Fundamental Aspects of Caring for the Person with Dementia

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Note

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The author and publishers have, as far as is possible, taken care to confirm that the information complies with the latest standards of practice and legislation.

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Kirsty Beart

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PART 1

Theoretical information and debates, explanation, and policies of care

CHAPTER 1

Imagine...

If you can, try to imagine the life you have now changing beyond all recognition. One day you wake up and don't know where you are. You ask someone near you where you are but they seem unable to understand your question. Why do they not understand – what is wrong with them? It is hard to contemplate this and fully comprehend the emotional turmoil caused by the symptoms of a dementia-type illness.

It is important to use this book as a resource for helping individuals live with dementia. This approach is in contrast to the traditional view that the devastation of this disease is all that is left of us, or the people we care for and love. It is assumed that when a person is diagnosed with dementia that their life is just one long problem and that their personality, intellect and relationship involvement will diminish unrecognisably and that we lose the ability to learn. This idea of ageing is a negative one and does little to help us live with dementia, never mind die with it! Many authors and theorists have continued to consider old age as a time in our lives when it is normal to become incapacitated. Dementia and old age have become synonymous and are inextricably linked within our modern culture. Despite this, depression is a mental illness which is much more common (Pilgrim and Rogers, 1999). Only around 2–5% of the population aged over 65 develop a dementia-type illness. Perhaps the statistics we need to look at are the links between dementia and depression. Within this group of 2–5%, there is a large increase in the numbers of people suffering from depression and anxiety. We have to ask why this might be and if there are possible triggers:

- Could be already depressed due to isolation, which is a common phenomenon for older people
- Under-stimulation, for different reasons, can induce apathy
- Feelings of a loss of control or personal autonomy can be common and linked with elder suicide
- Increased vulnerability due to physical illness and consequent depression
- Inevitable loss of spouse, roles etc.
- Ability to maintain successful relationships when younger seems to indicate less risk of becoming depressed in old age
- Effect of abuse in old age

If we accept that all these real-life issues exist for older people then we have to realise the need to try to assist them in dealing with them. This is, however, only part of the picture. The problem with dementia is that it does not only affect the old. Young people also can develop different types of dementia, including more specific ones such as Creutzfeldt–Jakob Disease, AIDS-related, Down's syndrome-related, pathology or tumours. The needs of younger people with these problems are different in many ways, but in the attitude we take to their prognosis we should consider similarities. The problem comes not just from ageist attitudes, but also from the disease approach discussed next. The need to see these people as being in need of support to cope, rather than requiring full nursing care to die, is of paramount importance in influencing how we deal with them.

Dementia is seen by society as an illness which requires medical care and support, and naturally the emphasis of care is expected to, and usually does, come from the NHS and social services. Despite this, many people still struggle with the problems on their own because of a lack of appropriate services, little awareness of support, and/or an unskilled workforce providing it. The brain disease model of the 1990s (Sayce, 2000) argues that mental illness should be seen as an illness and not as a consequence of poor morals, as it has been in the past. Despite the best intentions of this perspective to allow people with mental health problems social freedom, the down side is that the expectation associated with treatments and cures has been added on to mental illness. If a person is suffering from an illness we expect them to be at least treated, if not cured. When this idea is used with dementia the picture becomes very bleak, and the fact that there is no cure ensures an attitude of acceptance and pity. To consider the person as having gone, or being one of the 'living dead', means the loss of them as a person. However, those who are living with dementia are actually still here and able to communicate with the rest of us in some way, even if it is through smiling, crying, repeating words or pacing up and down the living room.

The social disability model argues that people with some kind of disability are not disabled by the impairment, but by the society within which they try to function. Seeing illness such as dementia as a disability within this framework can allow us to consider the plight in a different way. The person with dementia can be seen as a person and not as a disease without any hope of cure. The person's individuality can be maintained by accepting that everyone needs emotional attachment, even those who cannot clearly communicate that need. Naomi Feil (1993) introduced validation therapy, which led us into a pattern of thinking about the individual's thoughts and feelings as relevant in any situation. The carer has to learn how to interpret what the seemingly unrecognisable comments or behaviours actually mean. Kitwood (1997) discussed dementia as much more than just a medical disease. He believed that although there is a disease element to dementia it is not the only aspect, and it should never be considered in isolation. To do this would mean the loss of the ability to recognise anything other than disease, despair and loss. Kitwood argued that the ability to look at the behaviours of the individual as meaningful and to consider the effect that we, as carers, have on that behaviour allows us to communicate more effectively on the level which is needed to provide feelings of security and comfort to those we look after.

Despite this very positive slant on dementia we are still faced with the devastation that it leaves in its wake: the loss of the individual's known personality and the unpredictable nature of a new one; the feelings of frustration at not being able to remember; the feelings of fear and anxiety at the prospect of being unable to function independently; the feelings of apprehension and inadequacy as a carer in being able to cope; the frustration of being unable to provide the appropriate resource as a professional; and the inevitable anger, terror and sheer disappointment in your life's path! All of these experiences and feelings are the effects of dementia and are the reason we are here.

So, read this book with the aim of seeing the perspective of the person who has been labelled as suffering with dementia, and of the carers and professionals. Try to 'imagine' how it feels to be the other party (or indeed any of them) and then reconsider your contribution to the problems that you or they are faced with.

The book is split into two parts to help you identify the parts you need to read at different times or for varying purposes. Part 1 offers information and debate about the theoretical issues and explanations of dementia and memory loss.

Themes throughout the book include explanations of what dementia actually is and where it comes from in the first place. There are differing theories on this, and Chapter 2 establishes a basic explanation of the generally accepted definitions of dementia and its source. Learning about this helps us to understand a background to a very confusing and emotionally traumatic experience. This capacity to comprehend a little of what is going on for the person with dementia (sufferer) and the carer (professional and non-professional) can assist with developing an ability to adapt and cope with its effects, as well as influencing our reactions to the problems encountered.

Chapter 3 takes the reader into the area of finding out what people with dementia and memory problems need and want. It also considers the carer's perspective and the use of a holistic approach to caring. This involves the capacity to look at more than just a disease or any other single issue and consider the person and people involved in all aspects of their lives. Nurses, doctors, social workers, home support workers, voluntary organisation support workers, occupational therapists, physiotherapists and many more professionals are involved in caring for people with these problems, and the approaches that are discussed here in terms of assessment can be utilised by any of them with appropriate training and experience.

Establishing what the sufferer and carer need is most effective when led by an assessment strategy. This approach, however, will often be socially defined and based in cultural belief. Whilst this is not necessarily a bad thing, it does restrict people and the choices they are able to make about their own destiny.

A move towards more collaborative care approaches has meant that there has been a development in this area: helping people to live with dementia and memory problems as defined by them, rather than by the professional body and society controlling the person and their care, is the new culture in care and support.

Chapter 4 explains why this book was written in the way it was. The professional, political and ethical perspectives of care are discussed and given a background in an effort to explain the motivation of services and their ultimate goals. The interview transcripts are produced as a result of the vital collation of insight from carers and sufferers already living with dementia. This approach was taken to offer the reader insightful, understandable and practical guidance from reality to balance the professional research-based evidence of care.

Part 2 moves on to the more practical side of things. Many areas of concern for carers and professionals alike are similar. However, the experience of the problems will vary as each is influenced by the individual perspective. The reaction to problems or to living with dementia depends on this belief system. So the person with dementia or memory problems and the professional or non-professional carer can only bring their ideas and perspectives together to be able to benefit from each other.

The chapters in Part 2 consider the impact of the issues identified through the interviews as the most prominent areas. The carer's perspective is considered in conjunction with the sufferer's and a perspective on coping skills is offered. This expert teaching by those living with these problems is enhanced by evidence and research intermittently, but essentially is aimed at a combined approach of non-professional and professional carers using their own expertise to create quality care. All the text following is based on the assumption that this is a useful collaboration and that the learning points – 'How can we help ourselves and each other?' – are meant for professionals and non-professionals alike. All of the quoted text comes from the comments made by the respondents in Chapter 4. In this part they are broken down into themes and considered in more depth.

Chapter 5 begins with the psychological and emotional issues associated with dementia and memory loss. Identified areas of concern focus on the fear of dementia, personality changes, change in relationships, carer stress, and safety or rational risk.

Chapter 6 considers the support needed by carers and the support which can be offered by professionals. It introduces some legal concepts and issues, which services are generally available and the use of a collaborative approach to areas such as younger people with these problems. The use of medication and tech-