly 6. They were told that she would be alright and that 'she would just be a bit slow' but for Ann 'you just know really'.

Fifty plus years later and Ann and Derrick are still having to wait for the bus to bring Kay home from Day Services which can be anytime between 3.00 o'clock to ten past four. This is not something they expected to be still doing in their 80's. 'It's that long since we have had school children or school hours really'. Their day with Kay begins at 7.00 am and ends at 10 pm as Kay never goes to bed before them.

Kay brings a lot of joy and laughter to their lives. She does not like noises including her Dad's singing and is not afraid to let him know. When the family go on holiday they often take photographs with them so that Kay, who is unable to speak can show people. However she will only show certain people – and is very picky about who she shows. 'She also has another sense' and always seems to know when Ann and Derrick have bought her a new item of clothing and will go straight to the wardrobe.

'People that you know still aren't aware or realise what you do or have to do in your daily routine. Neighbours who have known Kay all her life I don't think realise". Only other family carers in the same situation. 'Our two sons

do to a certain extent but not really everything that comes with it – they just say ‘it’s good because Kay is keeping you young.’ They see Ann and Derek as more active than people they know of the same age. ‘There are people here who have lived as long as us in these houses and how their life is to ours is a world apart but if you look at them they don’t get out as much as we do.’ which Ann feels is probably why they don’t feel that old.

Looking after Kay keeps them young but it comes with a commitment. All plans have to be made around Kay’s schedule which other people do not have to think about. They don’t do anything in the afternoons as they cannot make appointments in the afternoons. ‘Everything finishes by 2 o’clock for us as we have to be back to get ready for Kay coming back. You go out in to the garden but your still looking at the time – it’s not relaxing’. They are constantly clock watching.

One of the he best things about being a family carer is the love and hugs they get from Kay. Well the hugs Ann gets...Derrick will do if Ann is not there. Even now when Kay does something different it gives them a buzz. Milestones are different. It’s the little things that brings a lot of laughter and joy. Other people would probably think it was quite stupid but for Ann and Derrick its progress. ‘Our expectations and milestones are different’.

Every year they have a holiday with Kay and their son and his wife. The grandsons are lovely with Kay – their great grandson who is 4 is a ‘rebel’ but is very kind with Kay – he quietens down with Kay and lets him cuddle her. Kay is very much one of the family. The boys and the grandchildren have gained from knowing Kay because they understand other people with learning disabilities more.

There is no doubt that Kay has bought a lot of hard work and worries to their life. They not only worry about the future when they are no longer around but have a constant worry about Kay’s health. “Because Kay cannot speak you are constantly looking for signs to see how she is” as its about ‘knowing when she is not well and what is wrong”. Kay has undergone some major operations which they have found very stressful as Kay does not like Doctors and Ann has had to stay in hospital with her as the staff do not understand Kay. They feel very alone when they go to hospital and feel that staff do not listen to them even though they know Kay best. It took 7 hours for Kay to have an MRI because they felt that staff did not listen to them.

Kay has brought a lot of joy to their lives. They love going out and seeing her enjoy herself and every weekend they head off out in the car whether it be shopping, going for a car ride or heading out for a cup of tea. The set routine is very important to Kay and if they tried to change it she would be very upset. Every year they go somewhere which involves flying even though each year they say they are not going to do it again. She has no perception of risk or fear and is happiest when the flight is bumpy. They love ‘everything about her’. ‘You have to think of the plusses.’

Looking back, in hindsight, Ann feels she should have sent Kay to respite at a younger age. She still finds it hard when she goes now – ‘it’s only 4 days but I hate it’ and she does not feel relaxed. If Kay was going on holiday Ann was

ok but feels guilty if she goes to respite. 'I feel guilty that I had her so I feel I've got to give her experiences – I owe her it really'. Kay enjoys respite as she enjoys the routine but Ann 'still feel's bad'. They regret not doing it when both Kay and they were younger.

Looking at the future, one of their sons has said he is going to take care of Kay. However he has said that he cannot take Kay to a place like April Cottage which Ann says 'doesn't help us really'. They do not think that is fair. Ann and Derrick feel that their sons do not really understand fully what is involved and how their life will change. It makes it hard for them as even though they know that Kay would be happy and over the moon at being able to live with her brother 'they don't know which way to turn to be honest'. They don't want their sons to have to take on the responsibility to that extent of looking after Kay and feel if Kay had gone to respite earlier when the boys were younger they would be more accepting. Someone told Ann that her son should have Kay for a week but he hasn't offered yet – 'it's very different when we are on holiday when I'm still there doing the bathing, the dressing and the washing".

Ann worked when she had her first son but not when Kay was young. Kay was often ill and Ann also spent a lot of time getting Kay used to going on the bus. They would try a few stops at a time until she would eventually go in to Oxford but that took a long time. 'It was all a big effort' As Kay got older Ann did a few jobs that fit around Kay's hours. She would love to have gone back to work but if Kay was ill there was no one to leave her with. Ann was definitely impacted the most. 'It was just too much'.

Kay spent a lot of time with Ann as Derrick worked a lot and would do football on a Saturday with the boys so it was always Kay and Mum. Ann thinks that is probably why Kay clings to Ann now. She calls her Dad 'old boy" and tells him to go away. 53 years on if Ann goes out, Derrick and Kay have a play fight each evening which Kay really likes as she likes the attention.

Reflecting back they were advised by their Doctor that by the time Kay was 16 they should be thinking of another way of living but 'we just haven't been able to do it'. Neither Derrick or Ann feel they would have done anything differently and have no regrets.

Prompted by watching a programme about learning disabilities they asked the boys quite recently whether they felt they had missed out on anything because of the attention they had given Kay but both boys said 'not at all' which they found reassuring.

They tried to carry on doing the things that the boys wanted to do which meant Ann and Kay would go with them but would stay back – they didn't not go but would go and have a walk.

A lot of people know Kay that we don't know.

Ann's hopes and dreams for Kay is that Ann is going to live in to her 90's so Kay will be in her 60's but after that she doesn't know and Derrick 'is going to live as well as I cannot manage on my own!' It would be hard and the worries would be double.

Their message to the government is 'stop causing us money problems'. 'It's one thing after another.' Constantly changing and not for the best – it's a constant challenge. 'We have had enough of it.' Sometimes they think about keeping Kay at home and not sending her to day services as Derrick is not sure what Kay is gaining from going other than a break from them. Ann feels it is important for her to be with other people.

'She won't go out because she refuses and they can't make her' – they feel it's always Kay's fault – she is quiet and Ann feels that she blends in to the background and is overlooked. Ann has given advice on how to get Kay to go out but families aren't always listened to. 'There are some staff who want to do it their way but in the end they don't do it their way as they end up doing it Kay's way'. JR staff were excellent and it makes it so much easier.

Pearls of wisdom – 'not sure we have done a very good job of it'. "I'm always thinking of what should I have done. What have I done wrong. I don't think of anything I have done right". 'We try – we can get things wrong".

"It's a very different life – there are lots of heartaches but lots of positives. We have had a lovely time and done some lovely things with Kay." They used to do holidays without Kay but not anymore as the options aren't there. 'I don't have the guilt feeling if she has gone on holiday. The guilt feeling is really big with us". Ann's parents used to have the boys to stay but not Kay. She feels that they thought Ann was coping – which is similar to their younger son. 'No one ever had Kay overnight'.

'You've also got to think of them and I sometimes feel because I haven't done it (sent Kay to respite earlier) I've not been thinking of Kay enough".