

Chief cook and bottle washer: life as an older male carer

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Figure 1. Older male carers project.

Over 51,000 carers in England are men over the age of 85 — a number which has more than doubled in the last decade (Carers UK and Age UK, 2015).

The older male carer story project collaborated with a group of 11 older male carers (all over the age of 85 and living in Dorset) to learn from their experiences. The research study was user-led and the men worked with the PIER partnership (Public Involvement in Education and Research), a group of media students, Bournemouth Borough Council and Poole Council's joint Carers Centre and Dorset Healthwatch to create a series of narratives and a short film (www1.bournemouth.ac.uk/about/our-faculties/faculty-health-social-sciences/public-involvement-education-research/our-resources/carers), as a way of sharing their insights and expertise with people working in health and social care.

The group are currently working on a guide for GP practices and community services based on the findings of the study.

CONTEXT

Older carers (over the age of 65) are the fastest growing demographic of carers in England and Wales, having increased by 35% between 2001 and 2011, as compared to an 11% increase across the wider caring population (Census, 2011), with predictions of further increases in the coming years. Unpaid care provided in the UK is predicted to be worth £132 billion per year (Buckner and Yeandle, 2015). Carers over the age of 85 are the only demographic of carers where men outnumber women (59%). Men are more likely to become carers in older age than at other times in their life and usually as a result of

caring for their partners. As such, older male carers are more likely to live with the person they are caring for. Many carers have physical and mental health issues themselves, and evidence shows that caring for someone further increases the likelihood of isolation, loneliness and depression and physical health problems. A Carers UK study (2015) identified that 54% of carers have suffered depression because of their caring role; and 77% felt more anxious. Forty percent of carers identified that they had missed medical appointments and discharged themselves from hospital due to concerns about care for the person they look after. Local data from the Bournemouth and Poole Carers Centre suggests that older male carers are the group least likely to ask for help and often present to them through GP services at crisis stage.

Seeking a better understanding and insight from older male carers is essential for society to learn how best to respond to their needs. The participatory nature of this study ensured that co-collaborators were recognised and valued for the expertise and contribution they could make to improving and shaping carer support and provision. The men identified some common themes, including the need to develop new skills and knowledge to undertake their caring role, such as providing medical and personal care, lifting and handling, cooking and cleaning. They expressed a desire to honour the vows they made when getting married; 'in sickness and in health' and a strong sense of duty and responsibility to their wives. The carers also identified a process of acceptance of their changing role and identity, while not knowing where or how to ask for help. Their advice to health and support services being — don't wait for us to ask.

Each carer's story was documented as part of the research study and excerpts, taken from some of the themes explored in the study, are shared here to give a voice to the male carers and an opportunity for community nurses and other practitioners to reflect on what the men have to say.

Sense of duty and commitment

J: To begin with [you feel] a certain amount of anger, then you get into a routine and a realisation of what has to be done and you do it because that's what being married for 64 years means, it matters. I care deeply for her and you do things.

H: That's the way things are at the moment. We have been married for 53 years. Because it's been a gradual illness, I got acclimatised to what I had to do — what my duties were really — I've accepted the fact that this is it and this is what I have got to do. I am her husband and her carer — if I only felt a carer it would mean I don't love her anymore, I do. My plan genuinely is to try and make her laugh at least once a

day. She laughs and when she laughs it's almost like her old self back again.

P:.. get up, put the kettle on, make a cup of tea, pour the tea out, present it, have breakfast, tidy up. Do the same every mealtime each day, all the way through the week, so, it is a continuous process.

Changing identity and role

The carers accepted their role and felt a duty of care for their wives but they discussed the significant impact this had on their own mental and emotional health. All of the men reflected on experiences of loss; of how their relationships with their wives had changed; of their own identity and status; and the loss of hobbies, friends and personal space.

D: [The biggest challenge to being a carer] is the lack of personal time, no question about that. I have got things I want to do, but looking after her you do lose a lot of personal private time.

M: I used to like playing snooker, going for long walks, going fishing — I've still got my umbrella and things for fishing but I haven't been for ages. I used to belong to a heart support group, but I had to give that up. That entailed going to lectures, meetings and going to dinners, outings and exercising twice a week for an hour. I've had to give all that up. I used to run a computer course and then two years ago I decided it was getting too much with all that I was doing with my wife so I gave it up.

J: You get out for a break when a nurse comes for an hour to do the shopping or go to the bank, do the usual things, but there's no life. That hits you quite hard; particularly because we had such an active life before.

F: I feel a bit more like a nurse every day, especially at night.

M: This still left me with all the shopping, the household, the

washing, the cleaning and the garden. There's cleaning of the house. [My wife] always kept a very clean house. If there is a spot on the carpet she points at it and I know what she means. I try and keep that up to scratch. I used to cook a lot of dinners, but since I wasn't very well at the end of last year I started to get Marks and Spencer ready-made meals.

Own physical and mental health

The 11 carers in the older male carers' story project had a range of health issues themselves, which made life as a carer more challenging.

W: I have got more things wrong with me than my wife. I've had gallstones, I've had a cardiac arrest, I've had stents fitted and I've had a pacemaker fitted and a whole host of things. Health conditions don't affect me at all, I don't know I have pacemaker or a stent. Just my age affects me and I can't do a lot of movement, hoovering or making the bed, walking up the stairs I am 'poofed'.

W: I have to get the groceries all online. I can't go to the supermarket, there was a time where I was falling down in the supermarket, as I was getting these jittery feelings in my hands first and then my legs and then I'd be on the floor, this happened four or five times — I do everything [in the house].

J: I suppose after a time that's where the depression gets in. In some respects it's a bit like being in a prison because you can't do anything. You're in comfortable surroundings, but it's nevertheless like a prison because there is nothing else, you don't go anywhere or do anything. I used to get up in the morning really excited to go to work. So, being confined particularly in the last three or four years has led to a certain amount of depression. You feel a sense of guilt for putting her somewhere and taking her away from her own environment.

Learning new skills

Most of the carers said that health and social care staff had assumed that they knew how to provide care, but said they had wanted someone to teach them how.

E: With all due respect to the advice people give you. I went to this thing, 10 weeks on a Monday night and they would talk to us about things. I thought don't tell me, show me. They are talking from a textbook or from years of experience in the classroom. I've washed jerseys and they've shrunk because I've put them in the machine and they come out fitting a three-year-old boy. How often do you change the bed? How often do you do this? You are learning all the time.

W: We are supplied with incontinence pads, but I don't get any help with how to do this and what is the best way to do this. Okay, you can look it up on YouTube, but that shouldn't be the way, you should have somebody come in here and say this is how you do it. This is something the nurse should be helping with, like how do you wash a person? They've been doing it for years. You feel help is there, but you're not getting it somehow. 99% of these things don't materialise. People have got the good ideas and it's all there, but it gets tied up with red tape.

Experiences of support and care

The carers had mixed experiences of professional care and support. They discussed the changing roles of health and social care staff over the years and how limited resources were. Those with good support identified a named person either through their GP practice, nurse or a social worker who would contact

them and check how they were. Consistency and continuity were important, with most frustrations stemming from changes in people involved, poor communication and a lack of knowledge.

M: I have to make sure things are done right with the carers five times a day. She has a specialist way of cleaning her teeth. I said to one nurse, 'you alright with our methods of cleaning teeth' and she said 'oh yes'. So, I go away and come back in two minutes and find she is cleaning her teeth with her false teeth still in, she hadn't taken them out. An important part of my caring is to see that she is cared for properly and well. I did ring the OT and she said that I need to get some side rails and she said she would organise it, but it still hasn't happened, but I haven't bothered to chase it.

F: Last year the social worker did an assessment on me and said I was managing well, I thought this was a bit of an exaggeration.

W: All these different people from all these different departments will come asking exactly the same questions and it seems as though they are filling in exactly the same form. Why on earth could they not have one person go and fill it all in and distribute it to other people; they are wasting time. You just get frustrated after a time and just accept it. You know nothing is going to happen, or there is a slim chance of anything happening.

One of two bereaved carers in the study, identified excellent care while he was caring for his wife, but said this all stopped when she died: 'I didn't receive a single letter or phone call from the surgery to see how I was'.

Advice for older carers

Despite the significant challenges for the carers, they all identified strategies and ways of coping which they had developed over time.

Not all of the men were able to maintain these strategies because of their caring commitments and own health, but those who did, reported significant benefits to their own mental health and ability to cope. The carers were reluctant to provide advice for others, 'everyone is different, you have to find your own way'.

Keep active

M: My son says that I'm working too hard. But I think it is the hard work that keeps me going, that keeps me active.

P: I like to do things with my hands, so I like gardening. I also go to a local society and the local museum as well as returning to help the carers centre which I learnt about through my social worker.

Have time for yourself

H: We have an arrangement that she knows I need a bit of time out now and again. I manage to do this. I manage to get out and play golf once a week.

Develop a routine

B: I have a break by doing something other than being in the house. I've kept bees all my life; still got some.

H: What I do depends on the weather. I go for a walk for maybe an hour; I only go if the weather is good. In the summer it's so much better. We have got a small back garden and we go out there if it's sunny. I say to her, I think you should have a walk and she goes out with her zimmer frame in the garden and sits in the sun. I dread the winter.

Make use of technology

H: At first I was concerned about leaving her. We had a buzzer system fitted. I used to say, 'I'm going to play golf. In an hours' time I will be coming pass the window, if you are in trouble, pull the middle blind down'. Now we have got a mobile phone, I was worried at first but not now. She knows she

Practice point

On reading the carers' stories, reflect on your own practice and engage in these conversations with carers you encounter.

can phone me, she only has to press one button, and she's got a buzzer and she is straight on to the daughter.

W: We also have a little camera [on the windowsill], because if I collapsed on the floor I could be there for days and no one would know. She [my daughter] can move the camera from her phone and see that we are not there, or can tell if the door is open or something.

Involving your wife in tasks

H: What makes things more manageable has been her being able to look after herself and help me around the house. If I wash up she helps with the wiping. She has a frame with a seat so she can sit down and do it. She helps me make the beds.

D: The thing I would say is, always involve your partner. We do everything together. We go

out, we go shopping, housework, the washing up, we always do it together, we do half each, or she will sit in the kitchen with me; to keep her fully involved and with all that is going on with the family and to keep her mind going.

CONCLUSION

What was striking about the male story project was the extent to which the older men were providing care over a 24-hour period. Even those with professional carers visiting several times a day were involved in shopping, cooking, cleaning, lifting and handling and providing medical and personal care. Some, particularly those with a professional working background, approached this as a challenge — something they needed to take control of and manage. All had to learn new skills and felt that they had learnt through trial and error. They identified community nurses and GP practices as being

Useful links

- ▶ Carers UK
www.carersuk.org
- ▶ Carers' Trust
<https://carers.org/>
- ▶ Age UK
www.ageuk.org.uk
- ▶ Queen's Nursing Institute — online learning resources for supporting carers
www.qni.org.uk/nursing-in-the-community/supporting-carers/

best placed to recognise the care they were providing and to provide help, support and guidance. The extent of their wife's health, and, in particular, if she had dementia, played a significant factor in the carer's ability to cope. Those who could still converse with their wives, who could share domestic chores, and who could leave their wives alone for short periods of time, appeared to cope better.

In particular, the authors were struck by the expertise of the older carers in knowing what would work best for their wives and themselves. On reading the excerpts, consider how you can use them to inform your practice and the support offered to older male carers in your locality. **JCN**

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I do everything like the meals. Breakfast, and then follow on with lunch and tea.



What have I learnt? I've learnt to cope a) on my own, and learned to cope looking after and caring for my wife.