

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](#)

Audio content is not available in this format.

[Clip 2: Part 2](#)

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.

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

Figure 2: Vaughan Melzer

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