

ROUTLEDGE REVIVALS

Forgotten People:

Positive Approaches to Dementia Care

Jonathan Parker

Bridget Penhale



**FORGOTTEN PEOPLE:
POSITIVE APPROACHES TO DEMENTIA CARE**

For our families, colleagues and friends

Forgotten People: Positive Approaches to Dementia Care

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Introduction

There is a surge of interest in dementia care from an academic and practice-focused point of view. There is a growing, almost palpable, anxiety throughout Europe about the millennium and social and economic needs resulting from an ageing population. There are fears for care and support from official bodies and social services, from the family and from private resources. Uncertainties abound, and much is discussed.

Not all is bleak, and there is also a great deal of optimism and excitement about the possibilities for future care practice in the social and health domains. Whilst both the authors are employed as academics, we have also practised social work for people with dementia and their caregivers. We have worked with the pain and the joy such experiences can bring. The aim of this book is to promote social work practice that sees the person first and starts from a clear value base of respect. We have drawn on some of our many experiences and provide illustrations of the positive work that can be done with people to promote a sense of well-being and, as far as possible, partnership.

In this present climate it may be argued that a book which outlines a range of theoretical approaches is outdated and what we need now is a procedural and more bureaucratic approach to social work practice. It might be said that this fits much more comfortably with care management and the newly 'down-sized' social services departments which increasingly adopt a purer commissioning role. If this was all social work was about, we might agree. However, social work is about finding that fit between personal, familial and social need and the demands and responsibilities society places on its citizens. Social workers negotiate a tense tightrope between individual and society. They are concerned with citizenship and the reciprocal flow of responsibilities and rights. In order to achieve this difficult task, practitioners need not only clear and effective procedures but tools and

models that can illuminate paths to tread with people through demanding times. The models, approaches and 'tools' we discuss provide just such an array. Like any toolkit, of course, they need to be employed appropriately, used for the right job and in a way that is skilled, safe and constructive. Social workers must operate from a clear value base which emphasises the dignity and personhood of individuals. The way an approach is used needs to be judged against this.

The book is divided into two parts. In Part I the context and background to dementia care is introduced, setting the scene for the presentation of a range of methods and approaches for practice in Part II. The methods are separated into three broad themes: action-focused and behavioural approaches, talking and counselling approaches, and more politically oriented methods. Of course, these often overlap – the separation we impose is for illustrative purposes and in no way implies that validating the worth and humanity of a person with dementia does not constitute a vital part of a task-centred approach to practice, for example.

In writing this book, we seek to champion the rights and responsibilities of people with dementia and the social work practitioners who work alongside them, and to add a small part to the important growing movement towards effective, competent practice that is underpinned by values which respect personhood and promote a person's choices in life. The debate concerning the use of models and approaches in social work rages on. It is clear that some practitioners still do not consciously and judiciously use the tools in their toolkit but rely on an intuitive 'feel' for the situation. Whilst this may be right in some circumstances, it is not underpinned by evidence – and if it is not systematic, it is hardly accountable practice. An explicit use of the models and approaches of value to social work will assist in making practice open to scrutiny and more of a genuine partnership. When working for people with dementia, the need to be accountable is strong. They may not be able to challenge practice for themselves.

The following case study provides an illustration of some of the reasons why we wrote this book.

CASE STUDY: JANET AND MARK

Janet and Mark Palphramand lived on the seventh floor of a large tower block just to the west of the city centre. They had lived there since it was built in 1969, and felt strongly that it was their home. They had been offered alternative accommodation in sheltered housing. It was believed that this would help Janet look after Mark since a recent stroke which had affected his mobility and speech. He also suffered from dementia, and had done so for a number of years.

When visiting, the social worker was asked: 'You're not from social services are you? The last one they sent seemed to sit there and listen but do the opposite to what we'd asked. All we want is help to get over this bad patch. But I want to know you *know* what you're doing.'

There are so many people to thank in connection with the writing of this book. To name them all would be impossible. Perhaps our greatest thanks should go to those people with whom we have worked over the years. They have inspired, saddened and yet heartened us. They are the people who make positive approaches to dementia care possible.



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Part I

The context for practice

The first part of this book sets the scene for contemporary social work in dementia care. Social work has gone through many changes in recent years. Some of these have been legislative, such as the implementation of the National Health Service and Community Care Act 1990 and the Carers (Recognition and Services) Act 1995. These changes have influenced policy and procedure in local authority social services departments throughout England and Wales, and similar upheavals have occurred in Scotland. Local government reorganisation has affected the delivery of social services and has consequences for the setting of priorities. All these higher-level changes influence the way social workers practise.

At the level of training, the introduction and revision of the Diploma in Social Work and the corresponding emphasis on competence for practice have again had a tremendous impact on what social workers learn, and consequently what they do in practice. The debate concerning professional education and training continues and is important to the pursuit of good ethical practice. However, in Part I we will introduce changes in the way dementia is approached and understood. Although the medical model remains predominant in the minds of many practitioners, care staff and for the general public, new approaches are gaining ground which encourage optimism regarding the quality of care and well-being that can be achieved for people with dementia and their carers. Chapter 1 will detail both traditional and developing models of dementia to set the stage for understanding. In the next two chapters this will be put into the context of policy and procedural change and developments in training for social work.



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1 What is dementia, and why are social workers involved?

Introduction

In the latter decades of the twentieth century there has been a tremendous shift in our understanding of social and health issues, and there have been corresponding developments with respect to dementia and ageing. We no longer automatically associate ageing with dementia, although increasing public knowledge of the condition has led to fears, concerns and beliefs that lead to further problems. Demographic and social changes have raised questions of care, family and individual responsibility which, in their turn, have created political and social debate about systems of welfare. Whilst research indicates clearly that family care and responsibility is as strong as earlier in the century (Parker, 1990; Twigg et al., 1990; Finch, 1989), the context of care and the impact it has upon individuals is well recognised and fuels the welfare debate.

This chapter will provide an overview of the context in which work with people with dementia and their families is carried out. The impact of dementia on those involved will be examined. Following on from this, we shall briefly introduce some of the models proposed for understanding dementia, and suggest that an integrated model proves the most useful for social work practice. Finally, we turn to a brief consideration of the caregiving role and the location of social work practice within the context described. This will form a link to Chapter 2, which deals with the development of community care and care management and the context of dementia.

Overview and impact of dementia

Improvements in health and welfare provision throughout the twentieth century, but particularly in the post-war era, have meant that the number of older people surviving into late old age has increased steadily. Life expectancy for men and women has also increased, although women can still expect to live longer than men by an average of some seven years and more women than men survive into old age (Arber and Ginn, 1991). This has been accompanied by an apparent increase in vulnerability: the incidence of disability also increases with age. This is not to say that all older people are frail and vulnerable, or that all older people will suffer from one or more disabilities, but that the likelihood increases with age.

The incidence of dementia also increases as people become older and live longer (see Marshall, 1996). Whilst the incidence of dementia is around 5 per cent at age 60, 20 per cent of who are aged 80 and over can expect to develop dementia (Jorm, 1987). Whilst this figure and the increased likelihood of developing the illness with age is of concern to many, it needs to be kept in perspective: 80 per cent of those aged 80 or over *do not* develop dementia.

In conjunction with this, figures are available concerning the provision of residential care for older people: this is fairly consistently acknowledged as being at around 5 per cent for those who survive into 'old old age' (over 80 years) (Allen et al., 1992). Therefore, 95 per cent of very elderly people do not live in or enter residential care and do not end their days 'in care'. The majority of older people remain living in the community, mostly in their own homes, being cared for, if necessary, by relatives and members of the family.

Increased geographical mobility and demographic changes (more divorces, more women in the workforce, more lone-parent families) have altered the profile in recent decades somewhat so that more informal networks of care may be less evident than previously. However, the majority of older people neither develop dementia nor require care provided by the state.

Within this overall context, it is also necessary to be aware that social and healthcare practitioners do not work with the majority of individuals, and that we work with individuals and situations that are or have become problematic for one reason or another. It is precisely the fact that we are principally involved with people for whom life has become difficult, if not impossible, that can lead to the development of some regrettable attitudes and notions concerning older people among care professionals. Institutionalised ageism is alive and well in health and social care organisations (Jack, 1992) and needs to be recognised and addressed by all those concerned.

For those individuals who do develop dementia and do require assistance and support from us, we need to remain sensitive to their needs and

able to respond to them as individuals. Whether it is the person with dementia, their family or their wider network which is in need of assistance, this should be provided in ways which are consistent with principles of empowerment and anti-oppressive practice. These should maximise opportunities for the person with dementia to be as self-determining and as independent for as long as possible, and decision-making capabilities should always be promoted for the individual concerned.

This can be a delicate and complicated area with caregivers and other family members who may assume natural rights to take decisions on behalf of impaired individuals; it will undoubtedly require skill and great sensitivity on the part of the practitioner in order to handle such situations effectively. Remembering the uniqueness of each individual's circumstances and situation, and working to empower and enable (rather than to protect) are useful and necessary tools in this type of work.

Nevertheless, the potential impact of dementia on individuals and their families should not be underestimated. Dementia is a progressive and terminal illness from which people do not, at present, recover. Its effects are irreversible (although they may be slowed down) and devastating. The impact in terms of workload and costs to health and social care organisations is significant, partly because of the numbers of individuals who are affected (although a relatively small proportion of the total older population, it is still a large number). The impact in terms of the effect on individuals and their families is, in our view, potentially of greater magnitude and includes such possible reactions as anticipatory grief and sorrow at the situation and the perceived loss of the individual as the condition progresses.

It is not possible to understand fully what a person with dementia experiences, although some valuable work in exploring this area has been taking place (Kitwood, 1990; Gilliard, 1997). However, as care practitioners we can listen, empathise and respond to individuals, whether they are the person with dementia or the caregiver. We can also draw on our own personal experiences in this area, where appropriate, although we must remain wary of over-identifying with individuals and their situations, and must remain separate and objective enough to really assist people. It is also crucial to retain a clear sense of who the person we are working with is at any point in time, what we are working to achieve, and what the impact of the illness is on a particular system and network of individuals. What we must also bear in mind is that this is likely to change over time, and we must always remain alert to this probability and to the nature of the potential impacts of dementia in our dealings with individuals.

Understanding dementia: The models

At first glance dementia may seem easy to understand and define, but there are many ways to approach it. The medical model is most widely accepted and understood, and considers dementia in terms of disease and illness or something being wrong in part of the body – in this case the brain. But to ignore other ways of considering the condition, concept or label is dangerous because it does not allow for an approach which acknowledges the uniqueness and worth of the individual, and this is what is important in the delivery of social work and social care.

This section will outline a range of sociological and psychological approaches to dementia that provide alternatives to the accepted models developed within medical settings. We will suggest that no single approach can explain dementia satisfactorily. Rather, an understanding which integrates medical, sociological and psychological thinking is best when seeking to offer help and support to people with dementia and their families. The following topics will be covered:

- *the medical model* – definitions, characteristics, clinical features and diseases causing dementia
- *sociological approaches* – structuralist, interactionist and ethnomethodological approaches
- *a psychosocial model*.

Activity 1.1

Before reading the rest of this section, note down your understanding of dementia. How do you define it? Can you pinpoint where your understanding comes from and how it developed? Keep these notes, as it will be useful to return to them throughout this chapter.

The medical model

Advances in public health medicine, vaccination, antibiotics and drug treatments, and the development of a strong organisational and professional base have ensured that the medical profession has established and maintained a high profile and a great deal of respect in the public mind in the Western world (Turner, 1987). We place our trust in doctors when threatened or incapacitated by disease, and it is a 'cure' we seek or expect when

suffering from a condition described, diagnosed and dealt with by them. This model reflects a linear process mediated by a medical practitioner, as shown in Figure 1.1.

Illness → Medical practitioner → Cure

Figure 1.1 The linear process of the medical model

Mental and physical health are often described as branches of the same tree, and approached with similar methods and skills. They are differentiated only by their specific knowledge bases. It is not surprising, therefore, that most people regard dementia as a clearly recognisable and describable medical condition. Whilst there are some problems with accepting this at face value – pathology differs from sufferer to sufferer and clinical presentation is unique to each individual – it is important to understand how the medical profession approaches dementia in general. Social work practitioners operate with a wide range of disciplines and professions. In order to execute their duties successfully it is important to be conversant with the approaches and models employed by others. However, the medical model leads to optimism about ‘curing’ or at least retarding progress, as seen in Figure 1.2. Although medical advances continue, this view is not borne out in practice, and may create false hopes. At first this may be necessary while people adjust to the implications of the diagnosis, but the search for a cure may detract from the search for quality of care in the longer term.

Dementia → Illness → Medical practitioner → Cure

Figure 1.2 The misplaced hope of the ‘pure’ medical model

Definitions

The Royal College of Physicians (1981) was concerned that all older people were being characterised by memory impairment, incapacity and loss of control. To counteract these misunderstandings it produced a report describing a variety of syndromes and the causes, or *aetiology*, of organic mental impairment in older people. The following operational definition of dementia resulted:

Dementia is the global impairment of higher cortical functions including memory, the capacity to solve the problems of day-to-day living, the performance of learned perceptuo-motor skills, the correct use of social skills and control of emotional reactions, in the absence of gross clouding of consciousness. The condition is often irreversible and progressive. (Royal College of Physicians, 1981, p. 146)

This kind of definition is generally accepted in medical circles (Gelder et al., 1989; Lishman, 1987). Dementia represents a deterioration of previously normal functioning as a result of underlying brain damage or disease. The definition is tightly packed and needs some explaining. Firstly, dementia affects all the person's thinking and problem-solving abilities: it is global. The impairment results in a progressive deterioration of all learned skills important for daily living, interacting and communicating with others and functioning as an individual.

This approach firmly places dementia within the province of the medical profession. Correct diagnosis of the disease is essential in deciding possible treatments, especially for reversible conditions and acute confusional states (Wilcock, 1990). It is important in making a prognosis and seeking appropriate medical care. Thus some argue for a precise definition describing a progressive condition associated with detectable neuronal or other structural brain pathology (Levy and Post, 1982). If it is progressive and cannot be halted, however, the hope associated with the medical model cannot be justified. Such a discrete approach is not held by most medical practitioners.

The psychiatrist Elaine Murphy (1986) adds to this debate her observation that an understanding of the uniqueness of each individual sufferer is important. She states that symptoms vary from person to person. This depends on a number of factors, including the site and progress of the disease in the brain and how the individual reacts to and copes with the situation. So the medical model does not preclude a consideration of individuals, their personalities and unique wants and needs. It is important to bear this in mind so that we do not ignore the importance and value of the medical model.

The importance of accurate diagnosis and definition of dementia is seen in *epidemiology*, the study of incidence and prevalence of disease in specified areas, especially in planning public and policy responses to deal with disease.

In 1986 Henderson undertook a wide survey concerning the epidemiology of Alzheimer's disease, to consider risk factors, add to the clinical picture, to provide information for policymakers, and to construct instruments for the study of dementia. Prevalence was difficult to determine because of differences in the age of the study sample, variations in living status, regional differences, lack of differentiation between diagnostic types, and also a lack of standardised diagnostic criteria.

In a review article, Kay (1991) reports a prevalence rate of 1–8 per cent among the population aged 65 years and over. Prevalence rises with age. Incidence studies require assessment at two distinct points in time, and relatively few have been carried out. In the studies that are available, the rate appears to treble for each additional ten years of age over 65 years.

Such studies are rare and difficult to assess, for the same reasons mentioned in relation to prevalence rates. In order for doctors to establish accurate prevalence and incidence figures, and for them to be any use, it is essential that they know what they are looking for.

Activity

Return to your original thoughts concerning dementia. In the light of the definitions provided by the medical model, can you say how these have influenced your understanding? What feelings are aroused by considering dementia as a disease – something being wrong or not working correctly in the person's brain? Does this have any implications for your approach to your work with people suffering from dementia?

Comments

Perhaps you have thought about how you respond when you first learn a person has dementia and to the thought that nothing can prevent deterioration. It may be that this view has affected our practices by steering us away from seeking quality care and relationships which value the individual and demonstrate respect. It may therefore be valuable to seek ways to identify these thoughts and prevent them determining a course of action stemming from the belief that 'nothing can be done'.

An understanding of dementia as a disease or organic impairment is useful to give an insight into the way medical practitioners approach the condition and to understand some of the processes involved, but it adds little to our knowledge for practice. When we come to consider characteristics and clinical features, we are able to see the impact of this underlying pathology and to make connections that may enhance our approach to people and the interventions and services we provide. The importance of interdisciplinary communication cannot be stressed enough.

Characteristics and clinical features

The clinical picture generally described is an impoverishment of memory, both short-term and long-term – including encoding information, storage, retrieval and recollection (Jorm, 1987). A change may be evident in person-

ality and mood. Hallucinations and delusions may also occur. The picture is, to a large extent, determined by the personality of the individual before the onset of the dementia (see Figure 1.3).

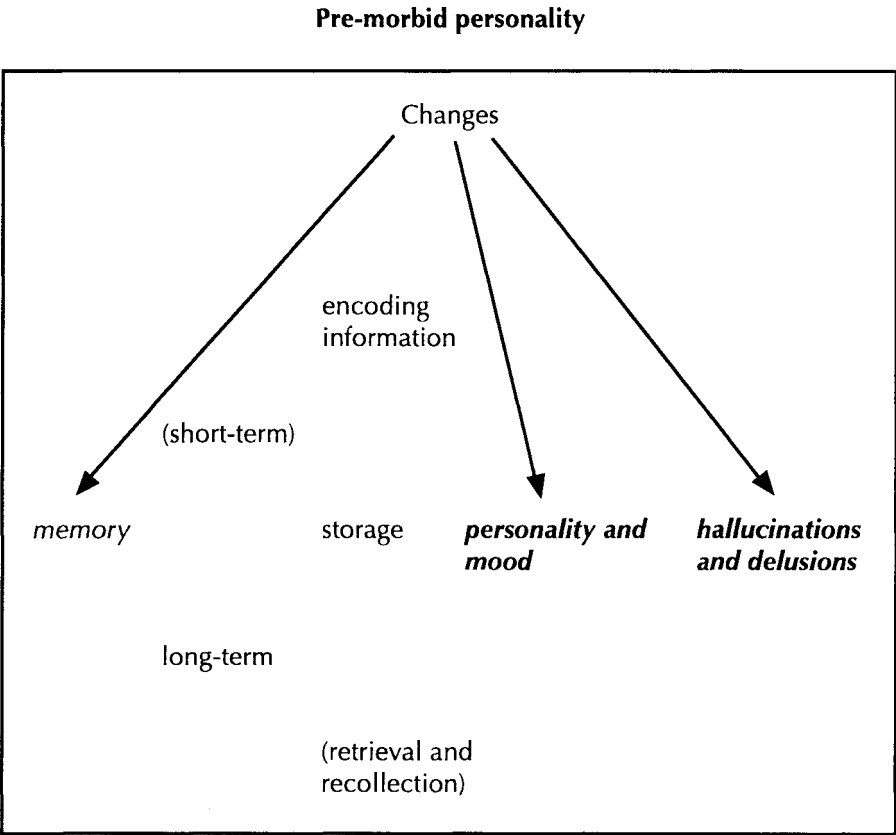


Figure 1.3 Clinical features of dementia

The primary medical descriptions are contained in Lishman (1987) and Gelder et al. (1989). The main points are summarised in Box 1.1.

Box 1.1 Clinical description of dementia

- **Behaviour** becomes disorganised and often inappropriate
- **Thinking** is slowed and impoverished
- **Speech** quality is lost, and meaningless noises are common
- **Mood** in the early stages is often characterised by anxiety and depression, and may change quickly or be blunted in the latter stages
- **Cognitive functioning** is impaired, new learning is difficult, and insight is usually lacking as to the degree and nature of the disorder.

A clear and simple description of the changes occurring in dementia is provided by Lodge (1988) (see Box 1.2).

Box 1.2 The main changes associated with dementia

- **Memory:** Assimilation of information and its retention is difficult, short-term memory is affected, and recent events are often quickly forgotten
- **Orientation:** The sense of time, place, and often the person, is disrupted
- **Grasp:** Making sense of what is happening, judgment and problem-solving is impaired
- **Communication:** Speech deteriorates
- **Personality:** Exaggerated or muted reactions may be noted
- **Behaviour:** Incontinence, wandering, noisiness, aggression may occur
- **Monitoring:** Self-monitoring is neglected
- **Reactions to disease:** These are specific to the individual; mood changes may be noted
- **State:** Whether it is reversible or not
- **Neurology:** Focal damage can cause additional problems.

The characteristics described in Box 1.2 are general, and each individual displays different sets and with different emphases. This depends on the