

## INTERVIEW WITH HILARIE – CAROLE'S SISTER

**Interviewer:** Can you tell me about Carole's capabilities.

**Hilarie:** Right Carole is very capable. She is able to clean and she is able to cook, she is able to clean and dust and sweep. At the moment she is pulling the wallpaper off the walls for me so we can decorate. When we do decorate she paints the bottom half of the wall. I paint the top half of the wall because she can't reach to the top so we do it between us. If I go up the ladder, she holds on to the ladder for me. We garden together, so all the gardening here we have done between us. Again, she is the foreman and I am the labourer. She goes off shopping by herself. She can go off, she goes off and we don't always have to write a list, she quite often remembers what she needs although she always comes back with more than she went off for, but she can do that and all the local shopkeepers know her so that they always just check with me is it alright you know for Carole to come in and buy whatever she wants and they always check about that. Any big shop we do between the two of us and we usually discuss what's going in the trolley, but I always notice that there's more of her things have gone in when we get to the check-out. Some of the things I had vetoed by the time we get to the check-out are still in, but she knows what she likes and so she can look after her own cleanliness, don't you Carole. If I cook, Carole washes up, if she prepares a cold buffet or a cold salad then I do the washing up. She can follow a recipe, so she makes her own cakes. She's superb at Yorkshire pudding. I can't make Yorkshire puddings, Carole makes superb ones, and I never do any ironing because I hate ironing and Carole loves ironing so she does all the ironing for the whole house.

**Interviewer:** Good at housework, very useful indeed. And what does she do in the daytime?

**Hilarie:** During the daytime, Mondays, Tuesdays and Thursdays she goes to the Park Head Resources Centre at Ashington which is a Catholic Foundation, run by a Catholic Foundation. It's a very small unit, there's only 30 people there at any one time which she loves. She was at Cramlington but it got too big for her, there were too many people and she couldn't cope with it.

Monday mornings they read the newspapers, they look at news and see what's been going on. So Sunday night

we have to read the newspapers so she's got something to talk about. Monday afternoon they're just in the process of changing what they're doing because each programme only lasts for about eight weeks or so and she was in a knitting group knitting squares to make a blanket for a baby. The idea was to have it before the baby was born but I think they've talked so much while they've been knitting the baby's actually been born now and I don't think the blanket's quite been finished.

Tuesday you're in a cookery club aren't you, there's about six of them and they plan their own menu, they have to come to agreement so that everybody agrees on what they are going to cook. They go out and shop and cost it. They then come and cook it. Then they eat it and then they have to tidy up the kitchen, put everything away and plan the following week's. On Tuesday afternoon you're part of the Horrid Histories which is all based on Terry Dealy's history books, "The Horrid Histories" and they're been doing those and just at the moment they've been doing some work because of all the celebrations for D-Day they've been doing some work on Anne Frank and they're just putting together an exhibition of all the work they've been doing.

On a Thursday you're in a cookery club and she actually gets to bring some of that home for me to taste. I'm not too sure yet what she does on a Thursday afternoon, I think she's still doing tasters because she's only been on Thursdays for a little while.

On Fridays she's at the Hepscott Park Horticultural Unit which is the same unit as Earth Balance and it's also attached to the Horticultural Unit across in Hexham. It's all part of the same thing, whereby they learn how to plant, care for plants, they have plant sales which cost me a fortune because whenever we go to a plant sale they all come up and say, 'Hilarie, I planted this and grew it, you have to buy it,' so I usually end up with a boot full and on Wednesdays Carol is my classroom assistant and comes to work with me at school to help me to work with my four year olds.

**Interviewer:** And tell me about her social life.

**Hilarie:** Her social life is quite busy.

On a Monday she goes to Gateway Club.

On a Thursday she goes to the B.P.N. Club.

Most weekends we're out somewhere Sunday morning even if it's only a quick walk round some of the local footpaths but we always try to get out somewhere on a Sunday. We're both members of National Trust and English Heritage so we go out to the Living History events and Carol's really in to, she really loves her history, mind you it's not surprising because my mother was a historian, so you know I more or less got weaned on history along with being weaned with mother's milk kind of thing, and at the moment we're into the Romans so we have to follow the Romans.

We also go off round different parts of the country looking at different properties. Half terms Carole chooses a city and we do a mid-week break in that city to explore and see what there is to find.

She loves going to the theatre and also likes doing the outdoor theatre events and the outdoor classical musical events that the National Trust put on. Any Shakespeare that comes up, usually the comedies, she likes to go to and I think we can safely say that her favourite is A Midsummer Nights Dream. She loves the ballet so if ever the ballet comes we go off to the ballet. Quite often I think you could say that I am really the chauffeur.

**Interviewer:**

And does she have any special friends?

**Hilarie:**

Not so much now that she lives with me. She did have special friends when she lived in Ponteland which is where my parents lived, but there was a group of fourteen or so handicapped people that lived there and they always did things together. My parents and their parents were friends, they lived round the corner type of thing, they did lots of things together, but gradually over the years our parents have died and the young people have either gone into care or live with brothers and sisters.

So for example, her very special friends, Simon is now in a home in Cramlington, Tessa is in a house in Hexham, Richard still lives with his mum and dad and Carol lives with me, across here in Bedlington, so they don't get to see each other all that often but when they do meet they carry on the conversation from when they were last together. So they've been meeting about four or five times a year and go off and do, either go out to the pub or go to a meal or might go to Kielder for a weekend away or you know they do something together.

**Interviewer:** What would you say Carole's limitations are?

**Hilarie:** Carole is a good talker, but she's not a good communicator so you have to know what she's talking about to understand what she's trying to tell you. Her memory like us all as we are getting slightly older is getting a bit weaker, she's beginning to have trouble with money. She's never been good but now she's not ... and because of her eyesight which she has had both cataracts, she's had cataract operations in both eyes, it means that she likes the security of being round people.

She tends to get a little bit panicky ... she used to be able to travel by public transport but now she gets a bit panicky. If two buses come together, which bus should I get on? Well Carole's answer to that is I'll get on neither and I'll go home. So she has some trouble that way. She needs somebody around just to remind her. You know as you get a little bit older we like to have somebody around to remind us. She needs somebody around just to remind her what she needs to do.

**Interviewer:** Does she have any other medical problems or special difficulties in care?

**Hilarie:** Actually although Carole is Down's she's got away quite lightly in that basically it's only been the cataracts. She's having a bit of tummy problems as she's getting a little bit older but basically that's all there's ever been and she just takes some tablets now to help her with her tummy and that sorts that problem out. But as I say, for a Down's person she's got away remarkably lightly.

**Interviewer:** So how long have you been looking after her?

**Hilarie:** Since ... this is seven years now. My dad died in 1997. Before then, although Carole lived with my dad I was always at the end of a phone-call if he panicked, and usually by the time I got across to Ponteland either dad or Carole had solved the problem and they just needed me for reassurance, but Carole's been with me full time now since my dad died.

**Interviewer:** So how do you find that? Did you know you were going to do that?

**Hilarie:** I had said to my parents very very early on that I would look after Carole if anything ever happened to them, I think what – eight / nine year old. Very, very early on. ....Carole had always shared my bedroom as a small girl

so I think it was always natural that I just turned round to my parents I think as an eight / nine year old 'don't worry, when Carole's older she'll just come and live with me', and I've always known that and my parents have always known that Carole and I would end up living together.

**Interviewer:** So that's never been a problem to you?

**Hilarie:** No.

**Interviewer:** And how's it been since it actually happened?

**Hilarie:** Well, we've had our ups and downs, shall we say. Carole is very dogmatic and she likes doing things in a certain way and it isn't always the best way shall we say, so we do have little arguments every now and then, but basically we've always been together. Although Carole lived with my parents and I lived in my own house she always had a bedroom in whichever house I lived in and she always had some of her things in my house so most weekends my dad would drive her across and she would come and spend the weekend with me and they'd come on a Sunday night for a meal, and Carole would then go back with them.

So it's always been the two of us, we have always done things together. Even in my twenties, if I was going off somewhere and we thought Carole would benefit from it, Carole came too. I always laugh that one holiday that my parents had without Carole they hated it and they came back after two days because they couldn't stand it any longer because they spent the whole of time the two days saying 'oh Carol would love this' and turning round to talk to Carole and finding she wasn't there and it was something similar because I have always been with Carole and to me it was nothing new, she just came in slightly more full time than normal.

**Interviewer:** And what about financially, has it affected you?

**Hilarie:** No it hasn't, because with my father dying, he split his income three ways – a third for my brother, a third for me and a third in to trust for Carole and if Carole's needed anything very very big or needed to do something very very big, we've dipped into her Trust fund. But we find in the main because of the benefits that Carole is entitled to we use those for the day to day running and any big bills I pay out of my salary or if we have something that's very big to find quickly we apply to the Trust fund. I apply to my brother in the Trust fund, and there's never been any

quibble about that at all. So it's about even stevens. I think if we hadn't had my father's Trust fund then yes we would have been having problems, but there's always the Trust fund to fall back on.

**Interviewer:** When did your mother die?

**Hilarie:** Mum died ten years ago, October. Mum died in 1991, dad died in 1997.

**Interviewer:** So how was the transition for Carole when your father died?

**Hilarie:** Again it was very easy because we had learned through my mother's death what to do. When my mother died Carole was excluded from everything. I think, you know, trying to protect her from what had happened with the result that Carole would never ever talk about mum. If we mentioned my mother's name it was 'she's gone', she didn't want to know, didn't want to have anything to do with mum.

Whereas with dad, the minute he was ... from diagnosis to death was only six months, it was pretty quick, and he'd never been ill before, but right from the word go, Carole was involved in every decision. Carole came to see the consultant, Carole knew what was going on at the hospital, in fact Carole got very good at helping dad do blood transfusions because she's so interested in hospitals and doctors, she could tell the nurses what to do and they let her do it. You know, with supervision. So she knew exactly what was going on.

She was at home, my father elected to die at home, Carole saw him deteriorate and the morning he died – he died very early in the morning – and we had a Macmillan nurse in with us because I was living in their house for the last six months of my dad's life and I said 'look, don't wake Carole we'll tell her later' but Carole appeared in the doorway and said, 'I'm coming dad, wait for me' and came in, kissed him and he died.

She never usually wakes up during the night, but that night she woke up and then she was fully involved in planning the funeral and everything so it's been ... and planning the buffet, yes, and you planned the buffet that was great. She was fully involved in planning the funeral, she chose the music for the funeral oratory. She chose the music because she said, well this is daddy's favourite, and handed over the music. I had one or two more

cuddles and she'd hold my hand a lot tighter but she was alright, because she'd been involved in everything she knew that daddy was going to live in Heaven with Jesus, with mummy and with my aunt. So she just told everybody so matter of factly that that morning you know daddy died and she just turned round to the nurse that was sitting with her and said daddy's now gone to sit with mummy in heaven. It was very magical. We had learned a lot with my mother's death.

**Interviewer:** Tell me a bit about your parents' experience with Carole.

**Hilarie:** Carole was the shock shall we say, they were only ever going to have two children, and then they found out that Carole was coming along. Carole was about three months prem. when mum was rushed in to hospital. Carole of course was prem. so she was very small. She came, she was sent home early, my mother knew there was something wrong because being the third child Carole wasn't reacting in the same way as we did. She couldn't feed properly, she didn't seem to be putting on weight. My dad built an incubator for Carole out of my dolls' cot with a bit ... he used to have chickens in the back so one of the big lamps from the chickens he put over my dolls' cot to keep Carole warm. At night time she was popped inside the bread oven – we had one of those big black ranges and of course when the embers went down Carole was just popped in to warm up and then back into the cot with hot water bottles all round her.

Nobody would ever tell my mother what the problem was. We lived in a small village and there was actually three Down's children born in that village in the space of eighteen months which gave them all ... they helped each other. My mother was considered to be a very cruel woman at the time and was told this in no uncertain terms by several members of the village because it was thought she was cruel to keep Carole at home and that Carole would be better off living with her own kind. When my mother finally got belligerent enough to stand her ground with a consultant he actually turned round and said, quite honestly, he said, this is when Carole got pneumonia, was rushed into hospital was given no treatment, no nothing, and they said "well be better off if she dies wouldn't it. Like her, what's the point of her living?"

My mother being my mother and my father being my father said that they would bring her home and they would look after her. They read books, they found any book they could and they found a book that gave them

some clues so the case was, get Carole sat up – she was never allowed to lie down again. If she wanted something in the play pen, it was put just out of her reach so she had to reach for it. I remember as a five year old playing a ball game with Carole for hours and hours and hours upon end to get her arms moving and her legs moving to kick the ball because she loved the balloon and balls.

My brother used to play a game with his friends and Carole. She would be in her pram outside and they would whiz round the garden on their bicycles and every time they came past Carole's pram they would bang it as hard as they could on the handle – remember those old sprung fashioned prams that used to bounce everywhere – but because Carole found then that she could sit up and look at what was going on she just kept screaming and screaming for them to do it more and more and my parents realised that, yes, she could sit up, so whatever she did she was never allowed to stop so the minute she walked, the minute she got on to her bottom she was never allowed to lie it down again, the minute she got on to her knees she was not allowed to go back on to her bottom, the minute she got on to her feet, she was encouraged to stay on her feet.

We lived then, when Carole was nearly two before she actually got up on to her feet to actually walk, it was after then we lived about two miles from the local post office, so we used to walk down, every afternoon, to the post office to post the letter to daddy who was working away from home at the time, my mother used to phone up the post office lady and say, we're on our way, have the ice cream ready, and the pot of tea and the juice ready, we would get down to the post office which was also a little café and Carole who had hated the walk but was made to do it would be rewarded because she'd walked she got an ice cream, and because of this she walked more and more and more and consequently up until a couple of years ago she could manage eight miles in a day. That was her limit. It depended on how steep it was. If it was very steep it would be about six, but on the flat, even to this day, on the flat she can put up quite a pace for a good four or five miles, but she forgets to breathe when going up hill, so if we're going up hill anywhere you have to say to her 'breathe, breathe' because she's so concentrating on going, going.

And my parents decided that Carole was not going to go to the junior training centre, she was going to have an

education and they fought from Carole being nine till Carole being eighteen for Carole to go into education. Now in one of the villages we lived in Carole went into an infant school for the simple reason that it was the Church school, we went to the church, everybody in the Church knew Carole so she went into the local school.

When we moved away from there she went into an ESN school and every six months my mother was called up to the education offices to have Carole assessed and every second year she had to go off down to London to be assessed in London and fight her case to be in an ESN school because Down's syndrome children did not go to school, they were not educable, therefore they only went to the junior training centres and my mother fought it until she was eighteen and then she went to the adult training centre in Leicester. But my mother fought it for the whole of Carole's life in school because the attitude still was until Carole was eighteen that Down's Syndrome are uneducable. If they learned to read, which Carol could, it's not really reading, they're just barking at print. If you can count, which Carole could – it's just rote, they haven't got a clue what they're doing, so Carole had an education up until she was 18 years old but my mother had to go and fight every six months to get Carole another six months.

**Interviewer:** So they didn't really get any help from anybody?

**Hilarie:** No. No. That's not strictly true, mum trained to be a teacher and at the college where she was there was they had just set up at Scraptoft in Leicester they had just set up a unit to train teachers to teach children with more severe learning difficulties. So the Head of the office there when mum had problems getting Carole into school was there to fight to help her to fight the corner. But my mother being one of these people, she read every single book she could and nobody was going to tell her that her child didn't have the right to live and nobody was going to tell her that her child didn't have the same rights as her other two children. When Carole was sort of school age, schooling was not a right. So there were one or two people along the way who and there were some officials that helped, but they always said, 'but don't quote us. If you ask us officially we'll give you the official reply, but between you and I and as long as you don't tell anybody where you got the information from'. So there were people who knew things should be changing but policy hadn't changed therefore they couldn't really do it.

**Interviewer:** So how would you say it's affected your life as a whole?

**Hilarie:** Not much really. Carole has always been included and mum always made sure that yes Carole had a lot more attention than Robert or I but we always got it as well so it was always the three of us. If she was doing something with Carole for example she would do it for Robert and I. If she was listening to me read and practice my reading book, she'd have me on one side and Carole reading with her on the other side. If she was doing Robert's ... so Carole was always included in whatever we were doing.

I think no difference at all except I made a decision very early on that Carole would go and come to live with me and I think subconsciously I don't even remember making the decision but I do know that I didn't know that if anybody ever asked me to marry it wouldn't just be me, it would be me and my sister at some time and I always made this perfectly clear to anybody that I ever dated. Or if it started getting serious, most people seemed to know this. It never consciously affected our lives at all.. Just because Carole was handicapped there was still, Robert's the middle child, there was still the middle child sibling rivalry. So those two used to fight like cat and dog. They still do. Carole just now turns her back on him and tells him to stop being stupid. They love each other dearly but I don't think there was any difference in our lives except that wherever we went, the only thing that did happen – Carole always came with us. If Carole was ignored or anybody was rude to Carole we never went back. So if you went to a restaurant, if Carole wasn't treated like the rest of us were we never went back. If you went to a cinema and Carole was treated differently then we never went back. If we went to a theme park, Carole wasn't allowed on the ride, well nobody went on it and we never went back.

So, no all the way along we've always known that Carole is handicapped, she's always known but she has always also reversely my parents always said right Robert and Hilarie are doing it, Carole does it too.

**Interviewer:** So it didn't actually stop you getting married or having children because you would have done it if you had wanted to.

**Hilarie:** Yes, quite. Oh yes it didn't stop me at all. Nobody ever came along that was right for me. Even had boyfriends at college, if we went out anywhere and Carole happened to be staying with me it was automatically, Carole are you

coming, because it was always known that Carole was part of the family, she was never any different.

**Interviewer:** So what would you say to parents who are being screened and realise that they are going to have a Downs Syndrome and need to make a decision about it?

**Hilarie:** There's a lot of heartache, there's a lot of fighting, but on the other hand there's a lot of love. The biggest reward you will ever get is the hug, like you did when you arrived, the hug that you will get . They are world's mimickers and yes there is heart ache because they don't make the jumps as fast as other children do, but they still make the jumps, they still learn, what you have to remember is instead of doing them in big steps, they take lots of little ones and as long as you can take lots of little steps, they will always get there in the end.

And the best thing I've always thought with Carole when I'm not very well is the hug and the great big bear hug that you always get. But it's not just Carole, you get it as well from her Downs Syndrome friends. If they know you're not very well, they haven't seen you for a little while you get that great huge bear hug and a big huge smile and a wet kiss and it's worth all the heart ache that's gone on and all the fight that you've had to put on.

People like my parents who fifty years ago had nothing and fought and fought and fought have now left the legacy for the parents of today's Downs Syndrome children to take it on into the next generation.