

## BOOK REVIEW

Brian Draper, (2013). *Understanding Alzheimer's Disease and other Dementias*. London: Jessica Kingsley Publishers. ISBN 978-84905-374-7

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### Intended audience

The book is directed towards relatives, carers and professionals involved in the care of a person with dementia. Case studies are used to illustrate the main points. Whether you know someone with Alzheimer's disease, are worried about your own memory, or just simply curious about the condition, this book is intended to meet your needs by providing an overview of Alzheimer's disease and other dementias.

### Organisation of the book

The early chapters set the scene by describing the various causes of memory impairment. In recent years much has been learnt about the risk factors for Alzheimer's disease and other dementias to the extent that plausible action can now be taken by most people during their early to mid-adult life that may reduce their risk of developing dementia in old age. Family concerns about the genetic risk posed to children and grandchildren are common and examined in Chapter 3. The moderate stage of dementia is described in Chapter 4. The dementia assessment process in Chapter 6 should provide family members with the opportunity to come to grips with the diagnosis and start planning for the future. The treatments available for dementia are covered in Chapters 7 and 8. With the advent of drug treatments for Alzheimer's disease and some other dementias, it is important to understand their indications and limitations. Some drugs are only designed to treat some of the psychological symptoms associated with dementia, for example, depression, anxiety and hallucinations. Others may improve memory and concentration. The different types of drugs available are covered along with other naturopathic and herbal remedies.

There are many psychosocial treatments used in dementia care; most are designed to improve the quality of life of the person with dementia and their carer. The fundamental approach is to adopt person-centered care. An

overview of these therapies is provided including reality orientation, aromatherapy and music therapy. If there are significant behavioural or psychological complications of dementia such as depression, hallucinations or aggression, various psychotropic drugs could be used or psychosocial treatments recommended. Interventions to prevent caregiver stress and depression are described, including the important role of the Alzheimer's Association and are the focus of Chapter 9.

The main types of services that are available in most developed countries are considered in Chapter 10. The numerous ethical and legal considerations for a person with dementia including: power of attorney, ability to make a will, guardianship and ability to drive a car are explained in Chapter 12. Staff of residential care face many of the same problems encountered by family caregivers - stress and frustration mixed with some job satisfaction as described in Chapter 11.

In many situations, early planning with the involvement of the person with dementia can avoid problems later. The person with dementia and their family should be encouraged to plan for the future by making sure that they have a valid will, enduring power of attorney and possibly enduring guardianship in place. The future of dementia care including the issues of prevention, early and pre-symptomatic diagnosis and disease-altering therapies such as gene therapy, stem cell grafts and vaccines are discussed in Chapter 13.

### Symptoms and course of dementia

Most types of dementia are gradually progressive as they course through mild, moderate, severe and advanced stages. This means that the symptoms of early dementia differ from those found at later stages. Apart from impairments in memory and orientation, the other symptom domains of dementia include language and calculation, executive and intellectual function, behaviour, psychological reactions, self-care and functional capacity

and social function. When independent social function is no longer possible, social interactions remain important. In a non-threatening environment that caters for the limitations in their function, most persons with severe dementia thrive. Supervised dance, exercise, music, games and involvement with simple chores often provide surprising insights into quiescent abilities. Some people, of course, have never enjoyed social activities and are unlikely to change. Others are too distractible to stay for long. Contrary to popular belief, most people are aware of deterioration in their memory. The majority, however, lack insight about the extent of their deficits and tend to deny that it is really impacting on their lives. Some people are very insightful about their memory loss and are acutely aware that it is abnormal. There is a general rule with dementia - 'last in, first out'. Languages and other skills acquired later in life are usually the first skills lost as the dementia progresses. Thus people from a non-English speaking background characteristically lose their English language skills before their native tongue is affected.

In many cases, rather than a change to the opposite, there is an exacerbation of pre-morbid personality traits. The temperamental, verbally abusive husband turns to physical violence. The quiet, shy person becomes withdrawn and subdued. The easily worried, emotional person becomes persistently anxious, 'clingy' and insecure. The suspicious, guarded loner becomes overtly paranoid. Such personality and behavioural changes will clearly have an impact upon the person's lifestyle, resulting in family tensions and disruption of long-standing friendships. Sometimes the family doctor is consulted, though often nothing specific can be found. It is usually when other symptoms occur and the diagnosis of dementia is made that the family may become aware that the changed personality and behaviour is part of the dementia. At times, irreparable damage may be done to relationships before the cause becomes clear. This is one situation where an early assessment by a psychiatrist or neurologist to clarify the cause of the changes may possibly limit the damage to family and social relationships. Depression may be an early feature of dementia. Sometimes the clinical depression shows no hint of dementia and responds to antidepressant therapy, the other symptoms of dementia emerging months or years later. At other times, repeated efforts to treat what appear to be depressive symptoms are unsuccessful, or are only partially effective. In these situations, apathy due to frontal lobe impairment often obscures the dementia diagnosis. In a third situation there is a mix of depressive symptoms and memory changes and it may be unclear for some time whether the memory problems are due to the depression or to early dementia. The volume discusses all such observations in detail.

## Assessment

The assessment process required to make an accurate diagnosis is outlined within the volume, including the medical examination, memory tests, investigations and information required from the family. The crucial

components are identified, including the need to develop a collaborative management plan involving the person with dementia, family, doctors and other healthcare personnel. The assessment of dementia ranges from initial detection of cognitive range to the full medical, psychological and social evaluation required to make an accurate diagnosis, address any active psychosocial problems, educate the family and commence appropriate treatments. This process is enhanced by the involvement of a multidisciplinary team. Frequently, local doctors will determine the correct diagnosis, but most will prefer to have this confirmed by a specialist. The advantages of memory clinics are that they are thorough and are usually multidisciplinary. Most of them routinely engage neuropsychologists for a detailed cognitive assessment, social workers to assess the family circumstances, occupational therapists to determine the person's level of function and community nurses in addition to one or more of the medical specialists. The final diagnosis and management recommendations are often determined by consensus opinion from the various team members. A geriatrician and multidisciplinary aged care team may better assess frail, older people and those with more severe cognitive impairment of long standing, in the person's home.

The diagnosis of any serious, incurable illness is harder to deal with in a younger person than in old age largely because such illnesses are 'out of phase' with what most of us expect to happen at that life stage. The life plans of the person with dementia and their families are permanently disrupted. Younger people with dementia are likely to be in the workforce and usually the dementia will mean early retirement. Unless they have been contributing to a good superannuation scheme or have disability insurance, this often means a significant reduction in family income with all its associated ramifications, including mortgage and debt repayments and lifestyle changes. Where a spouse retires early to look after a partner with dementia, there may be a similar effect. The type of support children need varies with their age, particularly in terms of how best to provide explanation. Fortunately, Alzheimer's associations have publications for children that can assist the involvement of children in dementia care and adolescent counselling services are usually helpful. If placement becomes a consideration later in the course of dementia, most families will find that there are few if any residential facilities that suit the younger person with dementia. No single model will fit the diverse range of conditions that cause younger onset dementia as the current volume makes clear.

## The impact of early dementia - pre-diagnosis

Depending on the type of symptoms that predominate, the early impact of dementia upon family and friends is quite variable. There is little doubt, however, that spouses and others living with the person with dementia experience the greatest impact. It is often not memory changes that cause the

greatest concern early on, particularly when the caregiver does not recognise the symptoms as being abnormal. The point when lifestyle changes are forced upon the caregiver is often the point when help is requested. These days, however, more and more people are becoming aware that memory changes may be due to dementia and it is increasingly common for the spouse to become concerned at the earliest signs of memory decline and therefore arrange an assessment.

## The impact of moderate dementia

The moderate stage of dementia requires some level of assistance from other people to enable them to maintain their function in the community at a level as near as possible to the level they enjoyed before the onset of the dementia. It is often in this stage that caregivers begin to realise the full extent of the various demands upon their time. While the deteriorating memory function is a problem, it is usually not the main feature of dementia that impacts upon the caregiver. It is more often the personality and behavioural changes that cause the most concern, with these changes having the greatest effect on those caregivers who live with the person with dementia, usually the spouse. During this stage of dementia, not only does it become very difficult for the person with dementia to live independently, but it also becomes very difficult for the co-resident caregiver to have a life of his or her own. The types of demands placed upon the caregiver include: disrupted sleep patterns, repetitive questioning and wandering which place demands upon the caregiver's time and cause enormous strain or burden. Some of these behaviours require extra supervision from the caregiver, especially the sleep changes and wandering, increasing the demands on their time and requiring them to be vigilant even when they need time for themselves to relax. Some other types of behavioural and personality change including aggressive outbursts and paranoid accusations, have a greater impact upon the actual relationship between the person with dementia and caregiver and can threaten the wellbeing of the caregiver. When the fundamental basis of a relationship is being undermined by such behaviours, even the most empathic, understanding and tolerant caregiver may come to a breaking point. Fortunately, these behaviours are far from universal and in many cases may improve with medical and psychosocial strategies. Probably the most important way of helping caregivers deal with these problems is through family education and support. The current volume describes these factors with admirable clarity.

## The impact of severe dementia

In severe dementia there is no semblance of independent function and so maintenance at home usually requires 24-hour care from family, friends and community support services. This involves assistance with all basic activities of daily living - feeding, toileting, dressing, bathing and

grooming. In addition, the behavioural changes tend to persist and often worsen before there is diminution as the dementia becomes more advanced. The reality is that very few caregivers are able to achieve this ambition; 24-hour care is enormously difficult to provide over a period of some years, even with the involvement of community services.

The other major issue confronting caregivers by this stage of dementia is the grieving process. Anticipatory grief, in which a person begins to grieve before the death of a loved one, is particularly common in severe dementia due to the premature loss of many of the personal attributes, otherwise known as the 'self', upon which the relationship was based, but it is also a significant factor contributing to caregiver stress earlier in the dementia. When your loved one no longer recognises you, is generally incoherent and lives in a nursing home, it is little wonder that it seems as if they have died. For some caregivers, the grieving process may be virtually completed before the death of the person with dementia. This often results in cessation of visits to the nursing home and irritation about being asked to remain involved. For other caregivers, anticipatory grief has the effect of drawing out the grieving process for a much longer period than with many other terminal illnesses, resulting in a chronic period of heightened emotions that may take years to resolve even after the death. The volume describes such issues well and with exemplary sensitivity.

## Advanced dementia

Many people with dementia die before they reach the stage of advanced dementia, particularly if they have other significant health problems. By this stage the person with dementia is completely dependent on caregivers for all aspects of daily living and has almost certainly been in long-term residential care for some time. Language skills are lost and many are mute. Memory function is virtually impossible to test. Most are unable to stand or walk without assistance, many are unable to sit up properly. Due to their lack of activity, passive exercises are essential to prevent contractures of arms and legs and routine pressure care is required to prevent the development of bedsores. Urinary and faecal incontinence is the rule. Most people, as the volume describes, die from infections (pneumonia, influenza), cardiac arrest or stroke.

## Diagnosis

The volume documents and categorizes the common types of dementia, particularly Alzheimer's disease, vascular dementia, fronto-temporal dementia and dementia with Lewy bodies and how they can be distinguished from each other in terms of differential diagnosis. An important message is that there are many conditions that can affect memory that are potentially reversible, including stress, anxiety, depression and the effects of medication, alcohol and other drugs. The dementia syndrome is an acquired



decline in memory and thinking due to brain disease that results in significant impairment of personal, social or occupational function. It is not due to a normal ageing process. Dementia is increasing in prevalence due to the ageing population and is projected to have a commensurate increase in its economic impact and burden of disease in Society. In recognition of the increasing impact of dementia upon Society, many countries have announced national dementia strategies in recent years. Apart from vascular dementia, the most common types of dementia including Alzheimer's disease are caused by the gradual abnormal accumulation of toxic proteins in the brain that result in neurodegeneration, in turn resulting in impaired neuronal function and cell death.

## Treatment

The last decade has seen many new drug treatments becoming available, offering temporary improvement for some, but hope for many. Psychosocial and other treatments for dementia are largely about assisting the person with dementia and their caregivers to live with the disease with the best possible quality of life. This is very similar to the holistic approaches used in other chronic illnesses. By concentrating on abilities rather than disabilities and by providing an emotionally supportive environment, psychosocial treatments allow the person with dementia to function at an optimal level. Having a daily routine for a person with dementia reduces the information load that they have to assimilate and reduces their stress levels. For an important event such as a birthday party, enrichment of the occasion with the favourite music of the person with dementia, colourful decorations, favourite food and close friends will assist the person with dementia to remember the occasion. Cognitive stimulation therapy was developed in the UK and involves regular interventions of themed activities that aim to actively stimulate and engage people with dementia while at the same time providing an optimal learning environment and social interaction. Session themes include games, food, using money, orientation and current affairs. The aim of the CST programme is to provide an environment for people to learn and strengthen their existing resources. All such interventions are well presented in the volume.

## Community care

Dementia can be such a distressing condition that the importance of continuing to 'live life' is lost to many people. This is a complex topic that has many nuances and the volume details these with precision. Tom Kitwood has drawn attention to the importance of personhood in dementia. He based his approach on the assumption that humans have five basic psychological needs - comfort, attachment, inclusion, occupation and identity - that in themselves gather around the central need for love. To understand these needs in the individual it is important to

know the person's biography and personality, so that their perspective of the situation can be respectfully integrated into their care and their opinions valued. It has become increasingly recognised that person-centered approaches to care underpin many effective interventions. Although person-centered care is a term describing an approach used by health professionals to meet the needs of their patients, for persons with dementia it also applies to their interactions with family and caregivers. In healthcare settings, person-centered care, in which the individual's needs and preferences are considered from a holistic perspective, is contrasted with task-centered care in which the focus is upon a specific task, such as dressing a wound or dispensing a particular medication. Some of the most powerful conference presentations have been given by persons with mild dementia, with themes such as fighting the stigma of dementia and the importance of having meaningful activities to live with a good quality of life in dementia. All services are based upon the principle of accurate assessment, both of the underlying cause of the mental decline and the actual needs of the person with dementia and their caregivers. Despite this, for most lay people the choice appears at times bewildering and at other times inadequate.

## Negative and positive aspects of caregiving

The concept of caregiver burden includes the objective practical problems caregivers face in day-to-day care and the subjective strain or emotional reaction that caregivers experience that might include symptoms of stress, depression and anxiety. Care givers have high rates of depression with some studies finding over 40% of care givers meeting diagnostic criteria for clinical depression.

Caregiving should not be characterised only by its negative attributes. Many caregivers report heightened feelings of love and affection for the person with dementia, which have arisen from their caregiving experience. The relationship may become closer with the sharing of life experiences that might not have otherwise occurred. There is often a sense of reciprocation in which caregivers feel they are repaying an emotional debt to the person with dementia. This is particularly the case with adult children who feel their parent has made sacrifices for them. Caregiving is full of challenges and for many caregivers it brings an opportunity to broaden their life experiences, albeit not necessarily in the way they had planned. Personal growth, as the volume documents, may be attained through the mastery of new skills and better self-awareness.

## Ethical principles

Because dementia fundamentally impairs the capacity of an individual to be autonomous, many ethical and legal problems that arise in dementia care occur around this

principle due to conflicts involving decision-making capacity. For example, competency to manage finances, to drive a car, to participate in research and to decide where to live are common areas of concern. Justice is about fairness and impartiality and the need to find a balance between competing interests with examples including balancing the desire of the person with dementia to live alone in their own home with the concerns of caregivers about hygiene and safety and balancing the potential benefits of a drug treatment against the risk of serious side effects. Ultimately, when a person with dementia is found to be incompetent to make a particular decision, it is essential that the needs of the person with dementia, rather than the needs of caregivers, health professionals or others, be the basis of the decision that is arrived at - in other words, the decision must provide a just and person-centered outcome for the person with dementia.

A fundamental impact of dementia upon an individual is to impair their decision-making capacity and hence their ability to remain autonomous. To have the mental capacity to make a decision, the person must be capable of understanding the nature of the decision and the effects that decision will have upon the person and others. It is important to understand that mental competence is not 'all or nothing'. For example, a person with dementia may be mentally incompetent to give informed consent for a complex medical procedure but competent to decide whether they wish to give their power of attorney to their spouse. It is crucial in respecting the autonomy of the person with dementia to ensure that they retain their rights to make decisions about things they remain competent to decide upon. A person with dementia whose finances are managed by their guardian, for example, may be able to decide upon where they want to live or what medical treatment they wish to receive. The guardian in these circumstances should not attempt to impose their will upon the person with dementia, although of course they have the right to provide their views on the matter. All such factors are considered by the volume with clarity and elegance.

## Some general rules of communication

General rules about communication with a person with dementia that include remembering that the person is *dementing*, not *demented*. This means that many mental functions remain relatively intact until the later stages of illness and these retained abilities should be tapped as much as possible. The volume definitively advises to try to communicate on an adult-to-adult level, but to keep things simple. Short sentences containing only one subject are better than longer ones. When asking questions, avoid the 'multiple choice' approach. Use gestures, speak slowly and clearly, but try not to be stilted. Communication should also be tailored to the needs of each person by respecting them as a unique individual who had a life before their illness (as well as now) and whose feelings need to be recognised and respected. In other words, it is necessary to take a person-centered approach.

Unfortunately, these services are unevenly provided in many countries. Others are poorly funded and resourced. Numerous programmes that have been piloted around the world aim to reduce the need for hospital care for physically unwell older people by providing a geriatric outreach service into the older person's home. The outreach service usually includes a geriatrician, nurses, physiotherapists and social workers who work in collaboration with the local doctor. The types of problems these services are particularly suited to treat include respiratory, urinary and skin infections, mild cardiac problems and soft tissue injuries after a fall. This might be initiated in the person's home following a referral from the local doctor, after an assessment in the local emergency department or following a brief admission to hospital to facilitate early discharge. For people with dementia, hospital admission can be extremely traumatic with increased confusion and behavioural problems due to the illness and new environment. Home-based care can often reduce these complications and improve the outcome.

## Community services

Community services, as the volume discusses, are particularly important in supporting people with dementia and their caregivers at home. There is a broad range of services available that focus on providing accurate assessments, minimising the effects of disability, providing support to caregivers and determining eligibility to residential care. These processes of assessment are often confusing for health professionals and care givers alike. The current trends in community services are to increase flexibility in care provision through innovative strategies. Family caregivers are the linchpins around whom most dementia care is based. Without the support of family members and friends, it is difficult for the person with dementia to remain in their own home. Initially, the support is largely emotional, but in the later stages it is also physical. Caregiving can be both rewarding and stressful, often at the same time. For most persons with dementia, there comes a time when it is beyond the resources of family and formal community services to maintain them at home.

Residential care options include hostels, special care units and nursing homes. Although often limited by availability, choosing the best option for the individual can be very difficult. Some hints are provided about how to make the choice. The quality of care in long-term care facilities has been a controversial area in recent years with a series of incidents being highlighted in the media worldwide. It is too simplistic to relate quality of care with the amount of funding available to a facility - some facilities that charge enormous fees and have a very attractive design can provide very poor care. However, a facility having adequate numbers of well-trained and reasonably paid staff with good leadership in a well-designed facility is likely to cost more than the average to run. The cost of having a quality long-term care system that is appropriately regulated and meets the needs of its

residents is perhaps more than what is currently in the system in any country.

Worldwide nursing shortages are accentuated in the residential aged care sector which has greater problems in attracting and retaining staff due to the nature of the work and relatively poor (compared to acute hospitals) pay rates. The high staff turnover endemic in many facilities typically exacerbates the difficulties in implementing the effective training programmes that are essential to improving dementia care. Special needs groups, residents with severe challenging behaviour, residents under the age of 60 years and residents from ethnic minorities are inadequately catered for now and are likely to remain so in the foreseeable future. For many reasons, it is a good idea for caregivers to prepare for residential care well before it is needed. This should involve finding out about medical facilities and becoming informed about facility features indicative of quality care. There are generally three types of residential long-term care facilities - low-level (assisted living, residential home), high-level (nursing home) and dementia-specific facilities. Only residents with severe behavioural problems need the latter. The volume details the facts and issues in these contexts in a manner which makes them easily assimilated by the reader.

## Conclusion

Brian Draper's writing style provides a coherent, comprehensive guide to everything you ever wanted to know about dementia but were afraid to ask. It is full of useful information and advice. These are exciting times in the field of dementia care. Scarcely a week goes by without the publication of new research findings that provide a better understanding of some aspect of the early diagnosis, potential treatment or prevention of Alzheimer's disease and other dementias. We are on the cusp of being able to reliably identify people before they develop symptoms of dementia and, more importantly, being able to provide interventions that will significantly reduce or eliminate their risk of developing dementia. Just how far away this is and how effective the interventions may be are matters of speculation. Overall, the volume provides a clear and coherent account of the state-of-the-art of dementia care and on this basis is highly recommended to all those colleagues with an interest in or responsibility for the care of persons with dementia.

## Conflicts of Interest

The author declares no conflicts of interest.