

'Carers need reassurance they're doing the right thing'

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When her husband Joe suffered the first of three heart attacks, Sue Dickens lay awake at night watching him breathe. "It was like bringing a newborn baby home from hospital. I felt very anxious and responsible. If Joe twitched, I'd worry that he was about to have another attack," she says. "His illness was a huge shock, an absolute bolt out of the blue. Joe had always been the strong one. Suddenly our roles reversed."

Joe, 61, a retired safety engineer, suffered his first heart attack at work in October 1993. The couple, from Doncaster, South Yorkshire, had just celebrated their 30th wedding anniversary. Joe had two more heart attacks within five months. "Joe had to slow down and that frustrated him," says 59-year-old Sue. "He couldn't carry shopping or drive for a while. I did those jobs instead. I wanted to wrap him up in cotton wool. That made him feel useless. His moods changed. Things that he would laugh off would become mountains out of molehills. I also wondered if his heart attack was my fault, that perhaps he'd done too much for me in the past." Joe is now on medication and had an operation in 1999 to fit a stent, a wire-mesh appliance inserted into an artery to keep it open.

Sue's experience is typical of the emotions that carers go through when a loved one is taken seriously ill. "A heart attack changes people's lives and their marriage," says Tracey Deakin, a staff nurse in coronary care at Doncaster Royal Infirmary (DRI). She runs the Carers Support Group, a self help body set up in January 2002 after two studies at the DRI revealed carers did not receive enough information. "A lot of responsibility is placed on the spouses for aftercare, while health professionals traditionally have just focused on the patient," Deakin says. "It's really important to help carers identify their own needs."

The studies of approximately 210 patients and their carers were carried out by the North Trent Coronary Heart Disease Collaborative (NTCHDC). The self help group is part of the National Coronary Heart Disease Collaborative programme whereby managers and health professionals share ideas to improve services. "Although patients felt they received sufficient information, the responses from carers were negative," explains Helen Tucks, the NTCHDC's project manager. "They said things such as: 'Everything is focused on the patient but not on me'."

Carers are told about the group when their partners are admitted to hospital. It runs parallel with patients' rehabilitation sessions. Most who attend – once a week for six weeks – are women aged 40-plus. They have the opportunity to air any worries, and they receive advice, on for example, stress management. "Carers are scared stiff," says Deakin. "Many say they sit up all night to check

their partner is still breathing. One woman was so frightened of leaving her husband alone that she didn't dare get her hair cut. When she did recently, it was a real step forward. She was looking after herself again."

"Couples can experience marital problems because of coping with their partner's mood swings or depression," says Deakin. "They feel as if they're walking on eggshells but they don't want to snap back because they're worried that an argument might trigger another heart attack. One man said he didn't resent putting his life on hold for his wife. But he felt really angry whenever he did the shopping. That's the only time he was alone and all his frustrations were bubbling up. He was reassured that it's okay to admit feeling resentful. Some couples also have sexual difficulties. They are afraid to resume a normal sex life in case they trigger another attack. If people can climb stairs without difficulty, it's safe for them to resume their sex life."

Dickens, who took part in the consultation process to establish the support group, has found its help useful. "A lot of emphasis is put on patients but the carer feels totally lost," she says. "Carers need reassurance that they are doing the right thing. One man couldn't believe that we'd been to Austria on holiday; he's always wanted to be within striking distance of the DRI. Today, people don't live as close to their families so carers can feel very alone. I'm not what you would call a typical group person but having other people to talk to does make a difference. You realise you're not the only one who's gone through tea and tears at 2am, and that there is light at the end of the tunnel. It's a matter of pacing yourself as a couple and finding a balance in your relationship again. Joe and I are on an even keel again because we know our limits. We still have a good life together."