

## Caring for Carers

*by Marion Shoard*

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A mother suffocates a violent son with Down's syndrome after caring for him for 36 years. An elderly man with dementia is abandoned in a hospital waiting room with a note from his wife saying she is on the verge of a breakdown because she cannot cope any longer. Just a couple of recent cases highlighting the plight of a forgotten army of people whose lives are devoted to helping others but who desperately need help themselves - the nation's carers.

In Britain, nearly six million people look after disabled, sick or frail people either in their homes or the homes of those they are caring for, without being paid to do so. They come in a variety of forms. Typical examples might be a middle-aged daughter living with a mother incapacitated by strokes, or an elderly man coping with a wife in the early stages of dementia while suffering from disabilities of his own. The efforts of such people save their fellow-citizens somewhere between £30 billion and £60 billion a year, yet they receive little help themselves from any quarter. The resulting strain often brings serious health and financial problems.

Carers' Rights Day, on December 2, was designed to highlight the plight of these people. It might be thought that the one section of society which might not need such a stimulus would be the Christian churches. Are Christians not enjoined to help their neighbours, particularly those who most need and deserve such help? And does not church infrastructure provide a ready means of doing this? You might think so, but carers are a topic which barely features on most churches' radar.

For example, none of the main denominations has an officer in place at national level to consider how best carers could be supported, even though many have paid, full-time workers to address the needs of other groups, such as children, teenagers and parents.

Yet caring is a topic on which churches are particularly well equipped to contribute. Carers need much more than the cash grants and physical support for which they look to the state. There are huge emotional and spiritual issues involved.

Embarking on caring can transform someone's life in the same way as becoming a parent, although sometimes even more dramatically. Carers often face great uncertainty about how long their task will last and how it may affect their future. If the caring project goes well it can be an enormously enriching experience for both the carer and the person cared for. But it can also become a nightmare from which no escape seems possible, and which is often compounded by the low status accorded to carers by society generally.

Yet caring is certain to become an increasingly urgent issue for all social institutions. Lengthening lifespans are providing more years in which to develop the incurable conditions which make day-to-day living difficult, such as osteoarthritis, osteoporosis, chronic heart and lung disease, Parkinson's and Alzheimer's. The number of people with dementia alone is expected to rise from its present 700,000 to 1.7 million by 2050, and many of those affected will be looked after by family members at home.

If the churches as a whole have yet to rise to this challenge, there are nonetheless individual congregations which are starting to point the way. Exeter Cathedral holds an annual Service of Celebration of Carers. The Dean welcomes not only carers from the whole of Devon (who are encouraged to play a part in the service) but also civic leaders, since part of the intention of the service is to publicize the role that carers perform. Usually carers are out of sight and therefore out of mind, and this compounds their difficulties.

Nikki McVeigh, the wife of the Anglican vicar in Westerham, Kent, has recognized the needs of carers themselves by creating a support group for them, which meets once a month for talks and mutual support. Mrs McVeigh arranges transport and the provision of substitute carers while the meetings are going on, while she and her husband, Paul, also make themselves available to deal with any crises which arise, day or night.

Events to which carers can bring their charges require less organization. Gaynor Hammond, a dementia project worker employed by a local churches organization, has set up a "friendship club" operating one morning a week for the carers of people with dementia at Trinity Baptist, Methodist and URC church at Rawdon in Leeds. This model has been copied at several other locations in Yorkshire. Carers told Ms Hammond that they would value more than anything the opportunity to hold a normal conversation, so she decided to copy the format of the church's existing mother-and-toddler group. Her group operates from 10 am until noon. Volunteers from Trinity and other local churches provide coffee and nice biscuits (and often also a cake to mark some celebration) and look after the people with dementia.

Gaynor Hammond, who now lectures at the Northern Baptist College in Manchester, explained to me: "The carers get the chance to moan to each other sometimes, chat about all sorts, and have a real laugh, which is something they probably don't do a lot, and that's a release. Also, somebody else might have a solution to a particular problem". But organisation is minimal: "It seems to be a very big thing that churches can do without too much effort, especially if it's done ecumenically, with volunteers from different churches. You need a warm room, a little kitchen and a big welcome, and if you can do that you can change the lives of many people".

Some activities laid on by churches may help carers indirectly, such as clubs and outings for older or disabled people, as this can free up time for the carers involved. For instance, several churches in Surrey offer clubs where disabled people can do artwork one afternoon a week. Such activities can give disabled people new confidence and be so absorbing that they continue to pursue them back at home.

Some churches have given priority to carers when revamping their church premises. St. Stephen's Anglican Church in Chatham, Kent has recently extended its buildings so as to provide more resources for community activity, and in particular dementia work, in the Medway area. A carers' group meets there along with a carers' education group, a group of Admiral nurses (who specialize in dementia care) as well as a small group of the church congregation who have been through an education course and as a result are now very active in supporting people with dementia and their carers. St Stephen's also plays host to meetings of a group of people with dementia, who enjoy cultivating part of the Garden of Remembrance.

Nonetheless, all these initiatives, admirable as they are, barely scratch the surface of the problem. Churches that have concentrated on providing for young families need to reassess their priorities. Perhaps they should designate their own carers' day to focus on what they can do to support carers, and to prepare them psychologically and spiritually for a role that more and more of their own flocks will find themselves shouldering. Are carers given special recognition in a church's mission statement? Do they feature as much as they should in prayers and sermons, so that Christian identity is seen to embrace carers clearly? Are individual church members looking for opportunities to offer the sort of help that carers really want?

Sue Jones, who cares for a paraplegic husband and a daughter with manic depression, organizes the Carers Christian Fellowship, which consists of 300 mainly isolated carers dotted over the British Isles. She considers churches could do far more to help carers: "A lot of carers say people in church will say, 'We'll pray for you'. That's about as far as it goes. But I heard a lovely thing the other day. A carer told me that somebody had said to her, 'We'll come to lunch with you. And we'll bring the lunch!'"

Of course, one of the best ways to help carers is to make life easier for their charges. Do church stewards offer as much help as they can to those with physical or mental difficulties and those supporting them when they arrive at a service? Is there help with wheelchairs? Are there large-print handouts and hymnbooks? Is there suitable comfortable seating? Older people, unwell and disabled people generally might benefit from what carers and cared-for need. A checklist could include:

- A hearing loop system and attention to ensure that microphones are used during services and other meetings
- good lighting (weakened eyes can need four times as much as light as those of a healthy young person)
- lavatories always available which are warm, clean and spacious, with support rails
- a warm church (cold buildings threaten the health of those whose temperature regulation mechanism has been compromised)
- adequate, comfortable seating within all church buildings together with ramps, grab rails, reduced-depth steps and even, hard (not gravel) surfaces outside (more than a third of people over 65 have mobility problems)

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Getting out of the house is frequently a problem for carers, so is transport offered? If it is, is this burden shared too? Always being the person who every week runs a disabled person to and from a meeting and perhaps shepherds him or her during it can turn that person into a "carer" as well, who might wish to share the load if only anyone offered. Can church meetings be held in carers' homes if that is what they would like? Are outings offered sometimes? Countless carers have told me, "I haven't had a holiday for years".

Pastoral care systems in churches tend to be geared to responding to short-term events such as illness or sudden death. Yet carers need continuous help. Has the pastoral support system in your church been evaluated to check that it caters adequately for carers? Are there "listening ears" - people prepared to be on hand to phone and visit carers frequently, even telephoning them every evening if they want this? Royston Methodist Church's pastoral system provides volunteers who come in and sit while carers go out. It also tries to put past carers in touch with new carers, to provide them with practical tips and moral support.

Joan Germany, Royston's Pastoral Secretary, told me that the team also tries to equip itself with knowledge of basic features of the state social care machine and with what voluntary organizations can offer, in particular through twice-yearly training days. Training can ensure not only that ministers and lay workers are acquainted with state entitlements and the various gadgets and types of help in the home that can prove useful, but also that the barriers to communication with groups such as those with dementia are broken down.

The condition of carers and those they care for often, alas, resembles that of the "sick" or those "in prison" whom Jesus charged his followers to visit. But for those involved in particularly demanding caring, there is perhaps an additional Christian imperative. These carers can find their whole lives taken over, so that they are deprived of the individual identity once imparted by career, hobbies and friends. Julia Burton-Jones, a Christian with a special interest in carers, argues in her book *From Generation to Generation* that this situation should be regarded as unacceptable by Christians, who believe that each person is made in the image of God and is of intrinsic value in his or her own right.

Certainly churches should surely be expected to take a lead in drawing attention to the problems with which carers grapple. They need to ask carers in their congregations and in their communities how they can help. The requirements will often be individual, but often meeting particular needs turns out to help others too. Extra seating outside a church for carers waiting for a lift home may be found useful by other parishioners too. Spiritual support for a person with dementia may turn out to benefit those who give it as well as those who receive it. But whether it helps us or not, to look after carers is surely central to our Christian duty. As Paul told the Galatians, "Carry each other's burdens, and in this way you will fulfil the law of Christ".

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