

**“My name’s Ian.
I’m caring for my
wife who is
suffering from
dementia.”**



**“My name’s Charlotte. I care
for my mum who’s got
terminal cancer and
has maybe two years
to live but may live longer.
I care for my mum at home.”**

Can you talk about some of the changes in your lives?

Mary was getting absent-minded; a specialist diagnosed she had early stages of dementia. It was a shock. Mary can’t speak much. She can understand what we’re saying but it’s difficult to get a reaction. Carrying the care of her in your heart...it’s getting worse, that’s the trouble...I just sit in the car and cry. Mary had a career in teaching, we had children and holidays, and we’d a happy retirement. We came and went and did as we pleased, thought it would go on forever, but it’s so sudden, it’s overtaken us. One difference I’ve noticed with other carers – most seem to have families quite close whereas I haven’t. I’ve got nobody who can pop round for half an hour. It all has to be organised and planned.

How did you come across Care for the Carers?

I went to one of these day centres with Mary; they told me about courses Care for the Carers run. I was made aware of the Forum and that was a big step forward because at the Forum there were all these groups and organisations, and I was able to find out so much more than I’d learnt before – a great help, and led to carers’ groups. There were other people in the same boat; we were able to compare notes and help each other.

What is helping you through these times?

I find it helpful having a pet. Mary and I always had dogs, and our recent acquisition is Katie. She makes a fuss of Mary, and Mary makes a fuss of her and likes to stroke her, Katie’s a very tactile little dog.

What is an object that is precious to you?

I got interested in silversmithing as a hobby – and in family trees. It turned out that years ago our family had a crest, which was a mermaid. I decided to make a mermaid out of silver as our silver wedding came up; I made it for Mary, as something special for us both.

**“Sixty years
together, and it’s
so different now.”**



What responsibilities do you have?

With my mum, I help her with all the shopping and the cleaning, and making sure she gets out – and more, the emotional support. I’ll help her through all her scenarios of everyday life. At the beginning I found it very difficult, and I think I still do now. It’s quite an emotional burden on me...I will seek help in some ways but also try and find strategies to work around it.

How does Care for the Carers support you?

If I’ve got issues, I can go straight to Care for the Carers, and they’ll give me the practical advice to deal with them. They do days out and a Young Adult Carers group so all of us meet up in a youth group. We have a structured hour of it, then have a bit of fun, and games, to relieve us from the caring role.

What do you want to tell the world about being a carer?

As a young carer, there should be more understanding in secondary schools because some people won’t understand the concept and why we do it. We haven’t chosen to do it, we do it out of love. It is a struggle but people need to realise that even if you’ve got a caring role you’ve still got to keep your morals and ambitions. I want to do psychology and sociology at university. I need to organise my life around that...make a life for myself.

What object is precious to you?

I had a mentor, and for my birthday she bought me a bracelet with a heart; it’s sentimental to me. When mum started to become unwell, I’d wear it to college to keep me going. It’s a good luck charm, reassurance. I feel like it’s my guardian angel.



**“You’ve got to carry
on, haven’t you, to get
through the difficult bits
and hopefully there’ll be
some light at the end...”**

Carers’ Words, Carers’ Lives

Reflections and objects from carers in East Sussex



Legacy is born of people’s knowledge and linked to experience. Care for the Carers believes it is important to listen to carers and present their insights and reflections. Our intergenerational *Carers’ Words, Carers’ Lives* heritage project continues as we produce five short films that feature carers telling their stories and talking about an object that has a special meaning for them.

Charlotte, Ian, Janice, Jason and John joined in conversation with our writer-in-residence Evlynn Sharp and film-maker Dan Bridge. Sadly, during this project, Jason’s father Peter passed away. Jason still wishes to offer to others the realities of caring for his dad. We deeply respect the courage of all the carers here who share their thinking and experiences making a legacy for us of their strength, determination, wisdom.

Jennifer Twist, Chief Executive Officer
Care for the Carers, October 2017

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Supporting Carers in East Sussex

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“My name’s Janice, I care for my son James who is 33 and has a unique chromosome abnormality.”

What do you think about the caring role and handling change?

Sometimes I’m restricted in what I can do in my life, I’m a carer before I’m anything else, my life is geared around the school day still after thirty years. But I love spending time with James, I wouldn’t have it any other way. I don’t see disability, I see a person, strong and funny. My husband’s great, my daughter’s great, we’re a strong unit, that’s what sustains all of us. We tick along, then something will happen major, and I think ‘coping strategies’. As a carer I’m ever inventing coping strategies. Everything changes and moves with time as life does.

What is your involvement with Care for the Carers?

A fabulous organisation, I’ve been involved with them as a volunteer for over 20 years. I’ve been on committees, in groups, I used to speak about carers’ issues in public, getting the message out there. I’ve been to the Forums and met carers through that – every carer has different concerns, every carer is unique in what they have to deal with every day.

Why does creative writing mean a lot to you?

I attended the Care for the Carers creative writing course, the perfect time. Writing releases something in you, it’s an amazing medium. There are so many things I want to get down on paper because if they’re not, they’re lost. I want to leave a legacy of something when I die.

Can you talk about the object precious to you?

The creative writing journal. My daughter bought me a journal to write in about my life, loss, grief, about what makes me who I am. And now I’d like to write about my son, this amazing man who is inspirational. I don’t think too far ahead in terms of how long is James going to live, how long can I care for him. I don’t think too far ahead other than to be the best I can be for people I love, and to write the book.

“Every carer has a different story to tell.”



“I’m John, I care for Pera my wife, she’s had dementia and other medical problems for about five years.”

As an unpaid carer, how has life changed for you?

I do the cooking, which I haven’t done for sixty years. My wife does nothing round the house now. I have to do the shopping; she comes with me...she puts things in the trolley, I take things out – I put things in we need! I’m lucky I’ve got three children, none of whom live near, but we’re a close family and they help. I just get on with it...

Do you get the chance for respite, and what would you want?

Holidays over the last five years have been two short breaks with my son-in-law while my daughter’s looked after Pera. I can get an occasional game of bowls, it’s a good relaxation, but I have to get a sitter to come in for Pera – that makes bowls expensive. What I want can’t be delivered, and that’s for Pera to get better. My life revolves around her, and it will for the foreseeable future.

How did you find out about Care for the Carers?

I went to the doctors, I saw a notice about Care for the Carers and I’ve been looked after by them. Jollies they do are pleasant, courses they run are useful...you learn a bit, in fact you probably learn a lot. The more you meet people, the more you know what a difficult task it is for everyone. I attend our group forum once a month. We talk of our problems – that helps to solve them. We have a speakers related to Alzheimer’s; things about the home which can help; organisations that give support. The creative writing course was better than I expected – I’m not a writer! It was a friendly group, I enjoyed it.

What object has a special meaning to you?

Bincoulars – they’re ancient but give me a good close-up when birdwatching, I can quickly get them focused. And the book *British Birds* – if I see a bird I don’t recognise in the garden, I can look it up as long as I remember what it was, rough size and colours.

“Caring is a full-time job, I find it hard.”



“My name’s Jason. I cared for my elderly father Peter who had a range of health conditions.”

How has being a carer changed your own life?

When you’re caring for someone then their needs come first. Your social life ceases, you have to be aware of time management. There are not enough hours in the day. A lot of time is spent on mundane, normal things, they’re not difficult, but it’s an accumulation of things – to pay bills, to get shopping, to cook food, to wash windows. For the first 18 months I was guilty of thinking, ‘I can manage, I can do everything, I’m fine.’ But it starts to wear on you.

What has been useful about Care for the Carers?

It’s somebody to talk to about things, and Care for the Carers has been a big help. One thing I suppose is more with single people, it’s actually nice, perhaps reassuring, when you get a pat on the back, somebody saying, ‘You’re doing ok, you’re doing a good job here.’ And practical things – Care for the Carers referred me on for help with going on courses and employment.

What advice would you give to other carers?

It’s about having contingency plans, for when things do get on top. You end up neglecting yourself a bit, and that’s not beneficial for the person you’re caring for. If respite’s available, that’s worth looking in to. It’s important to get any help that’s offered, be aware of what’s available, and to access what help’s out there as soon as possible.

What is a precious object in your life?

I come back to family. I come from a good family, loyalty’s strong, they’re all good people. My dad looked after me when I was a kid. When we first moved here, there was a basket hanging from the tree in the garden so dad used to put bread out, one of his regular things he liked to do. We’d cut it all up small for the birds and we’d put it in the basket. I find it therapeutic, going out and feeding the birds and watching everything come and feeding away.

“Some people are alone and there isn’t anybody there to help them.”

