

A labour of love

There are over six million people in the UK's hidden army of carers – they contribute billions to the economy every year. Many carers are providing unpaid care for people with arthritis. **Catherine Osborn** looks at the challenges they face

Who might be a carer for someone with arthritis? The truth is that carers come in all shapes and sizes, as Roz Hampson, advice and information manager at Carers UK, explains: 'There's no specific picture of what a carer looks like. A carer is anyone who looks after someone without being paid for it.' Many people who do this don't even consider themselves to be carers – it's just what they do.

Fourteen-year-old Catie Strutt often helps her mother Philippa, who has rheumatoid arthritis (RA), with household tasks. 'When my mum's not feeling well I try and help out by making cups of tea, making sure the house is tidy and making dinner,' she says. Philippa might not always need help, but it's great to know it is there.

Dawn Hunter's 14-year-old daughter Emily has arthritis. 'I've never considered myself to be a carer because Emily's my child and I care for her anyway,' she says.

For others, deciding to take on the role of a carer is an important decision. In 1999, Clifford Jones gave up work to become a full-time carer for his wife Catherine, who has RA. 'We talked about it and decided that our home life was more important than work,' he says.





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Caring can be physically and emotionally demanding work

When it comes to caring for someone with arthritis, the level of support needed can vary greatly. It could range from helping out with basic tasks like carrying shopping and opening jars, to providing 24-hour assistance including helping someone to wash, dress and go to the toilet.

Caring can also encompass helping the person you are caring for to access support from their GP or social services, for example. 'Being an advocate for someone with arthritis could involve going to doctor's or outpatient appointments with them,' says Val Harvey, who works on Arthritis Care's helpline. 'The carer can be supportive and give them the help they need to get through the NHS or benefits system.'

Pamela Ogden cares for her husband Keith, who has osteoarthritis and fibromyalgia. For her, it is not about taking control, but providing backup and making sure her husband's voice is heard. 'I always go to the doctor's with Keith,' she says. 'He doesn't always remember things because of his fibromyalgia and we've had some problems with our local hospital, so I go as a witness.'

The nature of arthritis means that the person being cared for may need help with something one day which they could do easily the day before. The condition can also change over time. 'My RA has pretty

much been under control for the last few years,' say Philippa, 'but recently I've had a muscle problem and so I've been in "asking for help" mode. I'm saying "I know I could do this before but I can't do it now. Can you help?"'

With some types of arthritis, flare-ups can also affect the levels of care needed. 'The care I give Catherine varies because of the nature of her condition,' says Clifford.

It's about being there emotionally, as well as doing all the practical things

'If she has a flare-up I'm on 101 per cent caring rather than 95 per cent, because I know there are times when she can't get out of bed.'

Caring can be physically and emotionally demanding. In addition to all the practical stuff, a carer for someone with arthritis can also find they provide companionship and a sympathetic ear when things get tough. Dawn sees this as part of her role. 'It's about being there emotionally for Emily as well as doing all the practical things. She can talk to me about anything.'

The pressure of caring can put a strain on the closest of relationships, with difficulties for both parties. Being cared for can be hard, especially for someone who was active and independent before they had arthritis.

Twenty-five-year-old Karl Clark gave up his job as a chef a year ago when he

developed arthritis. His wife, who works full-time, and his mother share his care between them and he's found it hard to come to terms with. 'Asking people for help has been my biggest problem,' he says, 'I was told that I should rest when my arthritis is bad, but I'm stubborn. I feel as though I'm losing my independence and that worries me.'

Philippa agrees. 'Your relationship with someone changes when you're getting stuck on the loo and you have to ask them for help. You lose some of your dignity and that's difficult.'

Taking on the responsibility of caring for someone with arthritis can also be difficult for the carer. The levels of care required can creep up imperceptibly and the carer may feel they have no choice, that caring is what's expected of them. 'Relationships can become very difficult,' says Carers UK's Roz Hampson. 'People often started out in a very equal position and the balance changes. Carers may feel resentful of what they're doing and then feel guilty about feeling resentful.'

Being close to the person you care for can also mean bearing the brunt of their anger and frustration. Dawn says when Emily was younger, this placed a strain on their relationship. 'It's been hard for Emily to accept her condition and, because I'm closest to her, I get the flack for it. We went through a period of disliking each other.'

So how can you avoid a negative impact on your relationship? Clifford says good

communication is one way of resolving difficulties. 'If there's a problem we talk about it straight away,' he says. 'If Catherine thinks I'm doing something wrong she knows she can tell me and we'll try it another way. I don't get offended.'

Philippa agrees that communication is important: 'You tend to take things out on the people closest to you. One good technique is to depersonalise things. Rather than saying "You always rush me when we're on our way out", you could focus on how it makes you feel and say "I find it hard to get ready to go out. Please can you help me?". You explain your point of view rather than blaming the other person.'

According to Arthritis Care's Val, learning about arthritis and its effects can improve the relationship between the carer and the person they are caring

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for. 'Try and gain an understanding of what the person with arthritis is going through,' she suggests. 'They can feel very depressed because they're grieving for what they've lost.'

Karl says that explaining how arthritis makes him feel has improved his relationship with his wife. 'You've got to let people know that if you're nasty towards them it's because you're not well. My wife knows now to let it go over her head. It's nothing personal. We've both learnt that.'

When caring for someone becomes the main focus in a relationship, it's not always easy to have fun and enjoy each others' company, but it's a good way of easing tensions. Fourteen-year-old Emily says she often spends time with her mum. 'We do a lot of things together,' she says. 'We go to the gym and go shopping and I always do the food shopping with her on a Thursday night.'

Keith and Pamela enjoy going on holiday together. 'I have my down days and so does my wife but we make sure we get away two times a year,' says Keith. 'We have a break and enjoy drinking wine and eating out together. It helps us both to take our minds off things.'

Clifford has been caring for Catherine for 29 years, but they still find time to have fun together. 'We can always see the funny side of things – if we lost that it would be dreadful,' he says. 'When Catherine's up to it, we like to go to the theatre or just get out of the house and have a cup of coffee somewhere.'

'My top tip for carers is look after yourself,' says Roz. 'It's easy to say and often very hard to do, but we encourage carers to tell their GP they're a carer, to get a social services carer's assessment [see box

Where's the benefit?

- Carers are entitled to a social services assessment of their needs. Assistance for carers might include respite care, aids and equipment or day care, for example. Contact your local social services department for more information.
- If you're a full-time carer you might be entitled to Carer's Allowance, which rose to £48.65 in April 2007. If you are in Northern Ireland, call the Social Security Agency for information

on 0800 220674. People in the rest of the UK can contact the Benefits Enquiry Line on: 0800 882 200, or visit:

www.direct.gov.uk/carers

- Applications for benefits and support can be complicated, but contact your local Citizens Advice Bureau (CAB) for information on what you're entitled to and how to apply. Look in the telephone directory for your nearest CAB or visit: www.citizensadvice.org.uk

above] and to make the most of the help that's out there. Carers can be so used to being in the caring role that they find it hard to say "actually, I need a break".'

Val also stresses the importance of taking a break: 'Many carers will say that it isn't possible. Even if they can't leave the house, it's important for carers to take some time

We're a lot closer than a lot of mothers and daughters now

to do what they like to do. Otherwise, they'll burn out and, instead of a loving relationship, it will turn into a chore.'

Pamela loves gardening and finds this gives her relief from caring. 'I take two or three hours out and mess about in my garden,' she says. 'I don't leave Keith, but I have my own ways of relaxing.' Clifford


also makes time for himself. 'I love cooking, reading and walking. I walk a mile in the morning and a mile in the evening.'

Support from other people and sharing your feelings can also make caring easier. Dawn believes that being honest about how difficult she found caring transformed her relationship with her daughter. 'At one stage I felt like a failure because I didn't feel I was coping. People would see me smiling and say they didn't know how I did it. It was a front, I was cracking up inside. In the end I went to see my doctor and after that I was able to talk about it. When I feel stressed out I tell Emily – we're a lot closer than a lot of mothers and daughters now.'

Simply knowing that support is available if you need it can make a difference to how you feel. If friends and family aren't able to help you, you could always find out about carers' organisations in your area. Most areas have a carers centre where you can find support and meet other carers.

If you feel isolated and would like to talk to someone you could call CarersLine or the Arthritis Care Helpline. If you need a break, the charity Crossroads arranges for trained carers to come to carer's homes and give them a break for a few hours a week.

Caring for someone with arthritis is demanding, but it can also be rewarding and can reaffirm the relationship between the carer and the person they care for. Catie believes she has learnt a lot through supporting her mum. 'I guess if anything it has made us closer,' she says. 'It's made me more aware of other disabled people and how hard it can be for them.'

Clifford believes that caring for Catherine has enhanced his life. 'Although I do a lot for Catherine I feel she gives me a lot back. Looking after her is an absolute pleasure. It wouldn't do for everyone, but it works for us.' 

Contacts for carers

- Carers UK – a campaigning and information charity for carers, offers a helpline (CarersLine: 0808 808 7777) and website forums and chatrooms for carers and they have details of carers centres throughout the UK. Website: www.carersuk.org
- The Princess Royal Trust for Carers – a charity offering carers' support services. Telephone: 020 7480 7788. Website: www.carers.org
- Crossroads – operates the Caring for Carers scheme: a trained support worker will usually come to the carers home and give them a break for a few hours a week. Telephone: 0845 450 0350. Website: www.crossroads.org.uk
- Arthritis Care's website – this has an informative section for carers – www.arthritiscare.org.uk/LivingwithArthritis/Caringforsomeone – as well as online discussion forums to participate in – www.arthritiscare.org.uk/GetInvolved/Discussionforum