



DEMENTIA CARE

THE ADAPTIVE RESPONSE

A stress
reductionist
approach

Paul TM Smith

Dementia Care – The Adaptive Response

A stress reductionist approach

PAUL TM SMITH

Research Fellow, Green Templeton College,
University of Oxford

First published 2013 by Speechmark Publishing Ltd.

Published 2017 by Routledge
2 Park Square, Milton Park, Abingdon, Oxon OX14 4RN
711 Third Avenue, New York, NY 10017, USA

Routledge is an imprint of the Taylor & Francis Group, an informa business

Copyright © Paul TM Smith, 2013

All rights reserved. No part of this book may be reprinted or reproduced or utilised in any form or by any electronic, mechanical, or other means, now known or hereafter invented, including photocopying and recording, or in any information storage or retrieval system, without permission in writing from the publishers.

Product or corporate names may be trademarks or registered trademarks, and are used only for identification and explanation without intent to infringe.

Typeset by Darkriver Design, Auckland, New Zealand
British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN 9780863888120 (pbk)

Contents

<i>Preface</i>	iv
<i>About the author</i>	ix
Introduction	1
1 What is dementia? The biological domain	5
2 What is dementia? The psychological and social domains	43
3 Modern contexts of dementia care	75
4 Stress and adaptive responses	91
5 Adaptive response: the original essay	103
6 Stress: concepts, considerations, appraisal and stress thresholds	133
7 Manipulating the social environment	161
8 Manipulating the built environment	191
<i>References</i>	217
<i>Index</i>	225

Preface

The process of re-establishing homeostasis disturbed by stress is called an adaptive response. This process is so named because it allows the organism to adapt to the influence of stressors. Stress signals from the periphery as well as from various brain divisions merge and activate the stress system. An activated state of the system is what is known as stress. This can lead to exhaustion of the reserves of the systems involved in the adaptive response which in turn is manifested as various diseases.

Different people react differently to the same stressors. Short-term exposure to the same stressor results in a stress that disappears relatively quickly in strong-willed and emotionally stable individuals. However, it tends to last longer in people with less emotional stability.

This book arose out of almost 30 years of working with and living alongside people living with dementia and their families and for the last 20 years managing and coaching staff to provide better care experiences.

In particular this book arises almost 15 years after an original essay (published here as Chapter 5) which earned me my first academic qualification in dementia care. The work came about after undertaking training in psychotherapy, group psychotherapy and in particular after achieving a Masters qualification in neuro-linguistic psychotherapy (NLP) and indirect clinical hypnosis which supplemented my nursing qualifications.

After almost 15 years as a qualified nurse I suddenly realised that just like the plumber always trying to find the leak, I had spent years looking for people to 'fix'. Training in different care philosophies suddenly opened up a world of alternatives for me. I hope this book does the same for you.

When I started seeing the bigger picture and adding lots of differing perspectives I realised that what was needed to be done did not involve 'fixing' people but was more about getting 'everything else' out of the way and allowing those people to 'be' or, more accurately, 'to become'.

This book, therefore, is about getting stuff out of the way!

Dementia is a stressor. Even at its most well lived the dementia syndrome provides a source of increasing challenge to the physical and emotional resources

of an individual. This constant challenge results in a condition of chronic stress punctuated frequently by a series of increasingly acute stress episodes.

At its most purely survived dementia can consist of a regular series of 24-hour catastrophic, acutely challenging and stressful experiences. Relief and respite from 'challenge' becomes elusive if the environment and the 'care' promoted do not adapt and evolve to their changing needs. Eventually, the person is overwhelmed and retreats from life.

The processes of dementing, therefore, can make the experience of day-to-day living an acute challenge. It is a challenge, I believe, that can be greatly mediated with educated and timely inputs from carers (family, professional or other) and where the caring contract is negotiated to preserve both dignity and quality of life.

This 'new contract' can begin, in the first instance, by changing our attitude as to what can and cannot be achieved by people living with dementia, and then by changing the way we subsequently plan and deliver care. You will not read the phrase 'dementia sufferer' in these pages.

The stressful experiences of living with dementia create an intolerable strain upon psychological and physical systems and, as we will demonstrate, it is through the continuing attack upon an individual's resources that these systems begin to fail.

This cycle of physical and psychological activation, coping and eventual failing leads a person into a downward spiral that is too often mistaken as the 'effects of dementia.' In reality, as this book hopes to illustrate, this is often not the case. This cycle can be something that can be prevented or at least mostly mitigated by those assisting the person, once it is understood.

This failure of the human system to be able to cope with the increasingly stressful challenges of day-to-day living may also be one of the major variants explaining the dramatic differences in survivability between individuals living with a dementia, and even if this is only a possibility it is incumbent upon us to attempt to help.

The premise of the adaptive response approach is simple: people living with dementia are often disempowered and overly 'protected,' leading to dependence and loss of confidence and ability. Conversely, people living with dementia are also often left to cope and struggle with tasks, environments and social and emotional demands that they are no longer equipped to deal with successfully. This leads to stress, distress and a failure to cope and thrive.

This book contends that carers armed with a sound knowledge of dementia, person-focused processes and knowledge of the effects of stress and its catastrophic impact when left unattended can make a real difference to the quality of life of those living with dementia. Further, I contend that when equipped with a firm understanding of whole-person-focused approaches and an awareness of our

human 'built in' ability to adapt and adjust, the experiences of those living with dementia can be enhanced as 'we get things out of their way'.

By the professional carer understanding their role in enabling, adapting and adjusting, living with one of the dementias, even in the dreaded care home, can become a life to be lived and enjoyed.

The findings from many caring and social science disciplines are gathered here in these chapters and have been synthesised using a systems model to demonstrate how we can combat the life-threatening reaction to the 'stress' of the dementia experience. This can be achieved by the acceptance and integration of a few simple principles, and we show how, by applying these same principles, we can optimise the caring environment.

For example, a simple principle applies to stress: too much stress – bad; too little stress – bad; stress that allows for and fosters growth and adaptation (internally or externally controlled) – optimum. (Note: we all need some stress as without it we would stagnate and reach the only truly stress-free condition – death.)

The adaptive response approach is about simple principles such as the above and is to be viewed as a biopsychosocial approach functioning from within a 'person-focused framework'.

The approach and principles suggested here adopt the work of Lazarus, Sapolsky and other modern stress researchers and seek to show that it is an individual's ability to appraise a stressor, rather than the nature of the stressor itself, which initiates and determines the response. If a person is unable to assess when a stressor starts or ends, the subsequent state of arousal can last from minutes to hours (and perhaps longer), and what is essentially a necessary and good process can become destructive and ultimately life threatening.

The premise is that when a system remains under stress for any length of time almost all coping mechanisms eventually become overwhelmed and exhausted as hypothesised by Selye as long ago as 1936. As subsequent research has shown, however, this in itself is not the true cause of illness from stress. It is in actuality the constant adaptation of the system that depletes the coping abilities and it is this constant striving to 'adapt' that negatively affects all activities of daily living.

Try to remember a time when you yourself were in the middle of a stressful situation, a time when you could see no way out of it. You did not know when a solution and, therefore, relief were coming. Were you able to think clearly for any length of time? Were you able to look forward to brighter times? Could you even get through the day without dropping things or bumping into furniture, or biting a loved one's head off? Were you shaky, could you sleep, did you pace the floor – was there great gnashing of teeth?

This inability to successfully appraise the stressor, its magnitude and how long it may last results in the engagement of mental and physical resources and reserves sometimes totally inappropriate in magnitude to those actually required. It is this cycle, if repeated regularly, that becomes incredibly destructive to both physical and psychological function.

As you may remember from your own stress experiences, after a while it becomes 'hard to think straight'. Cognition, although initially heightened by severe stress, is impacted severely and negatively by unremitting or repeated stress and the subsequent racing of stress hormones around the body. When we add this unremitting or regularly repeated challenge for someone living with a dementia we have created a natural disaster waiting to happen.

By understanding these basic principles and devising compensative and adaptive programmes of care (the individual plan of care or 'care plan') it is suggested that this destructive downward cycle can be interrupted and even broken.

These basic ideas which make up the adaptive response approach take great optimism from the 25-year-old theory of 'rementia' which, although contentious outside of the dementia community (even inside this community for some), nevertheless has been demonstrated in practice again and again.

Rementia (Kitwood, 1987) was postulated as a theory to describe the observed 'improvement' of cognitive abilities, mood and coping mechanisms of individuals living with dementia and a related drop-off in behaviours that challenge when positive changes were made to their physical and social environments and toxic elements were reduced or removed.

The theory is contentious only because clearly the person's 'dementia' does not get better in a physical sense (with neuronal regeneration, regrowth of lost tissue and so on) but the effects of rementia are clearly observable and measurable in terms of behaviour, mood and communication.

These positive effects, in my observation, occur when there is a match between the demands on the coping ability of the person and their means to meet them, and in the subsequent removal of the challenges that can no longer be adequately met.

The central premise of this book, therefore, is that once the negative toxic stressors of living within social and built environments are removed or better externally controlled, the better the person themselves can cope with the true effects of 'dementia'. They can then in turn become more receptive and responsive to the aid available to them and live their lives productively and happily.

The message of the book is an incredibly simple and positive one; it states that people living with dementia can live better lives and that these lives are enhanced

if we all work together towards this attainment. You can make a positive difference as a professional carer, a family member or friend with just a little knowledge and a lot of hope – this book hopes to provide a little of that for you.

The central aim of care, after all, is surely about providing quality to life not quantity in terms of years, although one invariably impacts upon the other.

A small note of warning: you may find some of this book challenging, even heretical to current wisdom about ‘dementia caring.’ It is a very complex subject we are attempting to understand, but I have tried to keep things simple. It is because I greatly respect you for purchasing this book and wanting to expand your current understanding and caring horizons that I have taken to heart what Albert Einstein instructed us: ‘Everything should be made as simply as possible, but not simpler.’

Now it’s up to you – go and make someone’s life better! (Oh, and by the way – get everything else out of the way.)

Paul TM Smith

October 2012

About the author

Paul Smith is a qualified nurse with 30 years' experience. For the last 18 years he has specialised in the study and care of those living with a dementia and has gained graduate and postgraduate qualifications from a number of UK and overseas universities in this subject area. He has also received qualifications in psychotherapy and group psychotherapy and is a master practitioner of neuro-linguistic programming. He has worked across all three sectors of care and, almost uniquely, has worked his way upwards from RMN and CPN to senior nurse roles and into management and senior management and to his current executive status.

Paul has worked as head of dementia development and care for the third and fifth largest UK care groups and on DoH projects, national guidelines and is part of the NICE stakeholder contributors pool and was a contributor to the creation of the national dementia pledge and is currently a member of the NHS Institute for Innovation and Improvement – Care Homes project and as head of mental health and dementia for HC-One group is running the FITS and GAS research project – a UK first in partnership with the DoH, the Alzheimer's society and the University of Worcester.

Occupying executive positions across a number of the UK's largest care groups, Paul has been able to study the application of various care models across hundreds of care homes, has shared the experiences of thousands of people living with dementia and their families and friends, and has developed award-winning teams and premises over the last 12 years. He has spoken and presented at national conferences and forums, has written and co-authored a number of articles and was a lead chapter contributor – on change management – to the MBA Book of the Year 2006, *The New Culture of Activity Therapy for Older People*, edited by Dr Tessa Perrin.

On top of all his working commitments Paul was greatly honoured to be a visiting research fellow between 2008 and 2010 at Green Templeton College, Oxford University. Paul is currently the Head of Mental Health and Dementia for the UK's newest and third largest care provider, the HC-One Group, where he leads in these areas for 15,500 staff members caring across 248 sites for over 12,500 people.



Taylor & Francis

Taylor & Francis Group

<http://taylorandfrancis.com>

Introduction

Dementia has many well-documented impacts upon those it affects and one of the most apparent to observers is its impact upon memory and cognition (the processes of thinking). Emotions, too, can appear unrestrained or inappropriate, and these effects in combination can lead to a heightened state of exertion, resulting in behaviours others often find challenging (acts of commission) or, in direct contrast, to an inward-turning or seeming introspection and retreat from life (acts of omission), which others find equally as challenging.

People living with a dementing condition can often exhibit changed and challenging behaviours that in reality have much more to do with the impacts of their environment and their care than on the actual physical changes occurring within the brain and its functional systems. The internal effects of these externally visible 'reactions' in themselves will exacerbate an already challenged and ageing body system.

Dementia is viewed by professionals in a number of ways, but most recent debate has centred on the validity of the nihilistic 'medical model' as opposed to the 'person-centred' model of dementia made popular in the 1980s and early 90s by social and clinical psychologists such as Gilleard (1984) and Stokes (1986) as well as most notably Tom Kitwood (1992) who founded the highly influential Bradford Dementia Group at Bradford University.

A simplistic overview of these two positions seems to be that the medical model views the damage occurring in the brain as being central to all the changes seen throughout the 'illness'. By contrast, the 'new culture' views the changes in the person as being created, at least equally, also by the changes in their social and psychological positioning. This positioning emerges as necessary to cope with the physical advance of the condition *and* as a coping mechanism to deal with the changing attitudes and values of society to their diagnosis.

After having spent almost 30 years caring or designing care, I feel that it is a dangerous position to believe that there is only ever one approach to anything, let alone to dementia caring, and a combination of both the above positions (and utilising a number of models lying between the two) seems to be the only way to ensure that the person is not marginalised by personal or political agendas.

Indeed, the emergence of the biopsychosocial model has allowed an intermediate position to emerge, and it is hoped, for the future of caring, that the remaining purists may be steered into a much more centrist agenda. To paraphrase the American psychotherapist Milton H Erickson, we should not try to fit people into our models; rather, where required, we should create new models.

This book strives to offer one such ‘model’ or approach which may be of particular relevance for care homes. This approach accepts that there are polar positions, but it attempts to add a further, more multidimensional mediated common ground. It is an approach that accepts the human being as a balanced system and as a dynamic force existing within other systems. Human systems are affected by both internal and external dynamics, and nursing has recognised this for at least the last 50 years (Neuman, 1982), so we are well positioned as a profession to argue for such a system of dementia care.

In particular, this book looks at the concept of stress and its effects upon the person living with a dementia and upon the functional systems of care homes, and how we as carers can adapt ourselves to get the best out of both.

This ‘systems’ approach will already be familiar to many professionals and should also resonate with those familiar with the emerging social care model.

It is also an approach for the ‘here and now’ as we in the UK, including the care sector, enter into a period of acute economic austerity: there are no excessive costs to the application of these principles – only effort and belief are required.

The ideas for adapting care processes and physical environments in this volume have been carefully referenced against the various regulation standards across England, Scotland and Wales. They have been reviewed in light of the changes to the way ‘outcomes’ are now measured across England with regard to the Health and Social Care Act (2008) and the various regulations (2010) covering the act and the introduction of inspection standards into Northern Ireland. They have been further enhanced by the inclusion of principles from the National Institute for Health and Clinical Excellence (NICE/SCIE) guidelines (2006) and the ‘Everybody’s Business’ process, and I have also taken into account the National Dementia Strategy for England, *Living Well with Dementia* (DH, 2009), and its neighbours’ strategies across the UK and Europe. The principles further concur with the Alzheimer’s Society’s service improvement programme *Quality Dementia Care in Care Homes* (Royal College of Nursing, 2002) and incorporate best-practice guidance from the *Evidence-based Approaches for Improving Dementia Care in Care Homes* programme (Fossey and James, 2008), the VIPS programme for improving dementia care (Brooker, 2010) and the ‘Building on Strengths’ programme for providing support, care planning and risk assessment for people with dementia (Sheard, 2003).

This is not a scientific textbook, but it necessarily includes medical terms and descriptions, generally explained as they are introduced. The carer needs to have a basic understanding of how the brain and body work when in good order, and how they are affected by disease.

Knowing how exciting the human potential is and understanding where that potential is housed will help you move from seeing those in your care possibly as sets of problems or symptoms to be ‘managed’, to seeing people with many strengths and potentials and to thereafter ‘working with’ them rather than ‘doing things to’ them.

I believe you should always be looking to find and to enhance the person. Sometimes this person gets lost or hidden away behind the ‘symptoms’ of the ‘illness’, but in good dementia care we are always the detective, searching for clues and aiming to remove the subterfuge to reveal the essential human being beneath the diagnosis. Take the opportunity to think of yourself as a modern-day Sherlock or Miss Marple and ‘detect’ all the clues of the person desperately hoping you will ‘find’ them above and beyond the diagnosis.

The first chapter introduces the biological domain of dementia, what the term itself encompasses, criteria for diagnosis, possible causes, prevalence, symptoms and common forms of dementia, along with a brief discussion of the brain and its organisation. The biological basis of dementia is elucidated by examining the effects of Alzheimer’s disease on the brain and its interconnected systems.

We are not just brains, however, but individual humans, distinct persons functioning and interacting in varied social settings. Chapter 2, therefore, discusses the psychological and social domains of dementia. It examines the different models of modern dementia care and introduces the theory of whole-person-focused caring – the so-called person-centred approach – along with positive and negative aspects of practice in dementia care and an overview of various therapeutic interventions. Chapter 3 continues this review of practice by looking at the progression of therapies towards modern dementia care, and the principles that underpin care today.

In Chapter 4 we look closely at the role of stress and specifically at reactions to it by those living with a dementia, as well as at adaptive nursing models.

I then present as Chapter 5 a slightly reworked version of my original essay on adaptive response (‘Dementia and the effects of stress and unattended emotion upon the human system’). This covers the consequences of stress for those with dementia and how stress can be managed or alleviated by adaptive response strategies.

The final three chapters expand on the material provided in Chapter 5. Thus

Chapter 6 looks further into stress and dementia, stress reduction, systems thinking and applying an adaptive-response care programme. Armed with an understanding of the role of stress, we need to be constantly seeking ways to compensate for negative arousal through manipulation of the social and built environments. These are areas that it is within our power to control and which directly affect the well-being of those with dementia. Chapter 7 examines how we can manipulate the social environment, through programmes of care and therapeutic relationships. Chapter 8 discusses how we can design a supportive care environment that reduces stress and enhances well-being.

By adapting care and the care environment it is possible to offer unique and individual approaches for those living with a dementia even in large institutions. Quality of life is possible at all stages for all people including, importantly, the care staff.

The book, therefore, hopefully will allow you to develop a concept of care and your place in it that focuses closely upon that part of us we call our being – our essential humanness – and will seek to dispel any thoughts you may have held about dementia care being focused on symptoms and managing risk. You will read then about person-centred care and about ‘personhood’, which is not to be confused with personality. Personhood has been described as a conferred state, a status given to one person by another, and which implies recognition, respect and trust. (Personality, on the other hand, is the product of the brain, its ‘hard’ wiring and the cumulative effect your life history has had upon the organ, leading to its adaptations which has ultimately brought about ‘you.’)

Ultimately, I hope to leave you with a simple caring philosophy to help shape your future practice. Care homes for too long have been associated with a type of care referred to as ‘warehousing’, in which people are treated and moved around like ‘objects’ or ‘products’ to be fed, toileted and put back in their rooms – a type of care aptly described as ‘task orientated.’

This book challenges that assumption, and it seeks to change the popular opinion of what care homes are, what they do and how they do it. It aims to help carers in rising above these negative perceptions and to begin to view care homes and the people who work in them differently. It is a tool to help you see the beauty of those you care for and work with, and to begin to allow you to appreciate the joy and skill of what you do, unselfishly, every day of your working career.

1 What is dementia?

The **biological** domain

The social model of dementia with regards to care practice in the UK is introduced in the NICE/SCIE guidelines: *Dementia: Supporting People with Dementia and their Carers in Health and Social Care*, as follows:

For many years, people with dementia were written off as incapable, regarded as little more than ‘vegetables’ and often hidden from society at large.

During the 1980s and 1990s, there was a move away from regarding people with dementia as incapable and excluding them from society, and towards a ‘new culture of dementia care’, which encouraged looking for the person behind the dementia (Gilleard, 1984; Kitwood & Benson, 1995; Kitwood, 1997).

People with dementia could now be treated as individuals with a unique identity and biography and cared for with greater understanding.

Building on this work, others (notably Marshall, 2004) have advocated that dementia should be regarded as a disability and framed within a social model. The social model, as developed in relation to disability, understands disability not as an intrinsic characteristic of the individual, but as an outcome produced by social processes of exclusion. Thus, disability is not something that exists purely at the level of individual psychology, but is a condition created by a combination of social and material factors including income and financial support, employment, housing, transport and the built environment (Barnes *et al*, 1999).

From the perspective of the social model, people with dementia may have an impairment (perhaps of cognitive function) but their disability results from the way they are treated by, or excluded from, society.

For people with dementia, this model carries important implications, for example:

- the condition is not the ‘fault’ of the individual
- the focus is on the skills and capacities the person retains rather than loses

- the individual can be fully understood (his or her history, likes/dislikes, and so on)
- the influence is recognised of an enabling or supportive environment
- the key value is endorsed of appropriate communication
- opportunities should be taken for rehabilitation or re-enablement
- the responsibility to reach out to people with dementia lies with people who do not (yet) have dementia.

The social model of care seeks to understand the emotions and behaviours of the person with dementia by placing him or her within the context of his or her social circumstances and biography. By learning about each person with dementia as an individual, with his or her own history and background, care and support can be designed to be more appropriate to individual needs.

Moreover, a variety of aspects of care may affect a person as the dementia progresses. Some extrinsic factors in the care environment can be modified, for instance noise levels can be highly irritating but are controllable. Other intrinsic factors, such as the cultural or ethnic identity of the person with dementia, may also have a bearing on how needs are assessed and care is delivered. Some aspects will be more important or relevant to one person than to another.

The social model of care asserts that dementia is more than, but inclusive of, the clinical damage to the brain.

(NICE/SCIE, 2006)

I could not have written a better introduction to the adaptive response principles than this, and if we start by broadly accepting the assertions of the social care model, as outlined above, we are ready to look at the biological basis of dementia, keeping in mind that dementia is more than, but inclusive of, the clinical damage to the brain.

It is often believed, even by some professionals, that ‘nothing can be done’ with regards to caring for someone with dementia other than to ‘make them comfortable, safe, warm and well fed’. This kind of thinking is referred to in academic dementia studies as ‘old culture’ or less accurately as the consequences of the ‘medical model’.

This opening chapter is designed to provide a better understanding of dementia within its neurological and physiological aspects. This book is not about the physical presentation of dementia as a disease, neither is it about population statistics and percentages, but for the lay reader or those new to the subject this chapter

by necessity introduces the subject in these terms. In the context of the book the overall model we provide here, when coupled with the contents of Chapter 2 (the psychological and social domains) is referred to as ‘new culture’ and more specifically as the biopsychosocial model (the dynamic interaction between the biological, psychological and sociological). Read together they provide a good introduction to modern understandings of dementia which you will need to appreciate the principles of adaptive response.

This chapter is quite basic. It must also be kept in mind that, as new science emerges, we are learning that even the way we thought we understood the brain as little as five years ago is now being turned on its head by theories such as adaptive plasticity (how individual brains change and adapt to environments or insult) and the connectome (the revolutionary emerging field of research that is showing that what we ‘are’ may actually be contained in between the connections made by our neurons and not in the structures themselves).

So while we must never deny the presence of a degenerative neurological pathology, it is hoped that as a result of your reading you see *people* before you see *disease*, and that you see people as having many existing, preserved and possibly new capabilities, as well as possessing current needs, wants and hopes.

It is hoped by the end of the following two chapters carers appreciate the uniqueness of each person and understand dementia not just as a physical disease but as being a collection of personality, life history, neurological impairment, present circumstances, physical and psychological well-being, current environment (both the built and social) and the collective future wants, hopes and desires of the person continuing to live within their family unit but now, of course, also living within the care home.

It is rarely stated, but people living with dementia at almost all stages of the disease process have a past, a present and a future. This means they also have dreams and aspirations – just like you and me. In fact the other thing that is rarely stated is that people living with dementia are, indeed, in essence you and me.

The biological domain

Each dementia is unique

When looking at dementia and the dementias throughout this chapter it is important to understand that we generally will be looking at the commonalities of the syndrome. There are recognised signs and symptoms, which tend to be universal – common to all – but dementia is not universal; rather, it is a very personal condition. Due to the individuality of our brains (each brain is slightly different at birth

to others, even in identical twins) and the unique neural connections and chemical pathways that develop within our brains as life's experiences imprint themselves on us, each dementia is unique to each individual.

This means that if there are 800,000 people living with dementia now in 2012 in the UK and that if around 62 per cent of these people are living with dementia of the Alzheimer's type (DAT), some 416,967 people are living with similar but *not* the same disease outcomes. Thus, there are almost 420,000 people living in the UK with their own variant of DAT!

Dementia is a syndrome

Dementia itself is not a specific illness or any single disease process; it is a term used to describe a collection of related diseases and pathologies. When different though potentially related disease processes lead to a similar result, this broad pattern of symptoms is grouped together for ease of reference, and this 'grouping' is referred to as a syndrome. A syndrome is a collection of signs and symptoms that can be commonly grouped together and are recognised as producing a similar outcome even if the causes may be different.

Therefore, we can state: *Dementia is a term used medically to describe a collection of various conditions or disease processes which produce similar signs and symptoms and therefore are referred to collectively as the dementias.*

There are well over 100 different types of 'dementia' currently recognised, and it is probable many more will come to light in the coming years, even though the general public commonly believe any reference to 'dementia' means someone with Alzheimer's disease.

There are a number of distinctive diseases within the 'dementia' groupings and these include some quite specific processes such as Alzheimer's disease, but we also find much more common processes resulting from common medical conditions such as vascular disease, stroke and from complications from physical illness such as diabetes, sexually transmitted disease (syphilis or AIDS) and even some types of poisoning.

Unique presentations

The spectrum of specific conditions generally grouped under the label of dementia is large and many of these individual processes have very specific presentations, particularly in their early stages. This means it is vitally important for professionals to understand how we should be responding to these various unique presentations (characteristics and associated behaviours).

We should also understand that these presentations (behaviours) in many

instances are related directly to the type of or 'stage' of dementia the person is experiencing, their pre-existing personality and how they are reacting to the dementing process, its effects, where they are living and to how they are being treated. (We discuss the validity of 'stages' on p. 49.)

Learning Tip 1: Individual care planning for early stages

It may be largely accurate to say that as most of the major dementias progress, the outcomes will be similar in the end. However, in the early stages of most dementias that are not Alzheimer's disease, very different features will be apparent and therefore different ways of caring for people should be designed and different types of care planning should be evident.

Indeed, when we take a psychological vantage point the respected author Michael Bender has suggested we do not apply the term dementia at all when we discuss this group of affected people, because their individual reactions to the dementing process can be so personal and unique. Instead, he suggests we use the term 'remedial or enduring cognitive losses' (Bender, 2003).

Graham Stokes, however, urges that 'when used judiciously' dementia can be a useful concept – it can be seen as a useful 'compromise diagnosis' which acknowledges a set of characteristic signs and symptoms and excludes a range of alternative diagnoses (Stokes, 2005).

(For ease of understanding we will at present refer collectively to 'dementia' and individually to specific sub-types, such as Alzheimer's disease, multi infarct, Lewy body and so on.)

Progression of dementia

Dementia is progressive, which means the characteristic symptoms will gradually get worse and the person will become more reliant on assistance and may as the process develops require full nursing care. At present there are no known cures or preventions.

There are a number of drugs currently licensed to alleviate some of the symptoms of Alzheimer's disease (rivastigmine, galantamine and donepezil for early stage, and memantine for mid to late stage), but these drugs are only appropriate in some instances and are effective only for some people and are clinically effective for only relatively short periods of time (months or years).

These drugs do not cure or stop the disease process. However, it is evident in some instances they can slow the progress of some symptoms throughout the time

the drug is being taken. But these symptoms return and are sometimes exaggerated once the medication is stopped.

How fast the dementing process develops depends upon the type of dementia and on certain factors, such as the previous and current personality, circumstances and life history of the individual and particularly their ability to cope with stress (Kitwood, 1997; Smith 2011).

Each person is unique and will experience dementia in their own specific way due to these pre-morbid features. It is vital to stress that during the dementing process what goes on around the person in terms of support, living conditions and treatment plays a tremendous part in whether the experience of dementing is well lived or, tragically, merely survived.

Criteria for diagnosis

Diagnosis of exclusion

Dementia is most often diagnosed by exclusion: it is what is left after all other sources of confused behaviour have been excluded, and this means that often a diagnosis of dementia will be reached when the person doing the diagnosing runs out of explanations for the problems the person is experiencing! It is also sadly true that most people in our care will have a 'probable diagnosis'; that is, they have what can only be described as probable dementia – we don't know what else could be wrong.

Familial dementia can of course be predicted and some other predictive tests now exist. However, for many, a definitive diagnosis is most often only possible after death. This can make the process of caring very challenging.

The World Health Organization (WHO) classifies the syndrome of dementia as follows for the purpose of making a diagnosis:

Dementia is a syndrome due to disease of the brain, usually of a chronic and progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation.

The primary requirement for diagnosis is evidence of decline in both memory and thinking which is sufficient to impair personal activities of daily living (ADL); the above symptoms and impairments should have been

evident for at least six months for a confident diagnosis of dementia to be made.

(WHO, 1992)

It is because of symptom-descriptive definitions such as the above that historically in hospitals and care homes it has long been thought that all persons with 'dementia' are 'suffering' the same 'illness'. Therefore, they have all been viewed in much the same way, which is that 'nothing can be done other than to keep someone safe, warm and fed'.

This is a very nihilistic but historically understandable approach to the care of people with dementia, and new definitions and paradigms are needed because we now know that a great deal can be done to improve the quality of lives of people living with dementia.

What causes dementia?

There are many, many theories as to what causes the various types of dementia. In some we are confident that we understand the origin, such as multi-infarct type dementia (stroke), vascular dementia (oxygen deprivation to brain structures through occlusion of blood flow), Korsakoff's dementia (alcohol abuse) and many of the various familiar and infectious causes.

There is a lot known about other dementias too, such as Alzheimer's disease, but their causes have not been definitively established. However, it can be said that, basically, Alzheimer's is a physical disease caused by changes in the structure of the brain and a shortage of vital chemicals that help with transmission of messages.

Alzheimer's and vascular dementia are the main types, and mixed dementia (the next most common) involves both Alzheimer's and vascular dementia. Dementia with Lewy bodies, a less common form of dementia, is caused by irregularities in brain cells, and there are many rarer diseases and syndromes that can lead to dementia or dementia-like symptoms. The relatively rare fronto-temporal dementia is a physical disease affecting specific areas and structures within the brain.

The main subtypes of dementia and their prevalence and possible causes are explored in more depth later in the chapter.

Risk factors for dementia

Various risk factors for dementia have become evident.

- **Age.** The risk of Alzheimer's disease, vascular dementia and several other dementias increases significantly with advancing age.

- **Genetics.** Researchers have discovered a number of genes that where present increase the risk of developing Alzheimer's disease.
- **Smoking and alcohol use.** Studies have found that smoking significantly increases the risk of mental decline and dementia: people who smoke also have a higher risk of vascular disease, which may be the underlying dementia risk. Large intakes of alcohol also appear to increase dementia risk.
- **Atherosclerosis.** This interferes with delivery of blood to the brain and can lead to stroke and to vascular dementia.
- **Cholesterol.** High levels of low density lipoprotein (LDL), the 'bad' form of cholesterol, appear to significantly increase a person's risk of developing vascular dementia.
- **Homocysteine.** Research now indicates that a higher than average blood level of homocysteine, an amino acid, is a strong risk factor for developing both Alzheimer's disease and vascular dementia.
- **Diabetes.** Diabetes is a risk factor for both Alzheimer's disease and vascular dementia.
- **Mild cognitive impairment.** While not all people who have this condition develop dementia, they do have a significantly higher risk compared to the rest of the general population.
- **Down syndrome.** Studies have shown that most people living with Down syndrome develop characteristic plaques and tangles of Alzheimer's disease before middle age. Many then go on to develop all the symptoms of dementia.

How prevalent is dementia?

Worldwide figures

Estimates of the prevalence of dementia worldwide vary greatly depending on who is conducting the research and the aims of the body using these figures. However, it is estimated that about 800,000 people are affected in the UK alone, with this number estimated to rise to almost 2 million by the year 2060. Some projections for dementia prevalence worldwide are shown in Table 1.1.

Prevalence in the UK

The conservative estimate released in 2007 by the Alzheimer's Society stated that there were 683,597 people with dementia in the United Kingdom. This represents one person in every 88 (1.1 per cent) of the entire UK population. For simplicity, the Alzheimer's Society rounded the figure to 700,000 for people with dementia in the UK for use in public messages. The society has in 2012 revised these figures

TABLE 1.1 Dementia prevalence 2001, 2020, 2040 by WHO region

	Consensus dementia prevalence (%) (80+)	New dementia cases (millions) per annum, 2001	Numbers of people (millions) with dementia, aged 80+			Proportionate increase (%) in numbers of people with dementia	
			2001	2020	2040	2001–2020	2001–2040
Western Europe – EURO A	5.4	0.79	4.8	6.9	9.9	43	102
Eastern Europe low adult mortality – EURO B	3.8	0.21	1.0	1.6	2.8	51	169
Eastern Europe high adult mortality – EURO C	3.9	0.36	1.7	2.3	3.2	31	84
North America – AMRO A	6.4	0.56	3.4	5.1	9.2	49	172
Latin America – AMRO B/D	4.6	0.37	1.8	4.1	9.1	120	393
North Africa & Middle East – EMRO B/D	3.6	0.21	1.0	1.9	4.7	95	385
Developed Western Pacific – WPRO A	4.3	0.24	1.5	2.9	4.3	99	189
China & developing Western Pacific – WPRO B	4.0	1.21	6.0	11.7	26.1	96	336
Indonesia, Thailand & Sri Lanka – SEARO B	2.7	0.14	0.6	1.3	2.7	100	325
India & S Asia – SEARO D	1.9	0.40	1.8	3.6	7.5	98	314
Africa – AFRO D/E	1.6	0.11	0.5	0.9	1.6	82	235
TOTAL	3.9	4.6	24.3	42.3	81.1	74	234

Source: Ferri *et al* (2005).

to 800,000 (Alzheimer's Society, 2012) and this rapid growth since 2007 shows more people than expected are developing a dementia and at a faster rate.

The total number of people with dementia in the UK was forecast in 2007 to increase to 940,110 by 2021 and 1,735,087 by 2051, an increase of 38 per cent over the next 15 years and 154 per cent over the next 45 years, but the revised 2012 figures may factor for even greater numbers.

Early-onset dementia (EOD)

Early-onset dementia (onset before the age of 65 years) is comparatively rare, accounting for 2.2 per cent of all people with dementia in the UK. It is estimated that there are now 15,034 people with early-onset dementia in the UK. However, given that this data was based on referrals to services, this number is likely to be an underestimation. The true figure may be up to three times higher (45,102 people).

Late-onset dementia (LOD)

The numbers of people with late-onset dementia (onset after the age of 65 years) continues to rise for each five-year age band up to the age of 80–84, and declines thereafter. Despite this, two-thirds (68 per cent) of all people with dementia are aged 80 and over, and one-sixth (17 per cent) are aged 90 or over.

The Alzheimer's Society estimated as at 2007 that 222,925 men and 445,641 women (total 668,566) in the UK have late-onset dementia; this represents approximately two women for every man affected. Both the higher mortality among men and the higher age-specific dementia prevalence in women contribute to the preponderance of women among the oldest people with dementia.

The Alzheimer's Society estimates that in 2012 some 424,378 people with late-onset dementia (63.5 per cent) live in private households (the community), whereas 244,185 (36.5 per cent) live in care homes.

Dementia types prevalence

It is estimated that 416,967 people with dementia (62 per cent) in the UK have Alzheimer's disease, the most common form of dementia. The next most common types are vascular dementia (17 per cent) and mixed dementia (10 per cent), accounting for nearly one-third (27 per cent) of all cases. Dementia with Lewy bodies represents 4 per cent of cases.

The distribution of types is different in men and women. Alzheimer's disease is more common in women, while vascular dementia and mixed dementias are more common in men (*see* Table 1.2).