Infomral carers count


The government strategy Caring About Carers acknowledges that state care provision can never replace that of informal carers.

The greater the turnover, the greater the number of individuals involved in care giving over time. Indeed, most people will provide informal care during their lifetime and the probability of becoming a heavy carer can accumulate. In a 75-year lifespan, six out of ten individuals are likely to assume heavy caring responsibilities at some point. Women have a 50-50 chance of being heavy carers at least once before the age of 59. Men must live 15 years longer on average to have the same chance of providing heavy care.

Most care-giving is based on close personal relationships, often inter-generational, and these largely define the volume, pattern and timing of caring episodes. Most heavily involved carers are looking after a spouse or partner (39 per cent) followed by parents or parents-in-law (27 per cent) and children (14 per cent).

Care for sick or disabled children begins mainly in the child-rearing years, before parents reach their mid-40s. Looking after disabled or older parents occurs mainly when carers are in their mid-30s to mid-50s, and the likelihood of spouse care increases with age and predominates from the mid-50s onwards.

The overall likelihood of becoming a heavy caregiver peaks in late-middle and early-old age, although above average rates for taking on a caring role (more than 15 per 1000 adults) span 40 years of adult life. Heavy care-giving occurs later for men: in people aged over 75, men are more likely than women to take on a caring role. Caring episodes vary in length from a few months to 30 years or more and most last no more than five years. Carers aged over 50, mostly women, might be looking after dependent children, adult disabled children or parents before the need arises to provide informal care for a spouse. Some carers will need support to resume their lives beyond the period of care, especially when it ends with the death of the cared-for person.

We know surprisingly little about how individuals come to define themselves as carers or what prompts them to seek help and services. The reasons include the severity of the care recipient’s...
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REFERENCES


FURTHER INFORMATION
www.carers.gov.uk

Box 1: The nurse’s role

Health promotion
- Enabling carers to maintain their health and wellbeing
- Encouraging stress management and time off
- Working with carers to maintain/improve the health of the care recipient

Practical support
- Offering training in lifting, mobility, basic nursing tasks
- Follow up, re-evaluating care arrangements

Emotional support
- Listening to carers, helping them to deal with their feelings about care-giving
- Enabling carers to adjust when care-giving ends

Information and advice
- Providing information, advice and advocacy, help with welfare benefit claims and sources of information
- Ensuring carers know their rights under the Carers Act and the forthcoming Carers and Disabled Children Act
- Advising on what to do in an emergency
- Providing information, with permission, about the illness or impairment of the person cared for and his or her treatment

Referral to other agencies
- Enabling access to health, housing, social care services

Symptoms, changes in his or her condition, the impact on the carer’s quality of life and relationships, his or her health beliefs and expectations of health advice and care. Older carers in particular often have health problems and a considerable body of research points to the onset and maintenance of stress-related illnesses, physical injuries, fatigue and other carer-related symptoms. Whatever the circumstances, the most important contact for many carers is their GP, the district or community nurse, or another member of the primary care team (Henwood 1998).

Family carers often regard care-giving as part of their normal responsibilities and are likely to remain invisible unless encouraged to talk about their situation. By brainstorming with colleagues, nurses can identify patients already known to be carers or whose relatives or friends care for them at home. Another approach is to ask about caring responsibilities when registering new patients or in routine consultations.

Annual health checks of people aged over 75 and special clinics provide an opportunity to identify particularly vulnerable groups of carers. Some practices distribute leaflets or letters with a tear-off slip for carers to return or ask patients to complete a questionnaire that includes a question about caring responsibilities. Others print a message on prescriptions inviting carers to identify themselves. Once a patient is identified as a carer, his or her record can be tagged for follow-up and future reference.

The nurse’s role
Nurses are well placed to take a lead in supporting carers and home visits provide good opportunities for understanding a carer’s circumstances. Box 1 outlines what the nurse’s role might include.

On the face of it, supporting carers could have major resource and workload implications for primary care. However, there is no evidence to warrant concerns about extra work or fostering unrealistic expectations. Many carers are already in contact with their GP and most simply want recognition of their role and reassurance that there is someone to turn to. Indeed, supporting carers through general practice could save time and money through fewer inappropriate enquiries, shorter consultation times and reduced prescription costs (Warner 1999).

Carer development
Projects in general practices and health clinics are evolving rapidly and various approaches have been taken to identify and support carers (CNA 1998). Many involve partnership working between GP practices, health clinics and a local carer’s resource centre or similar organisation. Some offer a fairly basic service, such as providing information to staff, maintaining carers’ notice boards and encouraging referrals to local carers’ groups. Some GPs have welcomed more active involvement and health and social services authorities are increasingly sympathetic towards funding such projects. A simple tool for monitoring the involvement of general practices has been developed by a Carers Health Partnership funded by joint finance in Bolton. It recognises four levels of increasing commitment to carers: acknowledging, identifying, supporting and including. Levels are monitored over time to pick up new initiatives or record changes.

The Carer’s Compass, based on the experiences of 19 carers’ projects around the country, provides a comprehensive checklist for use by primary care teams in audit and performance management (King’s Fund 1998, Banks and Cheeseman 1999, Unell 1999). The outcomes carers want are:
- To be fully informed.
- To be recognised and have their own health and wellbeing taken into account.
- Quality services for the person cared for and for carers to have a life of their own.
- Opportunities for a break from caring.
- Emotional support, training and support to care.
- Financial security.
- A voice in service development and delivery.
It also sets out the policies that primary care staff need to develop to meet those outcomes.

Conclusion
State provision could never replace the contribution of family and friends to care and since the early 1990s their needs have gained greater priority. Informal carers are increasingly recognised as essential members of the health care team. Almost all carers would benefit from some help and support to continue providing care and sustain other roles.
Supporting informal carers is now high on the government’s agenda for improving health and reducing health inequalities. Practice and community nurses are at the forefront of changes. Having an identifiable strategy for working with carers matters more than the strategy itself.