ing dose being in the region of 36-40 mg/day, with an experienced addict taking up to 80-100 mg daily. Methadone is well absorbed orally, producing peak plasma concentrations within two to four hours and peak clinical effects within one to two hours. The drug concentrations correlate well with respiratory depression and miosis, with the clinical effects lasting more than 72 hours in some subjects after a single oral dose.² As little as 40-50 mg may produce coma and respiratory depression in a non-tolerant adult.³ As the half life of methadone varies between 25 and 52 hours, overdose can lead to a protracted clinical course.

Methadone toxicity is more likely in those trying the drug for the first time before tolerance has had time to develop.⁴ Deaths related to methadone are increasing,⁵ with patients starting on maintenance programmes being at particular risk.⁶ Because the sedative and depressant effects of methadone do not develop immediately, it is easy to take a large amount without being aware that harm is being done. One addict's daily maintenance dose of 50-100 mg can cause life threatening poisoning in a non-tolerant adult.⁷ Although plasma methadone concentrations have been recommended as a routine way of monitoring treatment,⁸ interpretation must take into account whether the individual has

recently started treatment or is stabilised on a maintenance dose.

We recommend that patients with methadone overdose are admitted to hospital empirically for 72 hours, during which time their oxygen saturation should be continuously monitored with an oximeter and prompt referral made to intensive care if they suffer altered consciousness or hypoxia. Regardless of the duration of hospital stay, we also suggest that patients should be monitored with an oximeter for a further 24 hours after discontinuation of naloxone infusion.

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Caring for Older People

Carers

Anne F Travers

This is the seventh in a series of 14 articles edited by Eileen Burns, Neil Penn, and Graham Mulley

Caring by families and friends is the backbone of community care. Carers face physical, emotional, social, and financial problems. They need recognition, information, and support from the health professionals with whom they and the person they care for come in contact. Much information is available to assist carers and to enable their doctors to help them in their caring role.

"The primary sources of support and care for elderly people are informal and voluntary. These spring from the personal ties of kinship, friendship and neighbourhood.... Care in the community must increasingly mean care by the community."

Growing Older, 1981⁴

Since the 1950s there has been a gradual shift in the provision of care from hospitals to care in the community. A large proportion of community care is "informal," provided mainly by family. The general household surveys of 1985 and 1990 showed that there are as many as six million carers in Great Britain, providing varying degrees of care. The transition to the caring role is often slow, following the older person's physiological decline and gradual accumulation of diseases. However, some people are precipitated into caring for an older person—for example, when that person suffers a stroke.

Who cares?

Caring is an activity spanning all age groups. There is increasing concern over (and action for) young carers. The peak age for caring is the fifth to seventh decades, but many older people are carers. Over a third of informal care to people over 65 is provided by people over 70. One third

of older people can expect to become carers during retirement; they are more likely to provide intimate care and heavy nursing tasks and to care for a spouse.

Both men and women care, although men are considerably less likely to become carers. Once they have become carers, men and women have similar experiences of caring. If caring is defined as an activity that occupies 20 or more hours per week (to distinguish it from the provision of purely practical help), the prevalence of caring by men rises steadily throughout life, reaching 5-6% by their late 70s, whereas for women it peaks at 7% in their early 60s.

The prevalence of caring in ethnic minority communities is not known. It is likely to increase as the number of older people grows during the next decade. Caring spans all social classes, but those with more financial resources and greater skills as advocates for themselves and those they care for are likely to fare better. There is not usually much help to the main or primary carer from other family members or from "the community." Where care is shared, it is rarely shared equally.

There is a spectrum of caring from the heavily involved carers (often older carers and women, providing intensive help to spouses and parents or parents in law) to those carers who provide fewer hours of practical (not personal or physical) assistance to someone living in another household. Most carers of older people belong to the latter category, but about 75% of the total time devoted to informal care comes from carers living in the same household.

Types of care provided

Many carers who provide practical assistance rather than more intimate care are trying to combine their caring responsibilities with paid employment. Their caring work involves activities such as "keeping an eye on" the older person, companionship, shopping, transport, taking out for visits, help with paperwork and finances, and

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"Old cronies" by George Henry Boughton (1833-1905)

doing repairs and gardening. This group of carers is most unlikely to receive any statutory help.

In contrast, a minority of carers perform intimate personal tasks such as washing, dressing, toileting, and feeding and physical tasks such as lifting and transferring from bed to chair. Training, equipment, and professional advice are usually lacking.

Strains on carers

Older people who need personal and physical care may experience multiple disabilities and problems. In parallel with this, carers face physical, emotional, social, and financial problems. They are more likely than non-carers to have a longstanding illness or disability. The phenomenon of the emotional costs of caring is well documented. Surveys have found as many as half of those carers surveyed to have general health questionnaire scores in the morbid range (unpublished data). Sleep disturbance and difficult behaviour are the two problems independently associated with the greatest degree of strain on the carer. Incontinence, especially faecal incontinence, and many other factors are associated with emotional distress in carers. The stressful effects of sleep disturbance have not been recognised in any policy for substantial provision of night respite or night sitting services.

The social life of those carers providing intensive help is often restricted, partly due to the burden of extra time-consuming work and partly due to fear of leaving the dependent relative alone or with others. Many carers have not had a holiday for over five years. Particular problems are experienced by carers of people with mental illness, who may feel embarrassed to take the person they care for to a public place.

A Gallup survey of carers drawn from the general population in February 1996 showed that 45% received no help whatsoever with their caring role; 14% received help from social services and 34% from another relative.² Carers National Association's surveys of known carers in 1994 and 1995 showed that only a quarter had received an assessment in their own right and 60% did not know that they were able to seek their own assessment. Carers were less satisfied with the thoroughness and clarity of explanation of their own assessments than with the assessments of the person cared for. Only 32% of the former and 37% of the latter were confirmed in writing. Only about 40% of the carers considered that the assessment met their own needs.⁶

Finances

In general, carers have poor financial status. An advanced economics of caring has yet to be developed, because conventional economics has ignored all aspects of the informal sector. In 1993, the Institute of Actuaries estimated the value of unpaid care at £33.9 billion a year (compared to £7bn for all institutional care and £3.1bn for professional home care). Carers are often unaware of their entitlements, and the disabled older people for whom they care often are not receiving attendance allowance. Only 250 000 carers receive invalid care allowance. Age has important implications for people's economic resources, so older carers looking after elderly dependants are particularly disadvantaged. The February 1996 Gallup survey showed that, although 63% of those who are not currently carers would expect family or friends to look after them should they become ill or disabled, only 3% thought that their families should be responsible for funding this care. Sixty two per cent thought that the state should pay for the provision of such care and a further 28% that the costs should be shared evenly between family and state.²

There is a considerable opportunity cost engendered by the constraints on employment of those caring for older people. Many have difficulties in combining caring with traditional working patterns. In 1993 the Department of Health issued a booklet on employers and carers, emphasising the need for employers to make their management and personnel practices more carer friendly.³ A further financial problem is the extra expenditure on the older person, which may well exceed the attendance allowance—costs are incurred from extra heating, laundry, and buying in services. Also, the activity of caring itself is associated with an enormous opportunity cost in the time spent caring.

The Carers (Recognition and Services) Act 1995, originally introduced as a private member's bill, came into force on 1 April 1996. The act amends the National Health Service and Community Care Act 1990 in order to create a new duty on local authorities to assess the needs of individual carers (those providing a substantial amount of care on a regular basis) and to enable (but not oblige) the authority to provide appropriate services for carers. No new money has been provided to accompany the new duties. The bill also amends the law to embrace young carers and people caring for disabled children.

What do carers need from the doctor?

Carers need three things—recognition, information, and support—from their general practitioners and from the hospital doctors with whom they and the person they care for come in contact. Support includes respite—necessary breaks from caring.

Many carers do not recognise themselves as such. Many more are not recognised by the health professionals with whom they come into contact. They may be seen just as the "next of kin," and the considerable part they play in the care of the older person is simply not realised.

Carers appreciate acknowledgement of the role they are playing, even a simple listening ear: "How are things

"For too long, carers have been the unrecognised partners in our welfare system. Their services have been taken for granted. They have been regarded as a resource but not as people with their own needs. With the greater dependence to be placed by the Government upon care in the community it is time to bring the carers into the mainstream and give them the recognition they deserve. That recognition will inevitably cost money but it is long overdue."

House of Commons Social Services Committee, 1990⁵

Suggestions for action by medical practitioners

Action in primary care

- Carry out an audit of carer recognition and identification (a pack suitable for general practice is available free from Leeds Carers Health Project, Brunswick Court, Bridge Street, Leeds LS2 7RJ)
- Use a team approach in primary care (the North Yorkshire Health Authority's pack, "Working with Carers" (see information sources) is designed for just this purpose)
- Get a stock of Carers Emergency Cards from the Carers National Association (see below)
- Dedicate a noticeboard to carers' issues:
 - Include the contact phone number for local and national Carers National Association, Alzheimer's Disease Society, and local carers support groups
 - Put information about attendance allowance, invalid care allowance, and disability living allowance on the board
 - Put the address and phone number of the local carers' centre (if applicable)
 - Highlight both the regional and national carers' weeks
- Start a carers support group based at the practice

Action in both primary and secondary care—wards and clinics

- Ask patients about their hidden roles as carers or cared for. (Do not presume that weekly home care is the mainstay of a patient's "care in the community" nor that the daughter who accompanies her father to see the doctor is a concerned but otherwise inactive relative)
- Get a stock of information packs about local services that your social services department or Carers National Association have produced, and distribute these to the carers you identify—don't wait for them to ask
- Make a small library of the books mentioned here—to provide yourself with answers to the questions that carers raise over the management of such problems as difficult behaviour, repetition, wandering, aggression, and to lend to carers
- Make special arrangements for carers coming for an appointment about their own needs, if the older person cannot be left at home for long

going for you, Mrs Brown?" It is worth remembering that carers may not have the same general practitioner as the person for whom they are caring. Carers usually know the person they care for very well. When they sense the beginnings of a new clinical problem for the older person, they appreciate acknowledgement of their concerns and the chance to participate in decision making that does not override the views of the older person.

Carers appreciate honest and up to date information about the diagnosis and prognosis of the person they are looking after, even if the nature of the older person's diseases and disabilities means that the information is incomplete. The provision of such information is also part of the necessary process of working towards the eventual cessation of caring, brought about either by the death of the older person or by his or her entry into permanent residential or nursing care (or, more rarely, by recovery from illness). Giving such information is not intended to break the confidentiality of the doctor-patient relationship and should not ignore the wishes of the older person. Carers also benefit from information about dealing with the everyday physical, behavioural, and emotional problems of caring.

Just as importantly, carers (and the person cared for) need information about the statutory, voluntary, and private provision of services and about the financial benefits available. Doctors and other health professionals cannot be expected to know all the information that every carer needs. However, they should know where the boundaries of their knowledge lie and where to refer the carer for further information and help. Several measures that can be taken to inform carers are listed below.

ADVOCACY

Some doctors are frightened, unjustifiably, of opening the floodgates if they identify every carer of an

older person and refer her or him on to the statutory and voluntary sectors for services and for respite. However, carers can benefit from the advocacy of medical professionals in helping both them and the people they care for to gain access to much-needed services. This is particularly the case for the most disadvantaged carers, who are often elderly themselves: to hold back from referring disabled people and their carers may help to perpetuate the inverse care law.

Information sources

PRACTICAL INFORMATION FOR PROFESSIONALS

- *Working with carers—a resource pack for general practice* (published by North Yorkshire FHSA, 1994). This is a mine of information on what each member of the primary care team can do to support carers. Available from North Yorkshire Health Authority, 3rd Floor, Ryedale House, 60 Piccadilly, York YO1 1PE (tel 01904 631345); price £5.

- *Age Concern Fact Sheets*. This compilation of 34 information sheets covers an extensive range of practical problems of older people, such as attendance allowance, disability living allowance and housing benefit, help with incontinence, help with heating, sheltered housing for sale, holidays for older people, finding help at home, issues around nursing and residential homes, legal arrangements for managing financial affairs. It is continually updated. Available from Age Concern England, Astral House, 1268 London Road, London SW16 4ER (tel 0181 679 8000); initial subscription for a complete set costs £36.

- *Age Concern Information Circulars*. Monthly bulletins compiling news and information relevant to older people, their carers, and health and social service professionals. Information is grouped under headings such as community care, death and bereavement, disability, health and health services, housing, income, legal affairs, residential, nursing home and long term care, social security. Available from Age Concern England; annual subscription is £17.

INFORMATION FOR CARERS

- *The Carer's Companion* (written by Richard Corney; published by Winslow, 1994). Written by a clinical psychologist, this book gives excellent advice on dealing with the everyday emotional and practical problems of caring for people with depression, stroke, or dementia. There are comprehensive sections on sexual problems and shorter, helpful sections on toileting difficulties, insomnia, facing hurt and aggression, clinging, and wandering and forgetfulness. Available from Winslow Press, Telford Road, Bicester OX6 0TS; price £7.99.

- *Caring for Someone at Home* (written by Gail Elkington and Jill Harrison; published by Hodder and Stoughton, 1996). Chapters include deciding to care, respite, community care, benefits, financial matters and council tax, health rights, and practical caring difficulties. Available from the Carers National Association (address below); cost £5.99. This is sent free to carers when they join the Carers National Association.

- *Caring in a Crisis* is a series of seven handbooks published by Age Concern. The books cover caring for someone who has dementia, who has had a stroke, who is dying, who is going home from hospital, choices for the carer, what to do and who to turn to, and finding and paying for residential and nursing home care. Available from Age Concern's mail order unit (address above); each book costs £5.95 or £6.95; the complete set costs £39.95.

- *Pensioners and Carers* (written by Paul Brown, Anne Mountfield, and Alka Patel; published by the Directory of Social Change, London, 1995). This book, which is addressed to the older person rather than the carer,

includes comprehensive accounts of state benefits and grant making charities. Available from DSC Books, 24 Stephenson Way, London NW1 2DP (tel 0171 209 5151); price £15.95.

- *Caring at home* (written by Nancy Kohner for the Health Education Authority and the King's Fund, London; published by the National Extension College, 1992). Packed with comprehensive written and tabulated information on statutory and other services, financial and legal matters, time off and coping with day to day problems and feelings. Available from the publishers (tel 01223 358295); price £10.

- *Caring—How to Cope* (written by Janet Horwood; published by the Health Education Authority, 1994). Includes chapters on bereavement and stopping caring. Available from HEA Customer Services (tel 01235 465565); price £4.99.

- Help the Aged (St James's Walk, London EC1 0BE; tel 0171 253 0253) runs Seniorline, a free national information service for older people and their carers—telephone 0800 650065 (for hard of hearing callers - Minicom 0800 269626); open 10 am to 4 pm, Monday to Friday.

SPECIALISED INFORMATION

- *Keeping Fit while Caring* (written by Christine Darby; published by the Family Welfare Association, London, 1984). Available from the association (tel 0171 254 6251) or through public libraries. An account of how to lift, transfer, bathe, etc; details of equipment and keep fit exercises for carers, copiously illustrated with photographs.

- *Link on Lifting* is a two hour video showing techniques for lifting and moving disabled people at home. Available from HopeLine Videos, PO Box 515, London SW15 6LQ; price £19.95 plus £2 postage and packing.

- The Holiday Care Service (2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW; tel 01293 774535) is a charity which provides free information and advice for people with disabilities and their carers. It holds details of accommodation, transport, publications, guides, and sources of financial help for holidays in the United Kingdom and abroad.

- Age Link runs a freephone helpline for carers speaking South Asian languages, covering benefits, statutory and voluntary services—tel 0500 786000.

- The Alzheimer's Disease Society has produced audio tapes about dementia in Hindi, Polish, and Cantonese, with an English translation on every tape. An

Introduction to Dementia is available from the information section of the society (tel 0171 306 0606); price £3.95.

- *Caring for the Person with Dementia* (written by Chris Lay and Bob Woods; published by the Alzheimer's Disease Society, 3rd edition 1994) is packed with advice to carers about practical, emotional and financial problems. Available from the Alzheimer's Disease Society (tel 0171 306 0606); price £4 including postage and packing.

- *Safe as houses—living alone with dementia*. London: Alzheimer's Disease Society, 1994. A resource booklet and personal record card to aid risk management.

- *The 36-hour day* (written by N L Mace, P V Rabins, B A Castleton, C Cloke, and E McEwen; published by Hodder and Stoughton; 2nd edition 1996). A comprehensive account of the nature and practical management of the wide range of problems that carers of people with dementia may need to deal with. There are also chapters on caring for oneself and on residential care. Available from the publisher (tel 0171 873 6000), price £12.99.

- *Caring together—guidelines for carers' self-help and support groups* (written by Judy Wilson; published by the National Extension College, Cambridge, 1988). Practical advice on starting a group and making it work, including how to find other carers, organise meetings, produce newsletters and press releases, set up a telephone line, and deal with the problems that arise within groups. Now out of print but still available through public libraries.

- *Home Truths* (produced by BBC Radio 2's Social Action Team, 1995) is a booklet, aimed mainly at older people, about elder abuse and how to tackle it. Available for a large self addressed envelope with 31p stamp from Home Truths, PO Box 7, London W5 2GQ.

- The Elder Abuse Response Line, run by Action on Elder Abuse, takes calls from older people, carers, and professionals concerned about elder abuse. It is available on 0181 6799 7074 Monday and Friday 2 pm to 7 30 pm and Tuesday to Thursday 2 pm to 4 30 pm.

Organisations

- *Carers National Association* (20/25 Glasshouse Yard, London EC1A 4JS; tel 0171 490 8818; membership £3 a year) is the principal organisation for people who care for frail, disabled, or ill relatives and friends and for interested professionals. It produces a monthly magazine full of news and information on practical and political issues. It has developed an eight point Carers Code and has launched the campaign for "A Fair Deal for Carers." It has a training unit, running a range of courses for health and social service professionals and voluntary sector workers. In association with Boots the Chemists, the association has produced an eight page booklet entitled "Your guide to getting services," which is a step by step guide for individual carers to gaining an assessment under the community care legislation of the needs of both the carer and the older person. It has produced a "Carers Emergency Card" for carers to carry so that help will be forthcoming for the cared for person if the carer is suddenly taken ill or has an accident. The association operates an advice line, "Carers Line," between 1 pm and 4 pm Monday to Friday—tel 0171 490 8898.

- *Alzheimer's Disease Society* (Gordon House, 10 Greencoat Place, London SW1 1PH; tel 0171 306 0606; £8 minimum annual subscription) is the main organisation for carers of people with Alzheimer's disease or other dementias and interested professionals. It produces an excellent monthly newsletter that includes regular features on the latest dementia research, good practice in the statutory or voluntary sector, and practical accounts of caring.

Many carers provide practical assistance such as help with shopping or paperwork, transport—or companionship

It has produced a wide range of free information sheets and five freephone numbers for recorded information and advice, including legal and financial information (0800 318771/2/3/4/5). There is a wide network of active local branches, some of which provide services for people with dementia and their carers.

Further reading

Twigg J, Atkin K. *Carers perceived*. Buckingham: Open University Press, 1994. (Includes two fascinating accounts, one of the influences of feminism, kinship obligation, the New Right, and the disability lobby on the debate about carers, and the other on the role of general practitioners and consultant physicians.)

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Statistics Notes

Interaction 1: heterogeneity of effects

Douglas G Altman, John N S Matthews

This is the 24th in a series of occasional notes on medical statistics

In several types of study we may want to examine the consistency of an observed relation across two or more subgroups of the individuals studied. For example, in a clinical trial we might want to know if the observed treatment difference is the same for young and old patients or for different stages of disease at presentation. In an epidemiological study we might want to know whether the observed relation between an exposure and disease is different among smokers and non-smokers.

In such cases we are interested in examining whether one effect is modified by the value of another variable. This may be viewed as the examination of the heterogeneity of an observed effect, such as treatment benefit in a clinical trial, across subsets of individuals. The statistical term for heterogeneity of this type is interaction; the medical concept of synergy is the same thing.

While it may well be of interest to look for heterogeneity of effect, this is not always wise. In a controlled trial there are numerous subgroups which might be compared by splitting the patients according to sociodemographic or clinical categories at the start of the trial. In addition, for continuous variables such as age or blood pressure there are many ways of creating groups. Exploratory examination of many such subgroups is almost certain to throw up some spurious significant interactions, and in practice we cannot tell if a specific interaction is real or spurious. For example, in a randomised controlled trial comparing dexamethasone phosphate with placebo for preventing neonatal respiratory distress syndrome, the researchers found unexpectedly that the overall beneficial effect of the active treatment was present only in female infants.¹ Further studies would be needed to confirm the finding (or not). The refutation of such unexpected observations is common, and indeed in this case the finding was not replicated in further studies.²

Likewise, we can investigate the interaction between any pair of variables in a regression model. With 10 variables there are 45 such potential interactions and much scope for being misled. So, although we do not necessarily believe that all effects are truly independent, in many cases it is reasonable not to examine any possible interactions. For example, Pocock *et al* found a negative association between tooth lead concentrations and IQ (intelligence quotient) in children aged 6.³ Exploratory analysis revealed a strong association among boys and little association among girls. They

were rightly cautious in their interpretation as there had been no prior hypothesis about such an effect.

By contrast, when there is a specific prior suspicion of the existence of a particular interaction it is perfectly reasonable and desirable to examine it. A common example already mentioned is the interest in a possible difference of risk between smokers and non-smokers. For example, a study of Danish porcelain painters found that the adverse effects of cobalt exposure on lung function were more severe among non-smokers than smokers.⁴

Results of tests for interactions are likely to be convincing only if they were specified at the start of the study. In any study that presents subgroup analyses it is important to specify when and why the subgroups were chosen. Studies which present analyses without such justification can be difficult to interpret. For example, Penttinen found a significant excess of ischaemic heart disease in relation to back pain in farmers aged 30-49 and a non-significant difference in the opposite direction among those aged 50-66.⁵ He did not explain why this age division was made, nor did he note that there was no relation when the two age groups were considered together. Studies where subgroup definition has been guided by the data, for example concentrating on males born in October,⁶ should be based on statistical tests that account for any multiple comparisons that have been made⁷ and should be scientifically sensible; even then they should be treated with scepticism until confirmed in subsequent studies.

Problems of interpretation are exacerbated by incorrect analysis. We consider right and wrong ways to examine possible interactions in two subsequent statistics notes.

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