



## **Diverse perspectives on health and illness**

*Who cares?*

### **Presenter**

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Informal carers from the Milton Keynes carers project, together with the manager of the project, discuss their experiences of caring for their relatives. Carol Koromomy from the school of health and social welfare chairs the discussion.

### **Carol Koromomy**

Can we start with you Doris, would you like to tell us who you care for?

### **Doris**

I care for my husband, who has a severe back problem, and a very bad heart condition as well.

### **Carol Koromomy**

And how long have you cared for him?

### **Doris**

I've cared for him for over seven years now with his problem, and it will not improve it will only deteriorate.

### **Carol Koromomy**

Martin?

### **Martin**

I look after my wife, and we have four children, like Doris's husband my wife has a back problem, which is deteriorating, reduces her mobility. She's also suffered from depression for about ten years, I've been caring for her and her family for about ten years.

### **Carol Koromomy**

Right, okay, and you Jeanne, would you like to tell us something about yourself?

### **Jeanne**

Yes, I gave up work to look after my daughter who's a schizophrenic. She's a passive schizophrenic so we don't have any violent episodes but, she also has no motivation or interest in anything, and really it's a matter of just keeping her moving and keeping her going. When she first came to me, I also had her two children as well who were at the worst teenage stage, and were very disturbed. I had a very bad life for about three years, until I finally persuaded their father that he should have them, and life has eased off considerably since then.

### **Carol Koromomy**

Harvey would you like to tell us something about yourself please?

### **Harvey**

Yes. I manage Milton Keynes carers project. We're a local charity, that have been in existence in Milton Keynes for about eight years now, and we're currently in touch with around seven hundred carers in the Milton Keynes area.

**Carol Koromomy**

What would be really nice is to hear about what you actually do when you care. What about you Doris?

**Doris**

To be honest I do most things around the house. My husband isn't capable of doing very much at all, you know mainly because, he's got a bit of a shaking problem. Cannot do the garden because he cannot walk or bend properly, and is in considerable pain most of the time. So he depends totally on me.

**Martin**

I look after my wife, who has mobility problems. She, for instance, can't put on her shoes, I sometimes have to do that. She may need help getting out of bed. I manage the house, I am also looking after the four children. My youngest son is eleven, I really have brought him up. My wife's been in hospital for much of the time. It's generally just being there all the time, on call, and really just managing the house, the money and everything. When my wife first became ill, I was working for a large financial institution, and she became progressively less and less well, I was having to spend more and more time at home to care for the family, and eventually my employer said 'bye bye'.

**Carol Koromomy**

Can you tell me what impact that had when you lost your job?

**Martin**

Personally it was, devastating. That, one day I became unwell with depression myself, I took three months sick leave, and then was told that, I wasn't wanted back unless I could turn up next Monday, it was as brutal as that. Financially it was a huge shock, I think we went from, about five or six hundred pound a week down to state benefit, in the course of one week. The benefit system's very very hard to deal with, unless you're used to it, and because of that we found that we hadn't claimed everything we should have claimed. There's no help to make sure you do claim everything you're entitled to, and all in all, it was a huge change of lifestyle, that was governed by the fact I was now a carer, with very little money all of a sudden.

**Doris**

It's not only very little money, it's very little support. I found that there was no one to turn to, for instance with, with the children when they were so disturbed, I had so much problem, there is no counselling available for a grandmother, and her grandchildren, you know, there's family counselling, and there's counselling between mum and kids and so forth, but there's none at all for grandparents, so I had absolutely no help. I couldn't go to anyone to say...

**Martin**

I agree with that completely, we had four quite young children, first of all. The only involvement we had from social services, was to, come in, tell us everything we were doing wrong, not offer any support, had meetings, and eventually, because they felt the children were at risk, to put them on the register, this did not mean any more support. To us as a family, it was a complete waste of time, that we were expected to cope with this.

**Carol Koromomy**

So tell me what sort of support you would like?

**Doris**

I think the support you need, is to know that there is somebody there. In my case I haven't got any close family, and you know who do I turn to. You know, and you get sort of passed from one to the other, and everything, and I agree with Martin as well regarding the financial thing, we also weren't claiming the right amount of benefits and, you know, you hear from one, well I get this and they get that and, that's how you seem to hear it is by word of mouth you know, and I'm very grateful that Harvey does the carer's meeting, because until I'd been up to the city centre, I didn't even know this existed, and it's nice to meet other people that are in similar positions to what you are in, to discuss you know things that happen at home.

**Jeanne**

There is the welfare rights system, and I can't remember who first put me in touch with them, right from the start they were very supportive in... financially, in making sure that you were applying for everything you could get, and helping you get it too, because my daughter was turned down for disability living allowance, and I would have given up at that stage, but, when I spoke to them, oh no, they expect you to, you know you must expect to be turned down to start with, they do that you know automatically, just apply again, and they wrote the form and, then we got it but...

**Doris**

My husband's got a motorbility car, and in the first instance we were turned down for this as well. My husband is a very proud person, and didn't want to go any further, and eventually we did get it sorted out and, I'm very grateful the fact that he is at the moment able to drive, again I don't know how long for, because the spine and neck problem is proving difficult.

**Carol Koromomy**

So it sounds as if it's quite difficult to get to know what benefits there are available and...

**Jeanne**

It's almost impossible to get to know what's available in any area. I, my children, well the grandchildren had social services, they were on the 'at risk' register in Wales where they lived, when they came up here they were referred to the local services, and I called them in, and they came out and looked and said well, children fine, they're well cared for, they're fed, we don't consider you need us any more and that was it, they were gone in one visit. Although I must say, the social worker herself, personally was very friendly, and she did come back, more or less on an informal visit for several several months. They never offered any help of any kind, even though I obviously needed it.

**Harvey**

Yes I think first of all carers need recognition, and as a carer said the other day that I was talking to, well it's not just recognition it's actual respect. If we're doing the vast majority of care in the home, we at least to be recognised for that. and the next thing that we need is information. So many people suddenly become carers, and really have no idea as to where to go for help or support. A lady said to me one day, 'Thursday mother arrived, Friday I had to give up my job, Saturday I'm a full time carer, help.' It was only fortunate that she knew about our project and was able to contact us for advice and for information, as well as some support.

**Doris**

That's right. I do think also as well, that doctors should know the role that carers play regarding the person they look after. I think this is taken for granted that you're the wife or the mother, whichever and, it's your job to do it. I mean, alright you know I'm quite proud to do it you know but, it's the way it's, that you're taken for granted.

**Jeanne**

And me, Doris. My doctor is extremely supportive, but of course you can't just call on her every time you need. I think where the lack of support comes, is from the psychiatric services. As far as the consultant psychiatrist is concerned, he has a little patient that he puts in a dustbin, lifts the lid once every month or so, and sees her, earns his money, puts the lid back on and, forget that one. There is no support or help in that respect anywhere, even if I call on him for help.

**Martin**

I think carers who are looking after people who are mentally ill, you know suffer a double whammy, and that services for mental health patients are very poor. I mean it's a Cinderella of the health service, it's truly appalling, the way people with depression and schizophrenia are treated. But then the carers, are very much treated by the professionals, no, are very much treated by doctors in particular in my experience, it's just a sort of inconvenient appendage.

**Jeanne**

You're like the cleaner, you're, just keep out of the way and, the labourer.

**Martin**

I was, I was far from popular when I went to see my wife's psychiatrist, and he basically said in the end, I don't see why I should be talking to you, you're asking too many awkward questions.

**Jeanne**

You're lucky he actually did, he wouldn't talk to me at all, he even refused a visit, refused to allow me to visit him.

**Martin**

This exactly shows the attitude.

**Harvey**

Yes I quite agree Martin that the experience with other carers has been that, on the mental health side, the responses generally, patient confidentiality, we can't talk to you, or not interested in talking to you. Often leaving people, leaving carers completely in the dark as to what the side effects of medication might be, or how they can actually help the person themselves. So although there have been some improvements with new money on perhaps joint intensive support teams that have been set up, the basic response from many mental health care professionals is, that they're not really interested in the carers, and the role of the carers themselves.

**Martin**

I think in defence of the staff, the nursing staff in particular, are very caring, but as one said to me, you do realise we're running a fire station here. We will deal with the, twenty five most urgent patients, that we've got beds for, and the other X will be out in the community somewhere. But when I said that my wife was, really not well enough to come home, he did agree, and said 'well, it's a fire station dear'.

**Carol Koromomy**

So tell me some of the things that make it to you very difficult for you to continue to care.

**Jeanne**

Well from my point of view it's not difficult to continue to care, because I think we've been through the really bad time, and having coped with that, you've just learnt to do without any help, and to deal with it yourself, and Jackie, of course once the kids have gone too, life became a lot easier but.

**Doris**

It does become a thing that you take everything for granted, it's a way of life, you've altered your life from what it used to be, to what it is now, so you just carry on, you know, how best you can manage.

**Jeanne**

Becomes a point where there's no point in asking for help any more, so just grit your teeth and put up with it.

**Doris**

Well you know, I've a problem, you know, regarding getting my husband bathed, and this is my main problem, and I am having so much problem to get help regarding this and, I can manage everything else, and yet everybody else is prepared to send social services into help me, but the main thing that I do want help in, I'm getting left out again.

**Harvey**

Doris, I know the situation there, isn't it something like eighteen months since you've had a recommendation that you should have a shower, but as yet nothing has still been done about it.

**Doris**

That's right. No, this is my main problem. I mean I'm lucky that my husband is alright mentally and, to get him onto a stool to get him into a bath, he cannot sit in the bath, he must sit on a seat and, he's shaky all the time I'm doing it. You know people don't realise, if they were to come and see what is involved, and it is so degrading for him as well, that, you know.

**Harvey**

Yes, and this is often what causes carers to have back problems, and also very high level of stress. Most carers find, as one said, 'working at a hundred and ten percent', and another carer said, 'I'm too tired to call the Samaritans', and that just seems so much to put it in a nutshell.

**Jeanne**

In my own case, I haven't even had a care assessment, there's never been a care plan made for my daughter in the five years I've had her. She has no psychiatric nurse, she has no, nowhere to turn to.

**Carol Koromomy**

What do you do on those days, when it's really difficult to cope?

**Jeanne**

I have rung, for instance the day when I said I can't cope with the children any more, they've got to go, they didn't go that day, but the decision was made, and she just cried hysterically all day. I tried to contact the psychiatrist, and there's always a block at the secretarial level. She doesn't like the doctor to have any appointments or anything untoward, and I couldn't get hold of him, and I rang my doctor who was in surgery. She did ring back and said she would talk to me later, and then I got through to the psychiatrist again, and he did answer the phone eventually, and I talked to him about the problem, and he actually said, 'Well what do you want from life?' I just couldn't answer it, I mean what do you say to a question like that. and I just gave up, eventually got Jackie quiet, and put her to bed, and that was it, but that was all the treatment she had, for a very traumatic time when her children were taken away from her, and given to her husband which had been the one horror of her life, because he was quite an abusive man.

**Carol Koromomy**

And what affect did that have on you?

**Jeanne**

Guilt, terrible guilt, for a long time, and Harvey knows that too, in fact it was Harvey that got me over it wasn't it? He said the children couldn't go on living with a dead body, and that they needed to be away from their mother in order to cope, and it's true, that did happen, I was able to see it from that point of view, that it was the best thing for the children. and they've now grown up, and we're quite good friends again, but it was a very bad time.

**Doris**

People never understand I think what carers actually go through, that the carer must continue and put on the brave face all the time, which is not easy to do. Everybody has their down days. and in my case, if my husband notices I'm getting stressed out, he gets very uptight and...

**Jeanne**

I think too, people don't realise, because Jackie is walking, normal looking and coping, they don't realise just how bad she is and it doesn't come out, it's only what happens indoors that you see.

**Harvey**

Yeah I was very interested Jeanne to hear that you mentioned about guilt. So many carers, this is the really big thing, that guilt can take many forms. How do you learn to say no to someone without feeling guilty, that may feel that they're not doing enough, so they can feel

guilty about that, will feel guilty if they want to have time for themselves, and it's very difficult because, you have in the background always someone that's perhaps dependent on you, and if I do anything for myself I feel guilty about it.

**Carol Koromomy**

Right, so that experience of guilt actually, means that perhaps sometimes, there is an expectation for people to be able to care and to cope with their caring.

**Harvey**

Yes, there is an expectations perhaps from the person being cared for. There are expectations in society, well you know you ought to be doing that, and from professionals as well. So many, a perhaps GP will say, 'you are doing alright aren't you?' which isn't asking for a response at all, and if anybody else asks, well yes I'm fine. That's the normal answer I'm fine. If you probe after that a bit, you find, that no they're not fine, but of course who really wants to listen?

**Carol Koromomy**

Doris how do you cope with that?

**Doris**

Yes I agree with what Harvey says there that, you're taken for granted, that the answer is that you are fine, even if though, you are far from being fine.

**Martin**

I mean, every carer situation is different, I can only speak for myself. I wouldn't have chosen to be a carer, I'd have much preferred the, if you like the conventional family model where, husband goes out to work, and wife looks after the house and the children, but it wasn't to be for us. So, we have accepted that I think. What makes it very hard, is the lack of support, the lack of recognition, and that's not just from the system, it's even within the family. I'll just give you an example. I had a small windfall from a flotation of an insurance company I had a policy with, and at the end of the day there was a little bit of money left over, and I decided to have a holiday. My parents-in-law's reaction was absolute horror, that I was, going away by myself, just adding to the guilt.

Another thing from my own experience, is yesterday was actually my parents' diamond wedding, and the level of stress, as all sorts of things had happened in this week had gone wrong, I just couldn't go, I couldn't face everybody and saying, to all my relatives when they say how are you, fine, when actually what I wanted to say is I feel bloody awful. I just couldn't face going. The way I described it once to my GP was, I feel like a piece of elastic being pulled in about six different directions, and eventually it all snaps. But what I resent more than anything else, is the fact that, as a carer, I'm treated in exactly the same way as someone who is on income support, because they choose basically not to work, or they're a single mother. There's no recognition in the system, you are a carer, we're going to treat you in a different way. You know I'm not voluntarily on income support, I haven't done anything myself to get on income support. If we had a decent carer's allowance, and not a great suspicion all the time that we're fiddling the system.

**Jeanne**

You've joined the ranks of the wasters and the, and the losers.

**Martin**

There are lots of areas around money, which really do need to be addressed, and I actually feel very angry about. Having experienced the system for ten years, it is the unfairness of it all really does annoy me, upset me, and I do wonder whether we as carers have got to get together and kick up one hell of a fuss about it.

**Jeanne**

I think the answer would be, just to all flatly refuse caring, but we can't do that. But that's what we need.

**Martin**

Let's just go and dump all our patients in a local town hall, and have a day off.

**Presenter**

You'll have noticed that the informal carers expressed a lot of anger, and dissatisfaction, at the lack of recognition of them as carers, both by society, and professional carers, with whom they come into contact. It's clear from listening to them, that caring has overwhelmed their lives, to the extent, that it has become their main role.