

## Case Study 1

### John Pearson



**"When caring takes over your life - it either hits you like a train or it creeps up on you."**

When our son was diagnosed with Ring Chromosome 22 (a comparatively rare but very debilitating genetic abnormality) that was our train crash. He has severe learning disabilities, no communication, epilepsy and is autistic. He is now 25 and increasingly difficult to handle. Both my wife and I have back problems from lifting and handling.

Caring for my 85 year old mother-in-law, who has dementia, heart and thyroid issues crept up on us. Care in the Community failed her miserably and quite frankly she would not be around now if we hadn't taken her into our home.

The first thing carers have to realise is that life will never be the same and that you will have to constantly battle against local and central government. The higher the level of care provided by unpaid family carers the less support the local authority will provide - "flogging the willing horse" and "emotional blackmail" are phrases that spring to mind. Caring will seriously damage your health, wealth and you will become increasingly socially isolated. Things like holidays, visits to the theatre, cinema, concerts, dining out, etc that once you took for granted become rare treats.

If it was not for the support of family in running our business, neither my wife or myself could work. As it is I work 3 days a week and my wife works two – it's not easy and sometimes "the wheels come off", but we cope. Work is actually a form of respite for us, but those unable to work due to their roles as unpaid carers, they can easily find themselves consigned to a life of poverty relying on benefits like the woefully inadequate Carer's Allowance."

## Case Study 2

### Alex



Alex and Sarah

"I'm Alex and I'm a 21 year old student from Preston. I'm also a carer for my fiancé Sarah, who has Cystic Fibrosis. Me and Sarah live together in Bristol where I'm studying law at the University of the West of England.

In order for me to provide round the clock care for Sarah, without the need for her to be in hospital, I had to complete medical training on Cystic Fibrosis. A typical day starts at 8am when I'll get up and do some housework and general chores around the flat. I also have to check that Sarah is breathing and that her oxygen machine is still on. Some days I administer IV antibiotics. The rest of the day is then dependent on how well Sarah is. I may have lectures or seminars to attend but if Sarah is very poorly she will need more looking after and I need to be there, fetching a sick bowl when she needs one or rushing her to the bathroom. On those days my studies have to take a back seat.

As a full time carer I tried to claim Carer's Allowance but the rules say I cannot study and be a carer, so I was refused the benefit. I appealed against the decision and ended up taking the case to a tribunal. Unfortunately I didn't win but that won't stop me campaigning to get this rule changed.

I think the social security system for carers is a mess and there is so much more the Government needs to do for carers. In November 2008 I was elected on to Carers UK's Board of Trustees as the youngest ever Trustee. This is because I believe passionately that there is strength in numbers and as carers we need to push harder and campaign for the things that will make a difference to our lives."

### Case Study 3

Mrs Bridges, now in her late 70's looks after her son Harry, 41, the last of her children. He has Down's syndrome. They lead a quiet life. Harry goes to the adult training centre five days a week and the Gateway Club once a fortnight. They do not go out as they do not have a car and there is no public transport in the evenings or weekends.

Mrs Bridges had some trouble with her nerves a few years ago, soon after the very sudden death of her husband. Postern House was suggested for Harry and he went for a few respite weeks. She now feels that she does not really need a break from him, "it would be dull without him. He's all I've got to live for." Asked about his ability to carry out simple domestic tasks like cooking and ironing, she said that she did not really know what he could and could not do in this line because he did not need to do it, "my other sons didn't iron, so why should they expect Harry to iron?"

She said that she did not wish him to go to sheltered housing, "when I'm not here he's going to one of my sons....I should never want him to go into one of those places." Nor does she encourage Harry into any other activities.

"Of course I'm too old for a lot of things now....I expect he'd do a lot more if I was younger, but then I don't want to do these things. I like my, I like to sit down, I don't want to do too much....really it's like having a baby all your life."

## Case Study 4

Mr. Jukes is in his late 50's and has looked after his daughter Joanne, who is 34 years old, since the death of his wife in a road accident five years ago. Joanne has a severe learning disability and is only partially sighted. Mr. Jukes gave up his job to look after Joanne after his wife's death.

Four days a week, Joanne goes to a day centre and one weekend in four she stays with foster carers. Twice a year, she has a residential respite care when Mr. Jukes goes on holiday. He enjoys "getting away from the feeling of responsibility." On the days when she is at the day centre ("I couldn't cope without it".) he has time to organise services, make enquiries and "sort myself out." He is a keen photographer and member of a local club, although it is often difficult for him to attend evening meetings.

Joanne's sight is deteriorating and Mr. Jukes is dreading the day when she becomes more dependent on him than she is already. Mr. Jukes freely confesses to his feelings of anger at the burdens placed upon him, but distancing himself from her enables him to cope. "I'm concerned that for both of us, our quality of life is getting worse."

## Case Study 5

Miss Dekker, 53, looks after her 43 year old brother Tom, who has a moderate learning disability. Miss Dekker was made redundant about 18 months ago, shortly after her mother had a stroke. "I didn't think I'd get another job at my age, so I thought I might as well stay at home and look after Mum and Tom".

Miss Dekker, Tom and Mum have lived quietly together since the death of her father 20 years ago. Her mother is not a sociable person and Miss Dekker has not been in the habit of asking friends round and has never had anyone to stay.

Miss Dekker has to get up several times each night to put her mother on the commode. Tom attends a day centre five days a week. Although there are many things he can do for himself, he needs constantly reminding to do them.

Staff at the local hospital discouraged her from caring for her mother, as they did not feel she would be able to cope. "They couldn't have been more helpful, but you can't expect them to do your work for you." A local voluntary organisation provides two hours sitting a week so that Miss Dekker can get out to shop. "I feel guilty about asking them to come, getting out of my responsibilities." Social Services have offered a place for Tom in a semi-independent living complex. "I could never forgive myself putting Tom away just because Mum can't look after him anymore. Anyway, he doesn't want to go, he's always lived at home".

Her main problems with caring are the feeling that "you know where you're going ... I expect I'll eventually get into some sort of routine", and the sense of isolation, since her mother talks very little. Both programmed residential respite and day care have been offered. Day care has been rejected because "Mother didn't like it." Miss Dekker is still considering whether she might take up the offer of residential respite for "a few nights". Miss Dekker described her mother as a "very unhappy woman" and Tom "he's no trouble, I just have to keep reminding him to do things."