

THE ADUR
CARERS PROJECT

INTERMEDIATE
LEVEL

STUDY TIME: 10
HOURS

K202_1 Care and welfare in the community

The Adur Carers Project

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Introduction

The caring people do for family members or close friends is often difficult to define, as you're probably aware. Sometimes people are reluctant to be described as being a 'carer' because it signals a change in a relationship, or a change in someone's lifestyle.

How people talk about care, and the meanings that they give to what they do, can influence many aspects of caring relationships. It may determine whether help is provided in the first place, and also what kind of help is given.

In this course, you'll be listening to two audio clips featuring some carers in West Sussex. They are talking about their experiences of caring for members of their families.

The audio was recorded in 2000.

Participants in the audio programme:

- **Helen Robinson** is the presenter;
- **Jonathan Smith** is part of Adur Carers Association;
- **Jane Weston** is part of the Carers Liaison project;
- **Julie Runseg** is part of Adur Carers Association;
- **Les** and **Jane H** are carers;
- **Pat** is a telephone operator for the liaison office and was a carer.

Adur is an area in West Sussex.

This OpenLearn course provides a sample of Level 2 study in [Health and Social Care](#).

Learning outcomes

After studying this course, you should be able to:

- understand how carers can sometimes perceive their role.

The Adur Carers Project

1 The Adur Carers Project



Figure 1

This course features a project that has been set up to support those caring for a relative or friend at home – ‘The Adur Carers Mobile Information Project’. The project helps carers in the region to access the necessary services and resources.

An important aspect of the work done by Adur Carers is reaching out into local rural communities where people are isolated, and find it difficult to access services, and support. Setting up stands in High Streets and shopping centres allows them to contact people who may not even have realised that they were acting as a carer.

You will shortly be listening to two audio clips, which starts with a discussion involving Johnathan Smith and Jane Weston, who are both involved in local support services for carers in West Sussex. Jonathan is a qualified social worker who operates the **Adur Carers Mobile Information Project**. Jane provides ongoing support for carers through a sister project, the **Carers Liaison Project**, which offers longer-term advice and befriending.

You'll also be hearing from the carers themselves. Take some time to read up a bit of background about the carers, on the next page, before continuing to the two audio clips. This will give you an insight into their particular situations.

2 The carers



Figure 2: The Adur Carers Mobile Information Project

Through Jonathan and Jane, we hear from three people in different caring relationships. At the time of the recording, in 2000, Julie, Les and Carol were involved in caring roles. Pat talks from the point of view of someone who used to be a carer.

All three were willing to be interviewed, in order to share their experiences, despite having to reorganise their daily routines and give up precious free time. The interviews took place at a local advice centre.

Julie is the mother of a disabled child. Although she gets a break during the day, she has to escort him to and from school on the bus. The local education authority has made this a condition of his using school transport. The two double journeys take up most of the day, and she has only a brief period between late morning and early afternoon to get all her jobs done.

Les looks after his adult son, who has severe mental health problems and never leaves the house. Although Les does not have to provide a high level of personal care, he cannot go out very much because of his son's disturbed behaviour. His wife can cope alone for short periods, but she worries if she is left alone with their son for long. An added pressure for Les is the stigma attached to mental distress. He believes his

neighbours would react negatively, if they knew his son had schizophrenia, and we were only able to record this interview on condition that we used a pseudonym.

Carol cares for both her mother and her aunt. When she came in to speak to us, she brought with her a diary entry for a typical day (attached below). What is striking about Carol's diary is the physical labour of caring, the number of people coming and going in the course of a day, and the fact that personal care has to be fitted in alongside car repairs, housework, and other family commitments.

Have a look at [Carol's diary](#).

Pat Amsell is a volunteer who helps with the liaison project's telephone support line, which is operated by people who all have first-hand experience of caring.

3 Audio and activity

3.1 Caring relationships

Activity 1

Listen to the two audio clips. While you are listening, make notes on the different kinds of caring relationships being described. For each person, note down:

- how they feel about being a carer;
- what their main concerns are.

Audio content is not available in this format.

Clip 1: Part 1

[View transcript - Clip 1: Part 1](#)

Audio content is not available in this format.

Clip 2: Part 2

[View transcript - Clip 2: Part 2](#)

[View discussion - Activity 1](#)

3.2 Feelings about being a 'carer'

Carol, who looks after her mother and her aunt, feels the need to distinguish between being 'a relative' and 'a carer'. She feels that health and social care practitioners don't always recognise who the carer is.

Julie, caring for her 11-year-old son who has severe learning and physical disabilities, complains about ‘the disbelief’ about the extent of help she provides.

Les and his wife, whose son has severe mental health problems, noticed that they tended to be ignored at meetings with the psychiatrist at the hospital. As he puts it: ‘There's so much more psychiatrists could learn from talking in the early days to the carers’.

Jonathan Smith and Jane Weston see their roles as enabling people to recognise what they do as carers, and to get them the help they need. They do this by providing support and information about welfare services and rights. Jonathan points out how people often do not recognise that they are carers. This is partly because they do other things in their lives, and partly because carers aren't just one type of person. A carer ‘can be anyone’.

3.3 Concerns about being a carer

Some of the things people mentioned were:

- financial difficulties
- loss of status
- relationships if someone gives up paid work
- physical and emotional demands
- fears for the future
- having to ‘fight red tape’
- worry that they might seem to be overreacting.

Through their work, Jonathan and Jane identify other areas for concern. These include:

- neglect of carers' own health needs
- depression among carers
- problems arising if the carer's role comes to an end.

The last point draws attention to the fact that these carers, and the people who work with them, don't just mention problems and difficulties. Julie talks about feeling rewarded by her son's development, and Les points out that he and his wife still have a good relationship with their son. And of course, as Jonathan says, ‘Nearly a hundred percent of carers are carers because they love the person who they're caring for’.

Conclusion

This free course provided an introduction to studying Health and Social Care. It took you through a series of exercises designed to develop your approach to study and learning at a distance and helped to improve your confidence as an independent learner.

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This free course provides a sample of Level 2 study in Health and Social Care: <http://www.open.ac.uk/courses/find/health-and-social-care>.

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You can experience this free course as it was originally designed on OpenLearn, the home of free learning from The Open University - www.open.edu/openlearn/health-sports-psychology/social-care/the-adur-carers-project/content-section-0.

There you'll also be able to track your progress via your activity record, which you can use to demonstrate your learning.

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Figure 1: top and bottom left: Rose Barton; bottom right: Vaughan Melzer

Figure 2: Vaughan Melzer

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Activity 1

Discussion

The people talking on the audio clips identified a range of different reactions to their experiences as carers. At the beginning of the first clip, you heard a woman say, ‘I find the term “carer” acceptable now, but initially I didn’t’. However, other people had had experiences which had left them more ambivalent.

These matters are discussed in greater detail in Sections 3.2 and 3.3.

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Clip 1: Part 1

Transcript

Jonathan Smith

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

Carole

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

Pat

Well carers are all different, aren't they? Because they're all caring for different ... some with physical disabilities and some with mental disabilities.

Julie

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.

Helen Robinson

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

Okay, 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 ... 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 - 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 to people.

Hello can we help at all?

Man

I just saw the sign saying 'Carers,' and I wondered whether it applied to me at all. I mean, I 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 Smith**
- Do you want to step on the bus for a minute, and we'll have a chat?
- Man**
- Well, that would be nice thank you.
- Jonathan Smith**
- Yeah okaydoke.
A lot of people don't like walking into social services offices, or making a fuss at GP's surgeries, about the fact that 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 can come up and chat to.
- Helen Robinson**
- Carers are often referred on to the Carers' Liaison Project, managed by Jane Western. It's able to offer longer term advice and support.
- Jane Western**
- 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, that has a huge impact on people's lifestyles, generally.
- Helen Robinson**
- Julie is one of the people supported by the project. She describes herself as a 'parent carer,' looking after her eleven year old son, who has severe learning and physical disabilities.
- Julie**
- He can't sit up. He can't stand. He can't walk. 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.
- Helen Robinson**
- Julie had held a nursing post before she began caring for her son.
- Julie**

Even though I was qualified, and had actually worked on occasions with children with special needs, it doesn't prepare you at all for it. Because it is twenty four 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.

Helen Robinson

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 we're under, we do cope quite well. We're fortunate, in one respect, that we've got a decent sized house. So, if we want to, we will go in another room, just the two of us, and sit together, and that's it. But, if we were in a small house, and he was in with us all the time ... it would ... if he gets one of his periods where he's talking to himself continuously, it would drive you barmy.

Helen Robinson

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 long around. That's his problem, and he gets depressed about that. My wife, who's sixty five, and I'm sixty eight ... if we can survive say another ten years, then by that time he'll be forty three. He'll be middle aged himself, and perhaps he might find it easier to cope.

Jonathan Smith

I think the most difficult thing is actually the 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?

Helen Robinson

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

Carole

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.

Helen Robinson

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 that 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.

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Clip 2: Part 2

Transcript

Helen Robinson

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

Les

One thing we did find in the early days, when he was attending the hospital as an out patient - after he'd had his eight weeks in there, he attended for 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, "They're 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 is ignored, as though you're not involved. They don't see it as your problem. It's the patient's problem. 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.

Helen Robinson

Carers often say that 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, 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 Smith

There are health needs which are specifically to do with the caring 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 huge amounts of care.

Helen Robinson

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 Ampsell, who've had first hand experience of caring, answer calls and give carers an opportunity to talk freely, and in confidence.

Pat Ampsell

Carers Line can I help you? Are you getting any help at all?

Having been a carer myself I knew 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. 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 then, 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 the dogs ... just somebody different to talk to ... to just have a normal conversation. If you're looking after somebody with Alzheimer's, it's nice to know somebody's going to ring you.

Jane

Some carers have been supported for over two years after they've stopped being a carer. Whilst 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 in that but, when the person they're caring for dies or they go into residential care, those services all disappear.

Helen Robinson

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

Les

Very few people outside the family know its schizophrenia. They just think he's got an illness. But some of them, I suppose, think it could be a physical illness, because 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 say I have, but I haven't". You never mention the fact to people - that he's got schizophrenia. You just cover it up.

Helen Robinson

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

Les

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 we get on so well together, gives me the satisfaction of thinking we're doing the job properly.

Julie

If he learns to say a new word, you think, "Oh wow, it's happening". He came home from school this week with a tattoo - just a temporary one - and he was so chuffed. And I thought, "Well, this is the same as a child who didn't have any problems of eleven," 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.

Helen Robinson

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

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.

Helen Robinson

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

Carole

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 both or none really.

Helen Robinson

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

Jonathan Smith

Nearly a hundred percent 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.

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