Review Article

HOME CARE OF THE ELDERLY INFIRM AND DISABLED

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J. Agate, Taking Care of Old People at Home, Unwin Paperbacks, London, 1979, £1.50, 159 pp. ISBN 0 04 970004 9.
T. Dartington, Family Care of Old People, Souvenir Press (E & A)
Ltd., London, 1980, £3.95, 159 pp. ISBN 0 285 64885 3.
J. A. Muir Gray and Heather McKenzie, Take Care of Your Elderly Relative, George Allen and Unwin, London, 1980, £5.95, 202 pp. ISBN 0 04 6180168.

These three books are all intended for those caring, or about to take up caring, for a dependent elderly relative or friend living in the community. John Agate has been a consultant in geriatric medicine for twenty-five years; his book is based on personal experience. Tim Dartington is writing from personal experience of a different sort; his experience was gained when working for a London voluntary organization and as a social scientist at the Tavistock Institute of Human Relations. Muir Gray works in Oxfordshire as a community doctor and writes from medical encounters with, and interest in, the elderly and their supporters. Heather McKenzie is the Administrative Director of the National Council for the Single Woman and Her Dependants and, therefore, writes from her acquaintance with the problems of the many single women who are caring for a dependent elderly relative.

How does one explain the simultaneous desire of three different sets of authors to write books on home care of the elderly, or the appearance of so many books on community care of the elderly in 1979-80? It's true that old age and ageing are hot topics, or perhaps I should say 'trendy' topics, at the moment, and publishers are scrambling to get books on the elderly into print. Agate even states that the idea for his book came from his publishers. The answer lies first of all in demographic change. The proportion of the over 65s has increased rather dramatically, although not as much as was once anticipated. In the nineteen fifties it was predicted that by 1971 21 per cent of the population in the UK would be over 65. In fact, in 1971 the elderly were only 16 per cent of the population. By

1991 the proportion over retirement age is expected to be 17.3 per cent.3

However, a more important change has been in the number of people over the age of 75 years. In 1976 there were approximately two million women and one million men over this age and it is predicted that by 1986 there will be 24 per cent more of them. The over 75s are the people who make the greatest use of health services. For example, the number of GP consultations per year is 5.8 compared to 3.9 consultations per year for the group aged 45–64. According to the 1978 OPCS survey, over half of all elderly people report that they have some disability, 4 per cent of those living at home were found to be permanently housebound or bedfast, with this figure rising to 20 per cent in the over 85s. If these disabled people are cared for at all, it is most likely to be by a family member. Thus, the increase in the numbers of old and very old, and their propensity for illness, means that more families than ever before must expect to have an unwell old person in their midst. The market for home care books is now bigger than it ever was in the past.

The last statement is, of course, based on the assumption that family members want to care. There is evidence that many do willingly take on the role of nurse in times of need, and it certainly is the case that the whole of the health and welfare service of Great Britain would break down if families did not take on care. Nowadays most policy makers think of the community services as supporting the supporters, rather than replacing family support.

The increased political emphasis on community care has also, contributed to the recent growth of home care books. It is not fashionable to regard institutions as the best solution for the infirm elderly. Advocates for elderly people argue that considerable effort should be devoted to maintaining the infirm elderly in a state of dignity and as much independence as is possible in the community. They also argued that community care is less expensive than institutional care. (This argument has however been shown to be of doubtful value. See, for example, Macintyre. 7) So, we are at a point in time where community care is thought to be the strategy of the future. Presumably supporters now need books to help them to participate in the community care movement. Recent cuts in government spending, and continuing commitment to institutional care, make it highly unlikely that there will be any appreciable expansion of community services. It is, therefore, understandable that books on the care of the handicapped elderly at home have emerged now because community services will not be developed and families will have to do the caring.

A second question about this new outcrop of literature is worth asking. Why cover all, or nearly all, illness and handicap in one book? Surely this must mean that up to three quarters of any given book would be useless

to a care giver? Not so. The elderly who are handicapped tend to have multiple handicaps. Williamson et al., for example, reported in a study of disability among the elderly in Edinburgh that men had an average of 3.26 disabilities and women had 3.42 disabilities. Thus, if one takes on the care of an elderly person with heart disease, there is a good chance that he or she may, for instance, also have a foot disability and a urinary tract problem. Furthermore, illness in the elderly is less often an episode – many elderly recover from one illness to become disabled by another. Supporters can, therefore, expect to get lots of experience in general nursing!

In what other ways are these books useful? As enoted earlier, they are all aimed at care givers. My first comment, therefore, is that Family Care of Old People reads as a book about families, rather than a book written for families. Of course, to be fair to Dartington he does state, 'This book contains no checklist of practical advice...The approach here is to examine problems of help' (p. 14). He also says, 'This book explores possible ways of thinking about the care of old people' (my emphasis).

I have emphasized 'care' in the last paragraph because Dartington appears to be using the term in a much wider sense than one is led to expect. Instead of meaning physical care during illness, Dartington seems to be more concerned with how the elderly are treated in society generally. Hence, there is a discussion on the effects of retirement on psychological well-being, family dynamics, isolation, material changes and general public attitudes to the elderly. Great emphasis is placed on the 'rights' of old people, and their need to remain independent and in the community. One is given the impression when reading Family Care of Old People that all those who deal with the elderly are out to take away these rights, and that nearly everyone in the world but Dartington has negative attitudes to them. Of course, taking the side of the old person is not necessarily a bad thing. Agate states that he does so in Taking Care of Old People at Home, but somehow this notion comes across differently. He seems more willing to acknowledge that supporters have rights too, and that negative attitudes and behaviour are often unconscious.

Leaving aside the tone of Dartington's book, there are positive aspects of Family Care of Old People. In chapter 5, 'Getting Help at Home' (a chapter which does contain practical information), Dartington stresses that care givers should get help in time, preferably before a crisis develops, and that supporters should locate an 'advocate' who will help the supporter find help. The author points out, correctly, that the welfare services cannot be completely fair to everyone, and that there is nearly always conflict between those managing resources and those wanting help.

Perhaps the most interesting chapter of Dartington's book is chapter 6, 'Alternative Care'. Acknowledging that supporters frequently have to

discontinue care (noting in fact that families often ask for help when what they really want is relief from having to cope); he discusses the role of the GP as 'negotiator', and different perspectives and priorities of those involved in hospitals and old people's homes. This chapter provides real insight into the reasons for GPs and residential staff behaving as they do and may prompt the supporter to examine his or her own expectations of alternative care. Although much of this chapter is about supporters, supporters reading Family Care of Old People would find this section of the book useful.

Take Care of Your Elderly Relative and Taking Care of Old People at Home are both very 'useful' books, that is they are full of very practical advice as well as some emotional support for supporters of the elderly infirm. In lots of ways, Take Care of Your Elderly Relative is just a more comprehensive and detailed version of Taking Care of Old People at Home. On the practical side both give information on aids available for helping or nursing the disabled elderly; Gray and Mackenzie's book provides names and addresses in the text of organizations which can loan equipment or provide advice on the use of aids. It is also more comprehensive in that it contains chapters on legal questions and financial and housing matters. The chapters on legal procedures was, however, pretty heavygoing, so one might question its value to most care agents. Both books give good explanations of the common illnesses and disabilities in old age; Gray and McKenzie have a commendable section on strokes in which they explain not only what happens during a stroke, but the meaning of some of the medical terminology. This latter piece of information could be valuable when dealing with doctors and other health care professionals.

Although Dartington gives the reader some insight into the motives and behaviour of professional helpers, Gray and McKenzie give some excellent advice on how to go about getting that help. What is even more important, they tell the reader what to do when help is not forthcoming or when the service provided is unsatisfactory. For example, the supporter is advised not to write to his or her MP to complain until personnel lower down the ladder are contacted, say, the chief officer of a local authority department. Furthermore, Gray and McKenzie advise 'Don't give up... the time it takes to obtain help is often frustratingly long, but it is usually given to those who persevere' (p. 3). Agate doesn't really acknowledge that supporters may find great difficulty in getting help from professionals. Gray and McKenzie are, however, rather guilty of implying that the availability of help is endless, even though they do state at the outset (page 2) that 'Services may be in short supply or non-existent'.

Because services are so often in short supply or non-existent, supporters should know what services are available *before* they take on the role of

care-giver. Or, if they take on the role of nurse or care-giver they should carefully consider and regularly review their commitment to care, particularly the care of the chronically ill. Gray and McKenzie, to their credit, place great stress on the need for the supporter to maintain emotional independence, preserve the quality of his or her life, and get regular restbreaks and holidays.

Concern with the rights of supporters brings me on to my own particular interest in these three books. Earlier on I stated that because the elderly live longer and have multiple illnesses, books concerned with the range of illness, disability, etc. are now more important than they may have been in the past. However, my own research with the supporters of the dementing elderly has led me to the conclusion that caring for the confused elderly is very different from caring for someone with a chronic, but mainly physical disorder. I was, therefore, particularly interested in what each of these authors had to say about mental disorders.

Grav and McKenzie title their chapter about mental illness 'Mental Health in Old Age'. The section on 'causes' of mental disorders in old age is very good. Supporters often suffer needless anxiety because they do not know to what to attribute confusion or disordered behaviour; Gray and McKenzie handle this aspect of the topic well. For some reason a description of some of the symptoms of senile dementia is discussed under a section called 'Coping on your own'. The symptoms listed are explained clearly, but there is one glaring omision - the loss or lowering of inhibitions. My own experience with the supporters of the elderly with senile dementia indicates that it is the lowering of inhibitions which can be most distressing. One other curiosity emerges in Gray and McKenzie's account of mental illness in old age and that is the distinction, never fully explained, between 'brain' and 'mind'.

Agate titles his chapter on mental disorder in old age 'Problems of Mental Unreliability'. This is an excellent exposition – simple and clear, especially on senile dementia. I was particularly attracted by a paragraph at the end of this chapter in which the author questions the value of community care for the mentally disordered elderly. The burden and stress on the family of such a disorder may not justify community care.

There is a strong suggestion in Dartington's chapter 'Who's Confused?' that most, if not all, confusion and disordered behaviour in the elderly is somehow 'rational' behaviour. Old people are portrayed as becoming mentally ill because of feelings of loss and purposelessness which are a logical or natural consequence of the way old people are treated in our society. It can be argued that disorders such as depression have social causes, but few people accept that senile dementia has its roots in social factors. The section on senile dementia is altogether too short and the

symptoms poorly described, even though the author acknowledges that estimates of the prevalence of senile dementia run to 20 per cent of the over 80s.

If I was supporting a dementing old person Dartington's book would be of little comfort or utility, whereas Take Care of Your Elderly Relative and Taking Care of Old People do a good job covering the mental disorders of old age. Gray and McKenzie's book, is, again, more comprehensive with regard to this topic than Agate's book, but then – and this can be taken as a general comment – the book is also nearly four times the cost.

In summary, the similarities between the three books are greater than the differences. All examine and explain attitudes to old age, physical disabilities and illness, aids for nursing, mental disorders, services, both statutory and voluntary, and, finally, bereavement. Unfortunately, neither Agate nor Dartington have included an index which can make it difficult to find information after reading their books.

The final point which I wish to raise concerns the audience. Of the three books, Taking Care of Old People is most likely to be comprehensible to the less well educated supporter. As noted earlier, Take Care of Your Elderly Relative has a few rather high-powered chapters, one on legal questions in particular. Dartington's book, Family Care of Old People, is easy to read (and has some lovely drawings by Alison Chitty), although I did find that the author frequently veered away from the problem under consideration, thus introducing numerous irrelevancies. And, as stated before, the book is more about families than for families.

All three books should be read by professionals and volunteers concerned with the elderly. I do not personally agree with many of Dartington's views – especially his views on the dangers of labelling – there can sometimes be even worse dangers in not labelling – but the book is at least thought-provoking. All three books would also be most useful for anyone starting new research in gerontology – I wish they had been available when I entered the field.

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NOTES

¹ Titmuss, R. M., Essays on 'the Welfare State', London, Allen and Unwin, 1958.

² Bosanquet, N., A Future for Old Age, London, Temple Smith/New Society, 1978.

³ Central Statistical Office, Social Trends, London, HMSO, 1976.

⁴ Department of Health and Social Security, Welsh Office, A Happier Old Age:

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- A Discussion Document on Elderly People in our Society, London, HMSO, 1978. 5 Office of Population Census and Surveys, The General Household Survey 1973, London, HMSO, 1976.
- 6 Department of Health and Social Security, op. cit.
- 7 Macintyre, S., Old Age as a Social Problem: Historical Notes on the English Experience, in Dingwall, R., Heath, C., Reid, M. and Stacey, M. (eds) *Health Care and Health Knowledge*, London, Croom Helm, 1977, 41-63.
- 8 Williamson, J., Stoke, I. H., Gray, S., Fisher, M., Smith, A., McGree, A. and Stephenson, E., Old People at Home: Their Unreported Needs, *The Lancet*, 1974, 1116–20.