



## **Social Care: Past and Present**

*Talking about Care*

### **V/O:**

This is care, welfare and community, talking about care. People who provide care for a family member at home will tell you about their experiences. Although their situations vary, some common concerns and scenes emerge. First you will hear from workers employed by a voluntary agency in West Sussex and the carers they support.

### **Man:**

Well I think the stereotypical image of a carer is of a middle-aged woman looking after an elderly mother.

### **Woman 1:**

I find the term carer now acceptable but initially I didn't.

### **Woman 2:**

Well carers are all different, aren't they, because they're all caring for different sons, that sort of physical lifts, abilities and some's mental disabilities.

### **Woman 3:**

People perceive carers as just somebody being at home and looking after the person that they care for, they don't actually recognise that they have other roles in their life.

### **V/O:**

Many people providing support for relatives, neighbours or friends do not recognise themselves as carers. Jonathan Smith runs a mobile information project in West Sussex. He raises awareness of carers' rights and services by taking a specially adapted minibus out to local communities.

### **Jonathan smith:**

OK right, well we're off to Lancing today and we'll be parking outside the Co-op. We see up to about thirty people there but we'll see how it goes.

We've got a set of stands for outside the bus which have eight faces of young/old people, male/female and the caption is 'Which One Is The Carer?', which is supposed to be a challenge to people who are walking past to ask themselves 'am I a carer?', and it can be anyone from a young carer to an elderly carer, men, women, black, white, you know, the whole spectrum.

Now these stands go out just to let people know that we're here and a list of the sort of information that we can provide people. Can I help at all?

### **Man:**

I just saw the sign saying carers and I wondered whether it applied to me at all, I mean don't live with my father, he's much older than I am and he's almost completely blind now, and I have to keep popping in to see him.

### **Jonathan:**

Do you want to step on the bus for a minute, we'll have a chat.

### **Man:**

Well that would be nice, thank you.

**Jonathan:**

Yeah, okey-doke.

**Jonathan:**

A lot of people don't like walking into social services offices or making a fuss at GP's surgeries about the fact they're a carer. A lot of people are very shy of statutory services, and we're very informal, we park in town high streets, and we're just there and we're a couple of perfectly ordinary people who people who can come up and chat to.

**V/O:**

Carers are often referred on to the Carers' Liaison Project managed by Jane Weston. It's able to offer longer term advice and support.

**Jane weston:**

Well certainly for some carers it can mean giving up paid employment and I think that's one of the things that people often struggle with for a long time because it's a really big decision to make, and that obviously has effects in terms of relationships, status and certainly financially, and I think you know that has a huge impact on people's lifestyles generally.

**V/O:**

Julie is one of the people supported by the project. She describes herself as a parent carer, looking after her 11 year old son who has severe learning and physical disabilities.

**Julie:**

He can't sit up, he can't stand, he can't walk, and he's registered blind, he has got some speech but you have to know him to be able to understand his speech. He's fed through a tube in his stomach, so basically everything that he needs doing: his toilet needs, his hygiene needs, everything that I do for him, and also stimulation, playing with him, and he has to have someone with him all of the time because of his epilepsy.

**V/O:**

Julie had held a nursing post before she began caring for her son.

**Julie:**

Even though I was qualified I had actually worked on occasions with children with special needs, it doesn't prepare you at all for it because it is 24 hours ongoing, you can't just put your coat on and go home at the end of the shift. Unless people are actually involved in the situation they don't realise the extent of the care that is needed, and the physical and emotional drains on you.

**V/O:**

Les and his wife care for an adult son with severe mental health problems who still lives at home. Since retiring Les has become much more involved in providing emotional and practical support for his son.

**Les:**

We manage quite well, even though I say it myself, considering there's all the stress around that we do cope quite well. We're fortunate in one respect that we've got a decent size house so if we want to we will go in another room, just the two and sit together and that's it, but if you were in a smaller house and he was in with us all the time it would, well I mean if he gets one of his periods where he's talking to himself continuously it would drive you barmy.

**V/O:**

Les and his wife are aware that their son is often anxious about the future.

**Les:**

His biggest fear is what's going to happen when we're no longer around, that's his problem, and he gets depressed about that. My wife who's 65, and I'm 68, if we can survive say another ten years then by that time he'll be 43, he'll be middle-aged himself and perhaps he might find it easier to cope.

**Man:**

I think the most difficult thing is actually entry points for people into the structure which are quite problematic for people – how do they actually ask for help and where do they ask for help?

**V/O:**

The ambiguous nature of the caring role can make it harder to secure the right information. Carol who cares for both her mother and aunt explains.

**Carol:**

You have to fight your way through the red tape to have any care from the health authority or social services. Even the GP's they don't always see you as a carer. The receptionists don't see you as a carer. They see you as somebody who's a relative.

**V/O:**

Julie has had similar experiences.

**Julie:**

It's the disbelief. Recently I had to meet up with various members of health and social work professionals and discuss Luke's medical needs as they stand, and everything what I said was questioned and I came away thinking well, have I got it right, or have I over-reacted? They didn't believe what I was saying because if you look at Luke, he looks pretty good and he just looks like a child in a wheelchair; you actually have to live with him to understand the extent of his problems. People are very disbelieving.

**V/O:**

It can be frustrating if professionals do not share important information with close relatives.

**Man:**

One thing we did find in the early days when he was attending the hospital as an outpatient after he'd had his eight weeks in there, we attended for, you know, some months as an outpatient, the psychiatrist would never talk to us. They'll have the user or patient, or whatever you like to call them, up there and they'll chat to them and you're elsewhere in another room, and they can tell them their reading, they're doing this, they're doing that, all sorts of things they're doing with their lives, they just tell them naturally what they want to hear, and they don't call the carers in, the carer's ignored you know as though you're not involved, they don't see it as your problem, it's the patient's problem, and there's so much more psychiatrists could learn from talking in the early days to the carers, they seem to regard it as it's not your business, you know.

**V/O:**

Carers often say that they can find it difficult to get their own needs acknowledged. These can be substantial as Jane and Jonathan discovered in a survey.

**Jane:**

The carers themselves had very, very significant health needs, you know, and that included things like Parkinson's disease, Multiple Sclerosis, strokes, diabetes, depression, and that was the carers, not the person being cared for.

**Jonathan:**

There are health needs which are specifically to do with the care and responsibility so back problems are quite common amongst carers, stress and tiredness, and depression are quite common amongst carers.

**Jane:**

When we're contacted by older couples it's often hard to know actually who's the carer and who's the cared-for, often people are mutually dependent, but equally we do have disabled carers who we are in contact with who are still providing a huge amount of care.

**V/O:**

Emotional support is an important factor in maintaining a sense of well-being, and the Carers' Liaison Project has established a telephone support line. Volunteers like Pat Amsell, who had first-hand experience of caring, answer calls and give carers an opportunity to talk freely and in confidence.

**Pat:**

(ANSWERING PHONE) Carers-On, can I help you? Are you getting any help at all?

**Pat:**

Having been a carer myself I know how important getting the right information is at the right time, and how nice it is to have somebody that you can offload onto who is completely anonymous, and you can talk to somebody that you're never going to meet and you don't really know, better than you can talk to somebody that you do know, you know. Our carers' phone line is different from a lot of the phone lines, once somebody has rung us we ask them if they'd like a call back, and most of them say 'yes' so we ring them once a fortnight. Often it's just to talk about the garden, or the cats or dogs, just somebody different to talk to, to just have a normal conversation with if you've got looking after somebody with Alzheimer's, it's nice to know somebody's going to ring you.

**Lady:**

Some carers have been supportive for over two years after they've stopped being a carer. While someone is a carer, and particularly providing a great deal of care, their life is completely structured around the care for that person. There might be a number of people coming into the house to support them and that, but when the person they're caring for dies, or they go into residential care, those services all disappear.

**V/O:**

For those who don't feel they can talk about their problems openly the phone line can be a valuable resource.

**Man:**

Very few people outside the family know it's Schizophrenia, they just think he's got an illness, well some of them I suppose think it's a, could be a physical illness 'cos they see him walking around, he doesn't go to work, but there is that stigma attached to it, and even he will say I haven't got this illness you know, you say I have, but I haven't. You never mention the fact to people, you know, that he's got Schizophrenia, you just cover it up.

**V/O:**

The caring role is a challenging one but it also brings rewards.

**Man:**

Well I think the satisfaction comes from the fact that he says 'she thinks of us', the fact that he's still got a good relationship with us and you know we get on so well together gives me the satisfaction of thinking we're doing the job properly.

**Woman:**

If he learns to say a new word you think, oh wow, you know it's happening. I mean he came home from school this week with a tattoo, just a temporary one, and he was so chuffed, and I thought well, it's just the same as a problem who didn't have any problems at 11, and it was really nice to think that he was doing something that his peers were doing, and it's like wow, there is something going on in there after all, and you do actually feel quite rewarded that you've put in so much and you're now getting something back.

**V/O:**

Carol's relationship with her aunt is particularly important to her.

**Carol:**

I'm quite happy to continue. I don't feel that I would be happy placing my aunt in permanent care because she still has so much to give, and I would be lost without her.

**V/O:**

But after her aunt came to live with her, Carol had to decide whether or not to care for her mother as well.

**Carol:**

If my mother had become ill first I would have thought twice about caring. No problem with caring for my aunt because we've always had this closeness as friend, and I did live with her for a while. I think probably I would have avoided becoming a carer for a much longer period, I would have probably arranged for my mother to go into sheltered accommodation, or hoped she would have gone into sheltered accommodation. It was suggested to me by a professional when my mother became ill, that as I'd been looking after my aunt for so long it was time I booted her out and looked after my mother instead, which I took strong objection to, so as I'm looking after one sister I think I feel I have to look after the other – it's either both or none really.

**V/O:**

Most carers carry on providing support in spite of the difficulties and frustrations that they experience.

**Man:**

Nearly 100% of carers are carers because they want to be, because they love the person who they're caring for, so very few people are forced into it. I think some people find themselves in situations that they're finding very difficult, the fact that they have a relationship with that person, and a relationship they want to keep, makes them continue caring.